

"Community for All" Tool Kit Resources for Supporting Community Living



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THE COUNCIL
on Quality and Leadership

The Arc

**Center on
Human
Policy**

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National
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of
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TASH

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**Research and Training Center
on Community Living**

A photograph showing a diverse group of people, including men and women of various ethnicities, smiling and looking towards the camera. The image is partially obscured by the text above it.

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- The Arc of the United States - <http://www.thearc.org/>
- The Center on Human Policy - <http://thechp.syr.edu>
- The Council on Quality and Leadership - <http://www.thecouncil.org>
- National Association of Councils on Developmental Disabilities (NACDD) - <http://www.nacdd.org/>
- The University of Minnesota's Research and Training Center on Community Living - <http://rtc.umn.edu/>
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"Community for All" Tool Kit

Resources for Supporting Community Living

Table of Contents

- I. **Introduction**
 - a. Why this Tool Kit?
 - b. How to use this Tool Kit
 - c. Shared Statement of Principles
 - d. What is an Institution?
 - e. What is the Community?
 - f. Planning for Quality Community Supports for Moving Into the Community

- II. **People and Trends (Demographic Issues)**
 - a. Who are in the Institutions Today?
 - b. All People can be Supported in the Community
 - c. Trends in Institution Closure
 - d. Trends in Deinstitutionalization

- III. **Issues**
 - a. What's Wrong with Institutions?
 - b. Cost/Economic Issues
 - c. Quality of Life Outcomes in the Community
 - d. Choice
 - e. Safeguards
 - f. Family Issues

- IV. **Strategies**
 - a. State Strategies
 - b. Strategies for Advocates
 - c. Working with the Media
 - d. Position Statements
 - e. The Olmstead Decision

- V. **Personal Stories**
 - a. Personal Stories Collected in Anaheim, CA, May 2004
 - b. Stolen Lives Campaign Stories – May 2003, "Seeking Ways Out Together" (S.W.O.T.) Team, Titusville, New Jersey
 - c. Liz's Story

- VI. **Resources**
 - a. Packets Prepared by Groups Advocating For Institution Closure
 - b. Web Sites
 - c. Bibliography

- VII. **Indexes**
 - a. Author Index
 - b. Topical Index

I. Introduction

- a. Why this Tool Kit?
- b. How to use this Tool Kit
- c. Shared Statement of Principles
- d. What is an Institution?
- e. What is the Community?
- f. Planning for Quality Community Supports
for Moving Into the Community

WHY THIS TOOL KIT?

This tool kit was developed at the request of volunteers, advocates, self-advocates, and professionals concerned that the remarkable progress made towards the inclusion of people with cognitive, intellectual and developmental disabilities (our constituents) into the fabric and mainstream of community life in America was at risk. In some places in the United States there are those who would not only continue to deny people currently in public and private institutions freedom and opportunity through continued institutionalization but who also want to expand the role of institutions in the lives of our constituents.

The organizations contributing to this tool kit find that unacceptable, given all we know about how to effectively support all people, regardless of their disability, in the community. To fight the disinformation so common among those who favor continued segregation, this tool kit provides the philosophy, policy and research rationale that supports community supports and services for all people with disabilities, in the context of their families, their communities and their country.

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HOW TO USE THIS TOOL KIT

This tool kit provides:

- General information to strengthen real community inclusion.
- Background information for advocates involved in campaigns to close institutions.
- General information on community services, and resources for finding out more.
- Material to counter arguments commonly used by pro-institution advocates.
- Sample position papers, letters to the editor, op-ed pieces, and other materials that can be adapted for your own use.
- Ideas for organizing and advocacy.
- Information about policy and governmental action, and strategies that states can use in closing institutions.

The tool kit covers many more topics than are listed in the table of contents. These topics can be located by looking through the index. For example, workforce issues are covered in the section called "*State Strategies*" and the index makes this clear.

SHARED STATEMENT OF PRINCIPLES

We, the undersigned, are committed to assuring that people with disabilities have the supports needed to design and achieve lives of quality and meaning. Such lives are characterized by opportunity, inclusion, and participation. Supports for people with disabilities should be provided in a manner that recognizes people's inherent competence; reflects the personal preferences of each individual; conveys that the person receiving services is a valued, respected community participant; and assists individuals to achieve self-determined lives of mastery, satisfaction, and meaning. Such supports can only be provided in community settings. We therefore refute all arguments for institutionalizing anyone on the basis of disability.

All people have fundamental moral and constitutional rights. These rights must not be abrogated because a person has a developmental, psychiatric, or physical disability. People with significant behavioral issues and those with significant health concerns can be provided quality care and lead quality lives in the community.

All relevant research supports the fact that community settings result in improved quality of life in areas such as: opportunities for integration and social participation, participation in employment, opportunities for choice-making and self-determination, quality and duration of services received, contact with friends and relatives, adaptive behavior, and other indicators of quality of life. The most recent research (Gardner, 2003) establishes the fact that there is no trade-off of health and wellness, freedom from abuse, or safety when community affiliation, choice, and self-determination are increased.

Therefore, in fulfillment of fundamental human rights and in securing optimal opportunities, we the undersigned support the continued trends toward building community capacity, institutional downsizing, and the elimination of institutional care for people with developmental disabilities (based on the Center on Human Policy's *The Community Imperative*).

List of Participating Organizations:

- American Association on Mental Retardation (AAMR) - <http://www.aamr.org>
- The Arc of the United States - <http://www.thearc.org/>
- The Center on Human Policy - <http://thechp.syr.edu>
- The Council on Quality and Leadership - <http://www.thecouncil.org>
- National Association of Councils on Developmental Disabilities (NACDD) - <http://www.nacdd.org/>
- The University of Minnesota's Research and Training Center on Community Living - <http://rtc.umn.edu/>
- TASH - <http://www.tash.org>

RESOURCES:

Center on Human Policy, Syracuse University. (1979). *The Community Imperative: A refutation of all arguments in support of institutionalizing anybody because of mental retardation*. Syracuse, NY:

Author. Available: http://thechp.syr.edu/community_imperative.html

Gardner, J. F. (2003, Summer/Fall). Quality and accountability for 7 cents a day. *Capstone*, 20(2), 1, 3.

Towson, MD: The Council for Quality and Leadership. Available:

<http://www.thecouncil.org/council/about/Capstones/summer03.pdf>

WHAT IS AN INSTITUTION?

Issue

There are different definitions of an "institution." Some focus on services, some on size, while others focus on other characteristics of a setting such as control. Based on these varying definitions, it is clear that there are two major tasks related to institutions. One is to close the large public and private institutions. The second is to transform the community services system in order to eliminate mini-institutions within the community.

Definitions

One of the ways institutions have been defined is by the purpose or services that are supposed to be provided. For example, an institution has been defined in the Social Security Act (Section 1905(d)) as a place that "(a) Is primarily for the diagnosis, treatment, or rehabilitation for people with mental retardation; and (b) Provides, in a protected residential setting, ongoing evaluation, planning, 24-hour supervision, coordination, and integration for health or rehabilitative services to help individuals function at their greatest ability." This definition encompasses ICF/MRs of four or more beds if "active treatment" is provided.

Another way that institutions have been defined is based on numbers of people in a setting. These definitions are commonly used for counting and tracking the numbers of people in institutions over time. For example, the definition used by Braddock (2002) includes public and private facilities for 16 or more individuals. This includes publicly and privately operated institutions, training centers, state schools, and designated MR/DD units in state psychiatric hospitals.

Other definitions are based on various characteristics of the setting, and not just size. An example is Erving Goffman's definition: "A total institution may be defined as a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life" (Goffman, p. xviii).

Finally, there are definitions which do not include size as a factor and focus entirely on other characteristics of the setting. One example is the definition of Self Advocates Becoming Empowered: "An institution is any facility or program where people do not have control over their lives. A facility or program can mean a private or public institution, nursing home, group home, foster care home, day treatment program, or sheltered workshop." Definitions such as this raise the issue of the presence of mini-institutions within the community. Research conducted by J. David Smith provides an example: "When I first visited John in 1987, I was immediately taken with the institutional feel of the adult home where he was living. It had the look and smell of institutions I had visited years before... The term *home* connotes for me a personal

place, a place that belongs to its inhabitants and a place where individuality is paramount. A home is where you can be 'yourself' and where the inhabitants know one another well, even if they don't live in complete harmony. I find particularly disturbing the use of the word *home* for impersonal, anonymous places where people have little control over their own lives" (Smith, 1995, p. 57).

RESOURCES:

Braddock, D. (Ed.). (2002). *Disability at the dawn of the 21st century and the state of the states*. Washington, DC: American Association on Mental Retardation.

Centers for Medicare & Medicaid Services. (2004). *Intermediate Care Facility for People with Mental Retardation Program (ICF/MR)*. Available: <http://www.cms.hhs.gov/medicaid/icfmr/default.asp>

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall, Inc.

Smith, J. D. (1995). *Pieces of purgatory: Mental retardation in and out of institutions*. Pacific Grove, CA: Brookes/Cole Publishing Co.

INCLUDED WITH THIS SECTION AS A BACKUP DOCUMENT:

Federal definitions of "institution." (2004). Syracuse, NY: Center on Human Policy.

Federal Definitions of "Institution"

2004

The Social Security Act's definition of an intermediate care facility for the mentally retarded can be found in Section 1905(d): The term "intermediate care facility for the mentally retarded" means an institution (or distinct part thereof) for the mentally retarded or persons with related conditions if--

- (1) the primary purpose of such institution (or distinct part thereof) is to provide health or rehabilitative services for mentally retarded individuals and the institution meets such standards as may be prescribed by the Secretary;
- (2) the mentally retarded individual with respect to whom a request for payment is made under a plan approved under this title is receiving active treatment under such a program; and
- (3) in the case of a public institution, the State or political subdivision responsible for the operation of such institution has agreed that the non-Federal expenditures in any calendar quarter prior to January 1, 1975, with respect to services furnished to patients in such institution (or distinct part thereof) in the State will not, because of payments made under this title, be reduced below the average amount expended for such services in such institution in the four quarters immediately preceding the quarter in which the State in which such institution is located elected to make such services available under its plan approved under this title.

Medicaid, Section 483 of 42 CFR:

Intermediate Care Facilities for People with Mental Retardation (ICFs/MR)

Intermediate care facility for people with mental retardation (ICF/MR) services are an optional Medicaid benefit. *Section 1905(d) of the Social Security Act created this benefit to fund "Institutions" (four or more beds) for people with mental retardation or other related conditions, and specifies that these institutions must provide "active treatment," as defined by the Secretary.*

The ICF/MR Program was established in 1971 when legislation was enacted which provided for Federal financial participation (FFP) for ICFs/MR as an optional Medicaid service. Congressional authorization for ICF/MR services as a state plan option under Medicaid allowed

states to receive Federal matching funds for institutional services that had been funded with state or local government money.

To qualify for Medicaid reimbursement, ICFs/MR must be certified and comply with Federal standards (referred to as Conditions of Participation, found in Federal regulations at 42 CFR Part 483, Subpart I, Sections 483.400- 483.480) in eight areas, including management, client protections, facility staffing, active treatment services, client behavior and facility practices, health care services, physical environment and dietetic services.

Currently, there are 7,400 ICFs/MR. This program serves approximately 129,000 people, and all individuals receiving ICF/MR services must financially qualify for Medicaid assistance. Most of the individuals who receive care provided by ICF/MR have other disabilities as well as mental retardation. Many of the people who are served by this program are also non ambulatory, have seizure disorders, behavior problems, mental illness, are visually-impaired or hearing-impaired, or have a combination of these conditions.

An institution for persons with mental retardation or other related conditions, according to Federal regulations at 42 CFR 435.1009, is defined as an institution (or distinct part of an institution) that:

(a) Is primarily for the diagnosis, treatment, or rehabilitation for people with mental retardation; and
(b) Provides, in a protected residential setting, ongoing evaluation, planning, 24-hour supervision, coordination, and integration for health or rehabilitative services to help individuals function at their greatest ability. ICF/MR services are defined in regulations (42 CFR 440.150) as those items and services furnished in an intermediate care facility for people with mental retardation if the following conditions are met:

The facility fully meets the requirements for a State license to provide services that are above the level of room and board;

The primary purpose of the ICF/MR is to furnish health and rehabilitative services to persons with mental retardation or persons with related conditions;

The ICF/MR meets the standards specified in Subpart I of part 483 of this chapter;

The recipient with mental retardation for whom payment is requested is receiving active treatment, as specified in 483.440 of this chapter; and

The ICF/MR has been certified to meet the requirements of Subpart C of part 442 of the chapter, as evidenced by a valid agreement between the Medicaid agency and the facility for furnishing ICF/MR services and making payments for these services under the plan. ICF/MR services may be furnished in a distinct part of a facility other than an ICF/MR if the distinct part 1) Meets all requirements for an ICF/MR, as specified in Subpart I of part 483 of this chapter; 2) Is clearly an identifiable living unit, such as an entire ward, wing, floor or building; 3) Consists of all beds and related services in the unit; 4) Houses all recipients for whom payment is being made for ICF/MR services; and 5) Is approved in writing by the survey agency.

Mary Clarkson, Health Insurance Specialist & rule writer with CMS, was given the example of whether an ICF/MR of six or fewer persons would be considered an institution or a community service, she stated unequivocally that it would be considered an institution. She says one critical difference is that institutions are responsible for assessing and meeting all needs of the individuals who reside in them; whereas the state is responsible for assessing the needs of waiver participants, and providers are only responsible for meeting those needs that they are required to by the state's standards of participation and that they choose to provide. She also cited the requirement "to meet certain institutional criteria" that do not apply to community services, i.e., provision of nursing and other medical services.

Source: Centers for Medicare & Medicaid Services. (2004). *Intermediate Care Facility for People with Mental Retardation Program (ICF/MR)*. Available: <http://www.cms.hhs.gov/medicaid/icfmr/default.asp>

WHAT IS THE COMMUNITY?

The community is not one place, but is the places, urban, suburban, rural, South, West, North and East where Americans live. It is houses and apartments, schools and houses of worship, factories, stores, offices, ballparks, recreation centers and so much more. It is not an idealized place, like Lake Wobegon, where all are perfect. Communities have strengths and weaknesses, highs and lows. But community is the place where you make friends, have the choice of things to do or not do, where you share your joys and sorrows, where your parents brought you when you were born, where your grandparents live out their lives. It is where people care about each other or stay distant, again their choice. As our friend John McKnight says, communities are places with infinite capacity for caring, for acceptance and for opportunity. America has been built on the strength of its communities.

Community is not a place where you are isolated, deprived of the rights and experiences of other citizens when you have committed no crime, not been convicted of any offense. Community is a place where there are unlimited opportunities, not a place where because you are "different" or "special" or "exceptional" you cannot fit in, blend in, participate and contribute, give and receive.

Community is where all people belong, disability or not, in need of a lot of supports, or some or none. Community is possibility and opportunity and hope for the future. It is not a program, or services or an alternative. It is the only choice.

Community Capacity--Is It Enough--How to Build?

When John McKnight calls communities places that have infinite capacity, we agree.

The argument that the community does not have the capacity to serve all people, or people with the most significant disabilities is false. It is also a chicken and egg argument.

The nine states that do not have big congregate facilities for their sons and daughters with disabilities have developed the capacity to support each person, one at a time.

One of the things keeping institutions open does is robbing the community of the opportunity to develop capacity for each person. Communities are rich in resources and resources can be developed with dollars reappropriated from segregated facilities.

The community provider network has a diverse set of organizations, and there is the expertise in this country, in our providers, universities and other community supports for people without disabilities to figure out how to provide each person with a good life.

INFORMATION IN THIS SECTION IS BASED ON THE FOLLOWING:

Davis, D., Fox-Grage, W., & Gehshan, S. (2004). *Deinstitutionalization of persons with developmental disabilities: A technical assistance report for legislators*. Denver & Washington, D.C.: National Conference of State Legislatures. Available:

<http://www.ncsl.org/programs/health/Forum/pub6683.htm>

(see section on *State Strategies* for excerpts from this report)

PLANNING FOR QUALITY COMMUNITY SUPPORTS FOR MOVING INTO THE COMMUNITY

As we were developing this tool kit, we heard from people whose loved ones are in institutions, and who had concerns about community “readiness” and political awareness of some of the difficulties involved. We address some of these issues separately in many different sections of this tool kit. In this section, we want to assure readers that institution closure can be safe, healthy, and beneficial for people with disabilities and families, when good planning principles are followed. Many states and localities have already moved large numbers of people into the community, and in recent years have done so in a person-centered way, using planning tools such as “Essential Lifestyle Planning,” “Person-Centered Planning,” “PATH,” or “MAPS” (go to <http://www.family-futures.org.uk/index.html> and click on “Planning Tools” for more on some of these processes). The point here is that this has been done, over and over, and that there are many people in the field with the expertise to help.

Following are some questions posed by a person who knew we were working on this tool kit and who opposes institution closure. This person’s comments are in italics throughout this page, and are followed by our responses.

The person’s overall comment was, *“The first priority for inclusion in the ‘kit’ should be the tools and guidance to educate the groups on the art of developing the following information first, which can then be used as a firm foundation on which to pursue their desired goal”:*

<p><i>Developing and documenting the services that those currently in the institutions are now receiving.</i></p>	<p>Our response: A comprehensive, person-centered plan should be developed for each person who will be leaving the institution. There are many good formats, and you can view a description of them at the web address given above. The most important thing is to identify what the person needs and wants, and very specific information about likes and dislikes, medical conditions, treatments and medications. Replicating what the institution provided is not the point in such a plan, because institutions often provide services that a person does not want or need, and fail to provide things a person would really enjoy. However, the plan should encompass everything the person must have in order to be healthy and safe in the community. This document should be shared with those who will be providing support for the person, long before the person leaves. It is advisable to develop a transition plan for each person, spelling out how the person will move, who will be responsible at the time of transition for continuity of support, and how problems will be solved.</p>
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<p><i>Documenting how those services can/could/might be provided in the community.</i></p>	<p>Our response: see above. Most providers of services will take a person-centered plan and spell out how they will implement the plan. Michael Smull has some very good materials on this. Go to http://www.allenshea.com/perversion.html, http://www.allenshea.com/listentome.html, http://www.valuingpeople.gov.uk/pcp.htm, and http://www.elpnet.net/.</p>
<p><i>Researching and documenting the man-hours correlating to the documented services required and needed to absorb the potential additional requirement on services/providers in the community.</i></p>	<p>Our response: this is a standard process, though different from state to state. Remember, the purpose of moving people to the community is not to save money or conserve resources. It is to improve the quality of people's lives. Frequently, at the time of transition people need more support and, as they become accustomed to the community setting and the support staff become accustomed to them, the needs for supports diminish. This is an individual decision, not something that can be predicted or planned in advance.</p>
<p><i>Document IF, WHERE, AND HOW the services are actually currently available in the community to absorb the additional documented workload.</i></p>	<p>Our response: this is a red herring, and a favorite scare tactic of institutional proponents. If the services and supports for each person are developed individually, there is often nothing to SEE in advance of a decision to close an institution. Once it has been decided that a person will move, however, it should be possible for family members to visit people who are currently living in a setting similar to what could be or is being planned for a person. Before a person moves simple things can be arranged. The name, address and phone numbers of physicians, dentists, pharmacies, etc. can all be provided, and records can be transferred to those places so that they are acquainted with the person. Before a person's move actually takes place, they should approve where they are going to live, and they should visit several places to make sure they are pleased with where they are going. The fact is, if a state has decided to close an institution, then that state must ensure that services will be developed to meet the needs of everyone who will move. And in fact, that process has occurred innumerable times over the past two decades. In any closure, advocates would of course insist that the appropriate services be provided in the community.</p>
<p><i>Document the cost for each service required by each person currently served in an institution and the resultant total cost to the system to effectively provide a clear audit trail of the needed revenue.</i></p>	<p>Our response: The revenue streams are separate. Usually the institution and community service revenue streams are separate items in a state budget. The cost of the supports for each person, and the total amount of available resources, are an essential part of any plan, on an individual not a group basis. Some people will cost more in the community and some less but decisions about moving a particular individual out of an institution should never be made on the basis of saving money. The fact is that in an</p>

	institution, different people require different amounts and types of resources and supports, even though this is not costed out on an individual basis as it might be in the community. The potential or real cost of serving a person should not be an excuse for keeping him/her in an institution. See our section on <i>Cost Issues</i> for more information and argument on this point.
<i>Develop statistics reflecting the impact the closure of the institution will have on those individuals currently in the community as a result of the potential closure, i.e., how much longer will those people currently on waiting lists in the community and not receiving any services, or less services than required, be expected to go without services and how much longer will they remain on the "waiting list" as the result of a person discharged from an institution taking priority.</i>	Our response: There is no relationship between these two, and in fact, keeping people in the institution increases, not decreases, time on waiting lists. The people in institutions already have funds spent on them and those funds, when allocated properly, move to the community appropriation once the institution closes. It is a myth that moving people from an institution increases waiting lists. The opposite appears to be true in many cases, because some states find creative ways of serving people on waiting lists along with people moving from institutions.
<i>Document the services those currently in the community not receiving services require and cost these services out.</i>	Our response: This is a good waiting list strategy, but has nothing to do with getting people out of institutions.
<i>Develop a plan that ensures the documented residential placements, caretakers, professional services, and revenue will be in place in the community PRIOR to advancing to the next step of advocating to close an institution that is providing quality services for those with severe/profound mental retardation, those most medically fragile, and those with extremely serious behavior problems.</i>	Our response: A good plan must address all of these things, whether or not one accepts the assertion that quality services are provided in the institution. Advocates of institution closure should insist that such planning be done. See some of our other sections, too—such as the <i>State Strategies</i> section, the <i>Quality of Life Outcomes in the Community</i> section, and the section titled <i>All People Can Be Supported in the Community</i> . It should be obvious that you are not advocating for a system that “dumps” people, unsupported, into an unprepared community.
<i>The person's last comment was: Start with some variation of the above approach and I will be convinced that you are actually advocating in the best interests of our most severely disabled citizens who are now well cared for by dedicated direct care, nursing, medical, dental, and therapeutic staff in our institutions.</i>	Our response: no further response is needed to this comment, but let us hope that the person is now convinced!

We include in this section an article prepared by John O'Brien in 1995 when New York State was planning a series of institution closures. It reflects the thinking of the time—lots of emphasis on good planning, and awareness that compromises (especially in regard to individualization) might have to be

made. He emphasizes the importance of understanding which steps are compromises, so that more individualized planning can be done after a person moves if it couldn't happen when he/she first left the institution. Thus, he warns against building structures and infrastructure that cannot easily be changed during the years after a move. While that is a possible strategy, in other states advocates have insisted that all moves should be individually planned and carried out.

Person-centered planning efforts indicate that these plans can help people to get a good start in getting a life that makes sense to them. However, these same efforts also demonstrate that good planning is only the first part of the effort. Plans must be accompanied by implementation and on-going learning. It is fair to say that efforts over the past several years have strengthened the competencies of community services, and of community residents, in building capacity to support people with any kind of challenging condition, whether medical, behavioral, or forensic. This is where our efforts must be concentrated in the future. In many ways, it is sad that we must still spend time and effort on arguments about whether institutions should be kept open, or reopened. We know so much now about how to support people in the community, and we should be spending everyone's time in keeping the good that we have, in developing even more community capacity, and in learning from the people we support.

RESOURCES:

- Holburn, S., & Vietze, P. M. (Eds.). (2002). *Person-centered planning: Research, practice, and future directions*. Baltimore: Paul H. Brookes Publishing Co.
- O'Brien, J., & Lyle O'Brien, C. (Eds.). (1998). *A little book about person-centered planning: Ways to think about person-centered planning, its limitations, the conditions for its success*. Toronto: Inclusion Press.
- O'Brien, J., & Lyle O'Brien, C. (Eds.). (2002). *Implementing person-centered planning: Voices of experience*. Toronto: Inclusion Press.

INCLUDED WITH THIS SECTION AS A BACKUP DOCUMENT:

- O'Brien, J. (1995, Winter). Issues and challenges in developing individualized supports. In *Individualized services in New York State* [Policy Bulletin No. 4] (pp. 20-22). Syracuse, NY: Research and Training Center on Community Integration, Center on Human Policy, School of Education, Syracuse University. Available: <http://thechp.syr.edu/nysbisch.htm>

ISSUES AND CHALLENGES IN DEVELOPING INDIVIDUALIZED SUPPORTS¹

by John O'Brien

As states move toward providing individualized supports for people with severe disabilities, there are a number of challenges that will need to be faced at both the state and local levels:

It is important to build a common understanding of what we mean by individualized. This process of building a common understanding of individualized supports will entail the following:

At the direct service level, providing individualized supports means learning to:

- remain available to people as their interests and needs change;
- continuously increase the effective control people have over the supports they receive and the choices they make in their lives;
- revise and repair supports as people change and as better information becomes available;
- actively negotiate for necessary changes in agency and system practice and policy;
- make the best possible use of available system funds.

At the agency management level, providing individualized supports means learning to:

- match people with developmental disabilities and support people and sustain and contribute to the improved effectiveness of these relationships;
- focus problem solving and active search for community opportunities;
- develop community opportunities such as accessible housing and transportation, recreational opportunities, and jobs
- make available system resources as flexible as possible as opportunities and support needs change and actively negotiating for necessary changes in system policy and practice.

At the system level, providing individualized supports means learning to:

- negotiate common mission, strategies, and mutual accountability among the people and agencies that provide and govern services;
- continuously increase the flexibility and responsiveness of available public funds by creating new ways to insure accountability and new ways to budget and disburse funds.
- discovering and communicating what is possible for people with developmental disabilities;
- promoting learning from action by discovering and disseminating what works and what doesn't work in providing individualized supports;

¹O'Brien, J. (1995, Winter). Issues and challenges in developing individualized supports. In *Individualized services in New York State* [Policy Bulletin No. 4] (pp. 20-22). Syracuse, NY: Research and Training Center on Community Integration, Center on Human Policy, School of Education, Syracuse University. Available: <http://thechp.syr.edu/nysbisich.htm>

- systematically shifting the system's "center of gravity" from group provision to individualized supports;
- clarify the difference between truly individualized supports and improved versions of traditional approaches.

Significant resources are still being directed toward traditional agency-owned and agency-controlled services for groups of people. Most agencies that are providing individualized supports also direct large amounts of resources into traditional, facility-based services. Proceeding in these two directions at once is incompatible, both philosophically and programmatically. Continued effort needs to be placed on directing increasing proportions of resources into consumer-controlled, individualized supports.

The energy and resources directed toward developmental center closure will divert energy and resources from the provision of individualized supports. In the interest of timely closure, significant numbers of people will likely be placed in settings that are community-based, but not truly individualized. Effort should be made to ensure that these settings are created in such a way that they can be dismantled later (e.g., avoidance of purpose-built facilities and agency-owned facilities). In this circumstance, how many people benefit from individualized supports depends on how effectively service providers and local advocates deal with four key issues: (1) building commitment to organizing individualized supports; (2) redesigning systems and reorganizing patterns of service to provide individualized supports; (3) systematically, and very substantially, decreasing the time elapsed between identification of an individually responsive service activity and the final decision about allocation of DSO resources to provide that service; and (4) managing the closure of developmental centers in a way that frees resources (including leadership time) to focus on developing individualized supports.

As individualized supports are created, it will be important to include people with the most severe disabilities among those who benefit from these services. Many agencies have greatly increased their capacity to provide individualized supports to people with challenging behaviors. There are many fewer examples of people with the most severe disability labels (physical and intellectual) in individualized settings. Agency staff members often feel that inadequate funding rates are the greatest barrier to this. States and local agencies will need to work together to overcome these obstacles and find solutions which enable all people with disabilities to be supported in individualized ways.

Attention should be paid to avoidance of a situation in which agencies are pressured to expand and serve increasing numbers of people. Agency size is a critical factor in the provision of quality, individualized supports. Where necessary, effort should be directed toward the creation of new agencies, rather than pressuring or encouraging already large agencies to grow ever larger.

Person-centered planning is a tool that can be used to aid in the creation of individualized supports for a particular person. This tool will lose its effectiveness the more it becomes systematized and routinized as a way of planning across large numbers of people.

III. People and Trends (Demographic Issues)

- a. Who are in the Institutions Today?
- b. All People can be Supported in the Community
- c. Trends in Institution Closure
- d. Trends in Deinstitutionalization

WHO ARE IN THE INSTITUTIONS TODAY?

The residents of the institutions in the United States range in age, level of intellectual disability, additional conditions (other than intellectual disability), and functional limitations. The same can be said of those who live outside of such institutions. This section provides more information on those still living in institutions, because assertions are often made that these people are older and more disabled and therefore cannot be supported safely in the community. See the next section for more information on that.

In 2002, over half (55.4%) of the 44,066 people in large state institutions serving 16 or more people were between the ages of 40 and 62. Children under 21 comprised only 4.5%, those between 22 and 39 comprised 30.9%, and only 9.2% were 63 or over. Obviously, it is not the case that most of the people still in institutions are "old." Most have many years in which they could enjoy community life.

The Executive Summary and chapter included in this section provide information on who is still in institutions, and on the changes in the institution cohort over the years. For example, even though the proportion of all residents having profound intellectual disabilities has increased significantly, their actual numbers decreased by more than 41,100 people between 1977 and 2002, and between June 1996 and June 2002 their numbers decreased by about 10,700 persons. This rate is similar to or even slightly faster than the rate of decrease in people with less severe intellectual impairments.

Similarly, the percentage of residents of large state institutions reported to have functional limitations in various activities of daily living, or to have additional impairments as well as intellectual disability, remained stable between 1998 and 2002; but their actual numbers decreased.

Advocates can use the research studies cited here to look at their own states' statistics in regard to characteristics of residents in state institutions. Go to the first web site listed (you will need Acrobat Reader to download it, and you can get it free at www.adobe.com). The main point advocates can make, however, is that people with all of the significant disabilities that are usually cited as barriers to community living ARE living in the community. Community programs increasingly know how to support people with these disabilities. Most people with significant disabilities are now living, and have always lived, with their families.

INFORMATION IN THIS SECTION IS BASED ON THE FOLLOWING:

Lakin, K. C., Larson, S. A., Prouty, R. W., & Coucouvanis, K. (2002). Chapter 3: Characteristics and movement of residents of large state facilities. In R. W. Prouty, G. Smith, & K. C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2002* (pp. 31-46). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Prouty, R. W., Smith, G., & Lakin, K. C. (2002). Executive summary. In R. W. Prouty, G. Smith, & K. C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2002* (pp. iii-x). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

PLEASE NOTE: The entire report is available at <http://rtc.umn.edu/risp02/risp02.pdf> or <http://rtc.umn.edu/risp/index.html>.

INCLUDED WITH THIS SECTION AS BACKUP DOCUMENTS:

Lakin, K. C., Larson, S. A., Prouty, R. W., & Coucouvanis, K. (2002). Chapter 3: Characteristics and movement of residents of large state facilities. In R. W. Prouty, G. Smith, & K. C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2002* (pp. 31-46). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Prouty, R. W., Smith, G., & Lakin, K. C. (2002). Executive summary. In R. W. Prouty, G. Smith, & K. C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2002* (pp. iii-x). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

PLEASE NOTE: The entire report is available at <http://rtc.umn.edu/risp02/risp02.pdf> or <http://rtc.umn.edu/risp/index.html>.

Executive Summary

State Residential Services

Number and Size of Residential Settings

The number of state residential settings increased in Fiscal Year 2002. On June 30, 2002 states were directly operating 2,353 residential settings housing persons with intellectual disabilities and related developmental disabilities (ID/DD), 543 less than in the previous year. Of these 2,320 were facilities, special units or other settings primarily serving persons with ID/DD and 33 were facilities primarily serving persons with psychiatric disabilities. Nine-tenths (90.0%) of the state ID/DD settings had 15 or fewer residents, a proportion that decreased slightly from June 2001 (91.6%).

On June 30, 2002 every state except Alaska, District of Columbia, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia was operating at least one large state ID/DD facility. New Hampshire closed its only large (16 or more residents) state ID/DD facility in January 1991. In Fiscal Year 1994 Vermont, Rhode Island and the District of Columbia closed the last of their large state ID/DD facilities. New Mexico followed in Fiscal Year 1995 and Alaska did the same in 1997. In 1999, Maine's last large facility dropped below 16 residents and West Virginia and Hawaii closed the last of their large state ID/DD facilities.

The number of state community residential settings continues to grow and New York remains by far the largest operator of state community residences. State community settings (15 or fewer residents) decreased by 20% (522 settings) to a total of 2,087 in Fiscal Year 2002. By the end of Fiscal Year 2002, New York had 730 state community settings or 35.0% of the national total.

Number of Residents

The population of large state ID/DD facilities continues to fall. The population of large state ID/DD facilities on June 30, 2002 was 44,066, a decrease of 4.1% from June 30, 2001, continuing a trend first evident in Fiscal Year 1968. Between Fiscal Years 1980 and 2002 large state ID/DD facilities' average

daily populations decreased by 86,745 (66.2%) to 44,343 individuals. More than three-fourths (40) of all states reduced the average daily populations of their large state ID/DD facilities by 50% or more during the period.

The population of state community residential settings decreased in Fiscal Year 2002. During Fiscal Year 2002 the number of persons residing in state community settings (15 or fewer residents) decreased 1.0%, to an end of year total of 12,561 persons. The average number of residents per state community setting decreased to 4.4 from the 2001 level of 4.5 residents. New York accounted for nearly three-fifths (59.8%) of all residents of state community settings.

The population of persons with ID/DD in all large state residential facilities continues to decline. On June 30, 2002, the combined population of residents with ID/DD in large state ID/DD and psychiatric facilities was 44,333, a decrease of 4.7% from 2001. The estimated population of persons with ID/DD in state psychiatric facilities dropped from a population of 31,884 in 1970 and 9,405 in 1980 to 267 in 2002.

Nationally, the population of large state ID/DD facilities per 100,000 of the general population continues to fall. On June 30, 2002 there were 15.3 persons in large state ID/DD facilities per 100,000 of the general U.S. population. This compares with 16.1 persons in 2001; 16.8 in 2000; 18.0 in 1999; 19.0 in 1998; 20.0 in 1997; 21.9 in 1996; 23.5 in June 1995; and 99.7 in June 1967. Placement rates in 10 states were at 150% or more of the national average, while in 6 states with large ID/DD facilities they were less than half the national average.

A number of states made very substantial reductions in their large state ID/DD facility average daily populations between 1990 and 2002. The average daily number of persons with ID/DD living in large state ID/DD facilities decreased by 47.5% between Fiscal Year 1990 and Fiscal Year 2002. The largest proportional decreases in large state ID/DD facility average daily populations were, of course, in

Alaska, the District of Columbia, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia which closed all their large state ID/DD facilities. In addition, 20 other states reduced their large state ID/DD facility populations by more than 50% over the twelve-year period.

Admissions, Discharges, and Deaths

Admissions to large state ID/DD facilities decreased very slightly in 2002. In Fiscal Year 2002 an estimated total of 2,149 persons with ID/DD were admitted to large state ID/DD facilities, an increase of 11.5% from the previous year. Admissions were equal to 4.8% of the average daily population of these facilities during the year. Two states reported no admissions to their large state ID/DD facilities. Ten states reported admissions exceeding 10% of their average daily population.

Discharge rates from large state ID/DD facilities decreased substantially in 2002. In 2002 an estimated total of 2,785 persons with ID/DD were discharged from large state ID/DD facilities, an increase of 14.5% from 2,433 in 2001. Discharges were equal to 6.3% of the year's average daily population of those facilities (as compared with 5.3% in 2001). In 2002, 7 states reported discharges that equaled 20% or more of the average daily population of their large ID/DD facilities. Sixteen states with large state ID/DD facilities had discharges less than 5% of their average daily population.

The death rate among residents of large state ID/DD facilities in 2002 (1.9%) was within the range evident throughout the past decade. In 2002 a total of 803 persons with ID/DD died while residing in large state ID/DD facilities. The 1.8% death rate of 2002 is below the 2.0 death rate of 2001, and 1.9% in 1999 and 2000 but above recent rates of 1.7% in 1998, 1.4% in 1997, 1.7% in 1996, 1.7% in 1995, 1.5% in 1994, 1.6% in 1993, 1.4% in 1992 and 1.4% in 1990. The small increases in institutional death rates in recent years may be attributed to the aging and more severely impaired populations of large ID/DD facilities.

Expenditures

In 2002 expenditures for care in large state ID/DD facilities continued to increase and reached a national annual average of \$125,746.15 per person. Between 2001 and 2002 the average annual

expenditures for care in large state ID/DD facilities increased 6.6% from \$121,406.09 to \$125,746.15 (or an average of \$344.51 per day). Twenty-three states exceeded an average of \$350 per day; 23 states reported annual expenditures per resident exceeding the national average. The increase between 2001 and 2002 (3.6%) was much less than the 5.8% increase from 2000 to 2001. The average annual increase for the period 1990-2002 (6.3%) remained well below the 15.0% average annual increase between 1970 and 1989.

Facility Closures

The closure of large state ID/DD facilities continues. Three large ID/DD facilities were closed in FY02; 2 in Illinois and 1 in Michigan in Fiscal Year 2002. Between 1996 and 2002, 45 large state ID/DD facilities were closed, an average of 6.5 closures per year. This compares with an average of 1.25 per year between 1976 and 1979, 3.5 per year between 1980 and 1983, 2.75 per year between 1984 and 1987, 8.75 per year between 1988 and 1991, and 12.5 per year between 1992 and 1995. States report that two additional large state ID/DD facilities are projected to be closed in Fiscal Year 2003.

Resident Characteristics

The number of children and youth in large state ID/DD facilities continues to decrease rapidly, substantially more rapidly than the state ID/DD facility populations as a whole. On June 30, 2002 an estimated 1,983 state ID/DD facility residents (4.5% of the total) were 21 years or younger. This compares with 2,130 (4.5%) on June 30, 2000, 6,944 (8.7%) on June 30, 1991, 54,120 (35.8% of the total) on June 30, 1977 and 91,590 (48.9% of the total) on June 30, 1965. Children who were 14 years or younger made up only 0.7% of state ID/DD populations in 2002 as compared with 2.3% in 1991. At least 21 states had no large state facility residents who were less than 15 years old.

Large state ID/DD facility populations are overwhelmingly made up of non-elderly adults and increasingly of middle-aged adults. On June 30, 2002 86.3% of large state ID/DD facility residents were between 22 and 62 years old. This compares with 60.5% in 1977, 73.1% in 1982, 81.4% in 1987 and 84.3% in 1991. More than one-half (55.4%) of state ID/DD facility residents in 2002 were in the 40-62 year age range. This compares with 19.2% in 1977, 22.9%

in 1982, 27.3% in 1987, 32.5% in 1991, and 52.7% in 2000. This reflects the maturing of the “baby boom” cohort into middle age.

The number of large ID/DD facility residents of 63 years and older has declined by nearly 1,100 since 1977, even as the proportion of “aging” residents has increased. On June 30, 1977 there were 5,590 persons 63 years or older in large state ID/DD facilities; on June 30, 2002 there were an estimated 4,051. However, as populations of large state ID/DD facilities have been reduced by more than 70% over the same period, the proportion of persons 63 years and older has increased substantially (3.7% in 1977, 5.0% in 1982, 6.0% in 1987, 7.0% in 1991 and 8.8% in 1998, 8.4% in 2000 and 9.2% in 2002).

The proportion of ID/DD facility populations made up of persons with the most severe cognitive impairments continues to grow. On June 30, 2002, 63.0% of all residents of large state ID/DD facilities were reported to have profound intellectual disabilities. This compares with 45.6% in 1977, 56.2% in 1982, 63.0% in 1987, 64.8% in 1991 and 64.6% in 1998. Persons with mild or moderate intellectual disabilities made up 20.3% of state facility residents on June 30, 2002. This compares with 26.8% of state institution residents in 1977, 19.6% in 1982, 17.0% in 1987, 16.1% in 1991 and 17.1% in 1998. On June 30, 2002 almost half of all state ID/DD facility residents (48.9%) were persons with profound intellectual disabilities between the ages of 22 and 54 years old.

Although the proportion of persons found with intellectual disabilities among large state ID/DD populations continues to grow, their actual numbers continue to decrease. Between June 30, 1977 and June 30, 2002 the estimated number of persons with profound intellectual disabilities living in large state ID/DD facilities decreased by more than 40,000 (from 68,907 to 27,777). This compares to an increase of nearly 20,000 state facility residents with profound intellectual disabilities between 1964 and 1977.

The proportion of large state ID/DD facility residents with significant functional impairments continues to increase. On June 30, 2002, 37.0% of state facility residents were reported to be unable to

walk without assistance. This compares with 23.3% in 1977, 25.5% in 1982, 29.5% in 1987 and 32.4% in 1991. However, the total number of state facility residents unable to walk without assistance decreased by 20,232 between 1977 and 2002 (from 35,200 to 14,968). Similarly, in 2002, 56.1% of state facility residents were reported to be unable to toilet themselves independently. This compares with 34.1% in 1977. But between 1977 and 2002 the total number of people living in large state facilities who were unable to toilet themselves independently actually decreased by over 18,000 persons.

Most large state ID/DD facility residents are 40 years or older. With the increasing proportions of residents in both middle-aged (40-62 years) and aging (63 years or older) categories, on June 30, 2002 the majority (64.6%) of large state ID/DD facility residents were at least 40 years old. This compares with one-third (33.3%) of all residents 14 years earlier.

Almost half (47.0%) of large state facility residents have 2 or more sensory, neurological or behavioral conditions in addition to intellectual disabilities. On June 30, 2002 13.5% of large state ID/DD facility residents were reported to be functionally blind and 6.6% were reported to be functionally deaf. Seizure disorders were reported for 45.0% of residents and 19.4% were reported to have cerebral palsy. More than half (52.4%) of all residents were reported to have some form of behavior disorder and 45.7% were reported to have a psychiatric condition. About 47.0% of all residents were reported to have 2 or more of these conditions. In comparison, in 1977, 6.0% of state institution residents were blind, 3.6% were deaf, 32.5% had epilepsy, 19.3% had cerebral palsy, 25.4% were reported to have a behavior disorder and 35.1% to have two or more of these conditions.

Males remained a substantial majority among large state facilities’ residents. Males made up 62.8% of state facility populations in 2002. Males have made up a majority of state facility populations since the first national survey reporting gender statistics in 1904 when 53.1% of state institution residents were male. That proportion has very gradually increased over the years to 57.0% in 1977, 57.4% in 1982, 57.7% in 1987, and 58.5% in 1991.

All State and Non-State Residential Services

Number and Size of Residential Setting

The number of residential settings for persons with ID/DD is growing very rapidly. On June 30, 2002 there were an estimated 125,415 residential settings in which persons with ID/DD received residential services from state operated or state licensed residential service providers (excluding psychiatric facilities, nursing homes and people receiving services while living with family members). Since 1977 the number of settings in which people receive residential services has grown more than eleven-fold. In comparison, on June 30, 1977 there were 11,008 state licensed or state operated residential service settings; on June 30, 1987 there were 33,477; on June 30, 1992 there were 49,479; on June 30, 1995 there were 84,532; and on June 30, 1998 there were 104,765. Of all residential service settings on June 30, 2002, 2,320 were operated by states, with the remaining 123,095 residential settings served by nonstate agencies.

Most residences licensed or operated by states for persons with ID/DD were small and almost all people living in small residences were served by nonstate agencies. Of the 125,415 total residential settings on June 30, 2002, an estimated 124,156 (99.0%) had 15 or fewer residents and 117,823 (94.0%) had 6 or fewer residents. The estimated 122,069 nonstate settings with 15 or fewer residents made up 98.3% of all settings with 15 or fewer residents. The 116,189 nonstate settings with 6 or fewer residents made up virtually all (98.6%) of the settings with 6 or fewer residents.

Most large residences were also operated by nonstate agencies. Nonstate agencies operated 1,026 (81.5%) of the total 1,259 facilities with 16 or more residents. This compares to 80.8% in 1977, 82.7% in 1987 and 85.6% in 1999.

Number of Residents

Between 1977 and 2002, there was a steady increase in the total number of persons with ID/DD receiving residential services. Between 1977 and 2002 the total number of residential service recipients grew 58.5%, from 247,780 to a reported 392,740. Total population increases (both nonstate

and state settings) were limited to places with 15 or fewer residents, the populations of which increased by and estimated 278,391 between 1977 and 2002. Total populations of facilities with 16 or more residents decreased by 133,431 persons between 1977 and 2002. Between 2001 and 2002 residents of settings with 15 or fewer residents increased by an estimated 8,250 persons, while residents of facilities with 16 or more residents decreased by 3,255.

The national average rate of placement in residential settings for persons with ID/DD in 2002 was 136.2 persons per 100,000 of the general population. Twenty-nine states reported residential placement rates at or above the national average, with the highest rate (318.9 per 100,000 state residents) in North Dakota. The lowest placement rate (55.9 per 100,000) was reported by Arizona. Eight states reported placement rates 150% or more of the national average and four states reported placement rates 50% or less of the national average. The national average placement rate of 136.2 in 2002 was higher than the 2001 rate of 136.1 and the 1977 rate of 118.8.

In 2002 about 81.2% of the persons with ID/DD receiving residential services lived in places with 15 or fewer residents, 67.5% lived in places with 6 or fewer residents, and 44.6% lived in places with 3 or fewer residents. On June 30, 2002, residences of 15 or fewer persons housed an estimated 318,815 people (81.2% of all residents). Settings with 6 or fewer residents housed 264,920 residents (67.5% of all residents) and settings with 3 or fewer residents 174,976 (44.6% of all residents). Of the 318,815 persons living in places with 15 or fewer residents, 306,254 (96.1%) lived in settings operated by nonstate agencies. The 259,388 persons living in nonstate settings with 6 or fewer residents made up almost all (97.9%) or the 264,920 people living in places with 6 or fewer residents.

A substantial majority of persons with ID/DD who received residential services from nonstate agencies lived in smaller settings, while a substantial majority of persons who lived in state residences lived in large facilities. On June 30, 2002 nine-tenths (91.1%) of the 336,113 persons receiving residential services from nonstate agencies lived in settings of 15 or fewer residents, and more than three-fourths (77.2%) lived in settings with 6 or fewer

residents. More than three-fourths (77.8%) of the 56,627 persons living in state operated settings were in facilities with 16 or more residents. Of the 73,925 residents of residential settings with 16 or more residents, 44,066 (59.6%) lived in state facilities. In 1977, 74.6% of the 207,356 residents of facilities with 16 or more residents lived in state facilities.

Interstate Variability

Only one state reported a majority of persons with ID/DD receiving residential services lived in facilities of 16 or more residents. On June 30, 2002 more than seven-tenths (70.3%) of the residents of all settings in one state (Mississippi) lived in facilities with 16 or more residents. Nationally, 25.6% of all residential service recipients lived in settings of 16 or more residents.

In more than five-sixths (43) of all states a majority of persons with ID/DD received residential services in settings with 6 or fewer residents. On June 30, 2002 more than half of the residents of all settings in Alaska, Arizona, California, Colorado, Connecticut, Delaware, the District of Columbia, Hawaii, Idaho, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, South Dakota, Texas, Utah, Vermont, Washington, West Virginia, Wisconsin, and Wyoming lived in settings with 6 or fewer residents. In 21 states one-half or more of the residents lived in settings of 3 or fewer.

State and Nonstate Residential Settings by Type

Most people receiving residential services receive it in places that provide “congregate care.” Congregate care is provided in settings owned, rented or managed by the residential services provider, or the provider’s agents in which paid staff provide care, supervision, instruction and other support and include, but are not limited to ICFs-MR. An estimated 266,687 persons with ID/DD lived in congregate care settings on June 30, 2002 (67.9% of all residential service recipients). A majority of these persons (189,602 or 71.1%) lived in settings with 15 or fewer residents and over one-half of those 135,571 (50.8%) lived in settings with 6 or fewer residents.

The number of people living in host family/foster care is slowly increasing. An estimated national total of 42,272 persons with ID/DD lived in host family/foster care settings on June 30, 2002. This represents a 3.9% increase from one year earlier. Virtually all (99.96%) host family care residents lived in homes with 6 or fewer residents. Between June 30, 1982 and June 30, 2002 the estimated number of people in host family settings increased from approximately 17,150 to 42,272 (146.5%).

About 22.1% of persons receiving ID/DD residential services live in their “own homes” that they own or lease. An estimated national total of 86,694 persons with ID/DD receiving residential services and supports lived in homes that they owned or leased for themselves. The number of persons living in homes of their own increased 8.0% between June 30, 2001 and June 30, 2002. Between 1993 and 2002 the estimated number of people living in homes of their own nationally increased by 155.8% as the movement toward consumer controlled housing and supported living continued.

The number of people with ID/DD receiving residential services living in settings of 3 or fewer persons continues to increase. An estimated 174,976 (44.6%) were living in homes of 3 or fewer residents in 2002, more than 11 times as many as the 15,705 people in settings of 3 or fewer in 1982. Among 46 states for which these data were available, persons with ID/DD living in settings of 3 or fewer persons ranged from 12.9% to 94.7% of all persons with ID/DD receiving residential services.

Patterns of Change in Residential Service Systems: 1977-2002

The number of residential settings in which people received services increased much faster than the total number of service recipients. Between 1977 and 2002, the total number of residential settings in which people with ID/DD received residential services grew from 11,008 to an estimated 125,415 (1,039.3%), while total service recipients increased by 58.5%, from about 247,780 to an estimated 392,740 individuals.

The nation moved from large facility-centered to community residential services. In 1977, 83.7% of the estimated population of persons with ID/DD receiving residential services lived in residences of

16 or more people. By 2002, an estimated 81.2% lived in community settings of 15 or fewer people, and 67.5% lived in residential settings with 6 or fewer people. Only about 22.1% of residential service recipients lived in homes that they themselves owned or rented.

The role of the state as a residential service provider dramatically declined. In 1977, 62.9% of all residential service recipients lived in state residential settings. By 2002, less than one-sixth (14.4%) of all residential service recipients lived in state residential settings.

States reported a large number of service recipients living in their family homes. In 2002, an estimated 482,479 persons received services in their family homes. This equals 55.1% of all persons receiving ID/DD residential services in or out of their family homes. Recipients of ID/DD family-based services in states ranged from 7.0% to 85.0% of service recipients.

On June 30, 2002, there were an estimated 59,818 persons waiting for residential services. Based on reports of 36 states it was estimated that 59,818 persons not presently receiving ID/DD services outside their family homes are waiting for such services. It would require an estimated 15.2% growth in available residential service capacity to provide residential services to all of the persons currently waiting. The range of growth required to meet present needs ranged from 0.0% to 131.8%.

Medicaid Funded Services

Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR)

The total number of ICFs-MR from 2001 to 2002 increased by 8 facilities. On June 30, 2002 there were 6,623 ICFs-MR nationwide, as compared to 6,615 in 2001. Average ICF-MR size in 2002 was 16.7 residents; this compares with 186 residents in 1977; 74.5 residents in 1982; 37 residents in 1987; 22.5 residents in 1992; and 17.2 residents in 2001.

In 2002, the population of ICFs-MR continued to decrease. From 1982 to 1994 the ICF-MR program was notable for its stability in the number of persons served. On June 30, 1994 there were 142,118

persons living in all ICFs-MR. This compares with 140,684 on June 30, 1982. By June 1999 the total ICF-MR population had decreased to 117,917. The June 2002 population of ICFs-MR was 110,572, a decrease of 3,335 (2.9%) from the previous year.

Populations of large ICFs-MR have continued to decrease steadily. On June 30, 2002 there were 68,811 persons in ICFs-MR of 16 or more residents (62.2% of all ICF-MR residents). This represented a 43.0% decrease from the 120,822 persons in large ICFs-MR in 1987 and a 47.4% decrease from 130,767 large ICF-MR residents in 1982. The 2002 population of large ICFs-MR included 43,530 residents of state ICFs-MR and 25,281 residents in nonstate ICFs-MR. Between June 30, 1988 and June 30, 2002, large state ICF-MR populations decreased 14.3% (from 50,778), while large nonstate ICF-MR populations decreased by 10.5% (from 28,246).

Almost all residents of large state and nonstate residential facilities live in ICFs-MR. In 2002, 92.1% of persons living in all large state and nonstate facilities lived in ICF-MR units, and 98.8% of people living in state facilities of 16 or more residents lived in ICF-MR units.

In 2002, only 4 of 10 ICF-MR residents were living in state facilities. On June 30, 2002, 40.3% of all ICF-MR residents were living in state facilities. This compares with 63.2% on June 30, 1987; 77.2% on June 30, 1982 and 87.5% on June 30, 1977. The decreased concentration of ICF-MR residents in state facilities is associated with the general depopulation of large state ID/DD facilities and the increase in the number of community ICFs-MR. On June 30, 2002 there were 43,530 persons in ICF-MR units of large state ID/DD facilities (39.4% of all ICF-MR residents). This compares with 88,424 persons on June 30, 1987 (61.2% of all ICF-MR residents), and 107,081 persons on June 30, 1982 (76.3% of all ICF-MR residents).

The number of residents of community ICFs-MR decreased slightly in 2002. On June 30, 2002 there were 41,761 persons with ID/DD living in community ICFs-MR with 15 or fewer residents. This represents a slight decrease of 1.1% from June 30, 2001. Community ICFs-MR continued to house many more than the 25,328 persons on June 30, 1987, and the

9,985 persons on June 30, 1982. On June 30, 2002, 46.7% of residents of community ICFs-MR lived in facilities with 6 or fewer residents. Between June 30, 1982 and June 30, 2002 the total number of persons with ID/DD living in ICFs-MR of six or fewer residents increased from 2,572 to 19,497. The number of people living in ICFs-MR of 6 or fewer residents decreased between June 30, 2001 and June 30, 2002 by 407 residents (2.0%).

A relatively small proportion of persons with ID/DD in community settings live in ICF-MR certified residences. Nationally, on June 30, 2002 only 13.1% of the persons in settings with 15 or fewer residents lived in ICFs-MR. Persons living in settings with 7 to 15 residents were far more likely to live in ICFs-MR than persons living in settings of 6 or fewer residents; 22,264 (42.1%) of the 52,914 persons living in settings with 7 to 15 residents lived in ICFs-MR, while only 19,497 (7.5%) of the 260,100 living in settings with 6 or fewer residents lived in ICFs-MR.

In 2002 total ICF-MR expenditures were more than in 2001. In Fiscal Year 2002 total federal and state expenditures for ICF-MR services were 10.7 billion dollars. This was an increase from the 10.2 billion dollars expended in FY 2001. Comparable expenditures were \$8.8 billion dollars in 1992, \$5.6 billion in 1987, \$3.6 billion in 1982 and \$1.1 billion in 1977.

Per resident ICF-MR expenditures in 2002 continued to increase. In 2002 the average expenditure for end of year ICF-MR residents was \$97,190. This compares with the average 2001 per resident expenditure of \$89,858. The average 2002 expenditure was \$95,746, or 132.4%, more than the average per resident expenditure of 13 years earlier. States varied substantially in expenditures per ICF-MR resident, from more than \$120,000 per year in fifteen states to less than \$60,000 per year in 2 states. Total ICF-MR expenditures per person in the general population averaged \$37.27 per year nationally. Two states spent over twice the national average.

Medicaid Home and Community Based Services (HCBS)

Growth in HCBS recipients continues. On June 30, 2002 there were 378,566 persons with ID/DD receiving HCBS, an increase of 15.4% over the

328,159 recipients on June 30, 2001. In the twelve years between June 30, 1990 and 2002, the number of HCBS recipients grew by 338,728 persons (850.3%) from 39,838 HCBS recipients. The number of states with approved applications to provide HCBS increased from 42 to 51. Forty-five states increased their number of HCBS recipients by 1,000 or more between 1990 and 2002.

The number of people receiving HCBS is more than twice the number living in ICFs-MR. On June 30, 2002 the number of HCBS recipients (378,566) was 342.4% of the number living in ICFs-MR. Only eight years earlier on June 30, 1994 the number of ICF-MR residents (142,118) was greater than the number of HCBS recipients (122,075).

The number of people receiving residential services outside the family home with HCBS financing is substantially greater than those receiving residential services in ICFs-MR. Of the 51 states with HCBS programs, 48 were able to report, in whole or part, the residential arrangements of their HCBS recipients. These states reported residential arrangements for 267,893 individuals, 70.8% of 378,566 HCBS recipients on June 30, 2002. More than three-fifths (60.5%) of these HCBS recipients were receiving residential services outside their family home. Applying this statistic to all HCBS recipients on June 30, 2002 yields an estimated 229,032 persons receiving residential services funded by HCBS while living away from the home of their parents or other relatives. This estimated number of HCBS residential service recipients was more than twice the number of ICF-MR residents.

Expenditures for Medicaid HCBS recipients continue to grow and show substantial interstate variability. In Fiscal Year 2002 expenditures for Medicaid HCBS recipients were 13.4 billion dollars for 378,566 recipients, a per end of year recipient average of \$35,298 per year. Expenditures adjusted for average daily HCBS recipients were \$37,816 per person. This represents a 78.0% total or 6.5% average annual increase in per recipient average expenditures between Fiscal Year 1990 (\$21,246) and Fiscal Year 2002. The states with the highest per recipient expenditures in Fiscal Year 2002 were Connecticut (\$67,827) and Delaware (\$64,190). The states with the lowest per recipient expenditures in Fiscal Year 2002 were District of Columbia (\$7,340) and Missis-

sippi (\$12,201).

ICF-MR and HCBS Combined

Growth in the total number of ICF-MR and HCBS recipients has continued at a steady rate. The combined total of 489,138 ICF-MR and HCBS recipients on June 30, 2002 represented a 13.3% average annual increase between June 30, 1992 and June 30, 2002. Between 1992 and 2002 the combined total of ICF-MR and HCBS recipients grew by an average 28,042 persons per year. In comparison, between 1982 and 1987 the combined totals of ICF-MR and HCBS recipients increased at an annual average of about 4,995 persons. Between 1987 and 1992 the combined average annual increase of ICF-MR and HCBS recipients was approximately 8,000 persons. On June 30, 2002, HCBS recipients made up 77.4% of the combined total of 489,138 ICF-MR and HCBS recipients. This compares with just 16.4% fifteen years earlier on June 30, 1987.

On June 30, 2002 ICF-MR and HCBS community service recipients made up more than four-fifths of the combined total of ICF-MR and HCBS recipients. On June 30, 2002 residents of community ICFs-MR (15 or fewer residents) and HCBS recipients made up 85.9% of all ICF-MR and HCBS recipients. That compares with 83.8% on June 30, 2001, 81.9% on June 30, 2000, 80.2 on June 30, 1999; 78.3% on June 30, 1998; 68.6% on June 30, 1995; and 33.0% fourteen years earlier on June 30, 1988. In all states most of the combined ICF-MR and HCBS recipients were receiving community services.

There remains remarkable variation among states in ICF-MR and HCBS utilization rates. On June 30, 2002 there was a national ICF-MR utilization rate of 38.3 ICF-MR residents per 100,000 persons in the United States. The highest individual state ICF-MR utilization rates were 128.6 in District of Columbia and 123.6 in Louisiana. The highest utilization of large ICFs-MR were in Arkansas (50.5), Illinois (51.9), Iowa (50.5), Louisiana (59.6), Mississippi (69.6), and Oklahoma (58.5). State HCBS utilization rates varied from more than twice the national average of 131.3 in five states to less than half of the national average in seven states. On June 30, 2002

nationally there was an average of combined ICF-MR and HCBS recipients of 169.6 per 100,000 of the population. Individual state utilization rates for the combined programs varied from the highest rates in Iowa (285.5), Minnesota (348.4), New York (302.6), North Dakota (416.3), South Dakota (326.4), Vermont (301.0) and Wyoming (323.4) to the lowest rates in Kentucky (65.6) and Nevada (61.0).

Medicaid expenditures are disproportionately greater for persons in ICFs/MR than HCBS recipients. The annual Medicaid expenditures per average daily recipient of ICF-MR services was \$95,746 as compared to \$37,816 per each HCBS recipient. As a result, nationally in Fiscal Year 2002, HCBS recipients made up 77.4% of the total HCBS and ICF-MR recipient population but used only 55.4% of the total Medicaid HCBS and ICF-MR expenditures. In FY 2002 for the fifth consecutive year in the majority of states HCBS expenditures were greater than ICF-MR expenditures.

Differences in state benefits from Medicaid spending continues. Almost any measure of each state's relative benefits from Medicaid funding yields significant interstate differences. Indexing Fiscal Year 2002 federal reimbursements for ICF-MR and HCBS programs in each state by federal income tax paid by residents of each state, 6 states received over twice their relative federal income contributions tax back in benefits, Iowa (\$2.06 in benefits per \$1.00 contributed), Louisiana (\$2.26), Maine (\$2.68), North Dakota (\$3.60), Oklahoma (\$2.05) and West Virginia (\$2.41). By the same measure three states received back less than half their relative contributions (California, Colorado and Nevada).

Nursing Home Residents

The number of persons with ID/DD in Nursing Facilities continues to decrease slowly. On June 30, 2002 there were 34,820 persons with ID/DD in Medicaid Nursing Facilities. This compares with 38,799 on June 30, 1992. Nationwide, in 2002, 8.1% of all persons with ID/DD receiving residential services and 6.6% of all with ID/DD receiving services through Medicaid ICF-MR, HCBS or Nursing Facility programs were in Medicaid Nursing Facilities.

Chapter 3

Characteristics and Movement of Residents of Large State Facilities

K. Charlie Lakin, Sheryl A. Larson, Robert W. Prouty and Kathryn Coucouvanis

This chapter provides information about the characteristics and movement of residents of large state residential facilities for persons with intellectual disabilities/developmental disability (ID/DD) in FY 2002. It is based on a survey of all large state-operated facilities for persons with ID/DD with 16 or more residents or distinct ID/DD units for 16 or more persons within large state facilities primarily serving other populations. A description of the state facility survey is provided in the "Methodology" section ("Individual Large State Facility Survey").

Characteristics of Residents

Table 1.14 presents a summary of selected age, diagnostic and functional characteristics of residents of large (16 or more residents) state ID/DD residential facilities for persons with ID/DD (hereafter "large state facilities") on June 30 of 1977, 1987, 1991, 1996, 1998, 2000, and 2002.

Age of Residents

There has been a continuing aging of the population of residents of large state facilities since 1977. Age statistics are based on reporting large state facilities

Table 1.14 Characteristics of Residents of Large State ID/DD Facilities from June 30, 1977 through June 30, 2002

Characteristic		June 30 of the Year					
		1977 (N=151,112)	1987 (N=94,695)	1996 (N=58,320)	1998 (N=51,485)	2000 (N=47,329)	2002 (N=44,066)
Age	0-21 Years	35.8%	12.7%	5.0%	4.8%	4.5%	4.5%
	22-39 Years	41.3	54.1	44.6	38.1	34.4	30.9
	40-62 Years	19.2	27.3	42.7	48.9	52.7	55.4
	63+ Years	3.7	6.0	7.7	8.2	8.4	9.2
Level of Intellectual Disability	Mild/No ID	10.4	7.2	7.4	7.6	10.2	10.4
	Moderate	16.4	9.8	8.9	9.5	9.8	9.9
	Severe	27.6	20.0	17.8	18.3	17.7	16.7
	Profound	45.6	63.0	65.9	64.6	62.3	63.0
Additional Conditions	Cerebral Palsy	19.3	20.5	22.6	23.5	21.9	19.4
	Behavior Disorder	25.4	40.7	45.7	44.4	47.4	52.4
	Psychiatric Disorder	NC	NC	31.0	34.3	42.0	45.7
Functional Limitations	Needs assistance or supervision walking	23.3	29.5	35.7	38.9	35.4	37.0
	Cannot communicate basic desires verbally	43.5	54.8	59.4	59.6	59.4	58.1
	Needs assistance or supervision in toileting	34.1	46.6	57.0	59.5	55.9	56.1
	Needs assistance or supervision in eating	21.4	37.8	50.9	56.4	48.4	51.4
	Needs assistance or supervision in dressing self	55.8	60.5	66.1	69.9	65.3	62.6

NC = statistic not collected in that year

for June 30 of 1977, 1987, 1991, 1996, 1998, 2000, and 2002. These statistics are based on the reports of state facilities housing 77.2% of all residents on June 30, 2002 (and between 76% and 91.5% in earlier years). As shown in Table 1.13, the proportion of children and youth (birth to 21 years) living in large state facilities declined from 35.8% of all residents in 1977 to 4.5% of all residents in June 2002. Despite the substantial increase in the proportion of residents 63 years and older in large state facilities, from 3.7% in 1977 to 9.2% in 2002, the total number of residents 63 and older actually decreased by about 1,338 residents (to an estimated 4,054) between 1977 and 2002.

The most notably changing age cohort of state facility residents in recent years has been that of “middle age” persons (40-62 years). Between 1991 and 2002 this group grew from 32.5% to 55.4% of all large state facility residents, as the demographics of the “baby boom” became increasingly evident. In June 2002, 64.6% of all large state facility residents were 40 years or older. This compares to 22.9% in June 1977, 33.3% in June 1987, and 50.4% in June 1996.

Despite the rapid proportional growth in persons 40 years and older, between June 30, 1996 and June 30, 2002, the actual number of individuals 40 years and older living in large state facilities decreased by more than 900 persons. About one-half of the overall decrease in large state facility residents who were 40 years or older is attributable entirely to the decreased number of residents who were 63 or older. Between June 1996 and June 2002, the number of residents

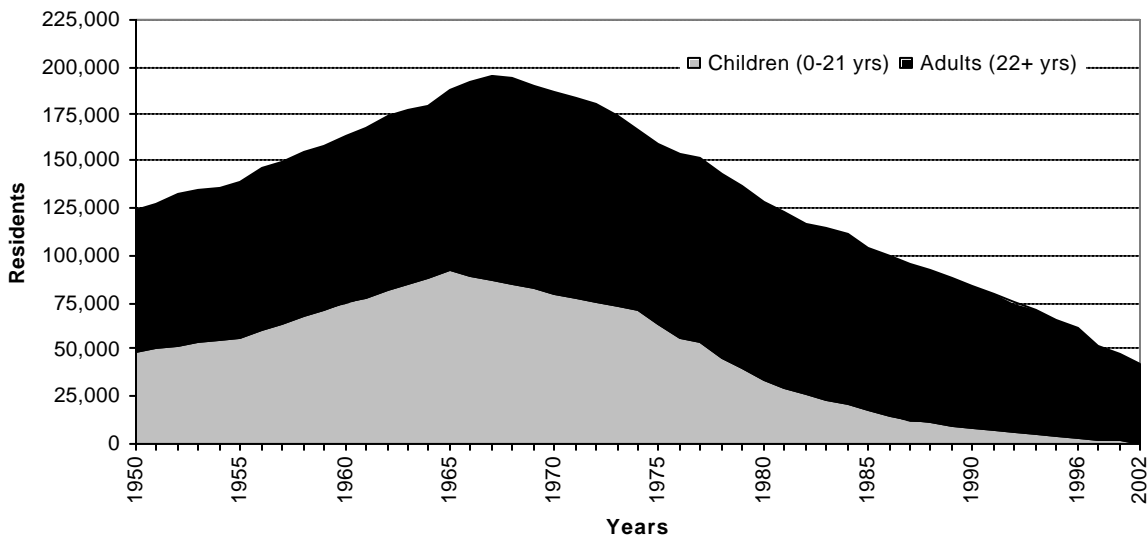
in the 40-62 group decreased by about 480 and the number of persons 63 or older decreased by about 440. As will be evident from admission statistics presented later, the shifts among the age categories during the last four years was primarily because the stable residential population of the large state facilities grew older and “aged out” of the young adult category (22-39 years) and into the middle-aged category. Middle-aged individuals being admitted to large state facilities contributed relatively little to these shifts.

As shown in Figure 1.6, the June 30, 2002 estimate of 1,983 children and youth (0-21 years) making up 4.5% of the large state facility population nationwide reflects the dramatic decreases during the second half of this century and particularly the past quarter century. In 1950, 48,354 of the 124,304 large state facility residents (38.9%) were 21 years or younger. By 1965 the population of children and youth had increased to 91,592 and made up 48.9% of all large state facility residents. Subsequent annual decreases brought the population of children and youth to 54,098 (35.8%) in 1977, 12,026 (12.7%) in 1987, 6,908 (8.7%) in 1991, 2,916 (5.0%) in 1996, 2,130 (4.5%) in 2000 and eventually to 1,983 in June 2002 (4.5%).

Level of Intellectual Disability

Table 1.14 also presents a breakdown of the reported level of intellectual disability of residents of large state facilities on June 30 of 1977, 1987, 1996, 1998, 2000, and 2002. In 2002, based on the reports of facilities

Figure 1.6 Total and Childhood (0-21 Years) Populations of Large State ID/DD Facilities, 1950-2002



housing 76.2% of all large state facility residents, there were an estimated 4,583 large state facility residents with mild or no intellectual disability (10.4% of all residents) as compared with an estimated 15,716 in 1977, 6,818 in 1986, 4,316 in 1996, 3,913 in 1998 and 4,826 in 2000 . It is notable that the proportion of persons with mild or no intellectual disabilities in large state facilities, after having decreased by each year since 1962, from 20.7% in 1962 to 7.4% in 1996, began increasing in 1998 (to 7.6%) and continued in 2000 (to 10.2%) and 2002 (to 10.4%). There were approximately 650 more persons with mild or no intellectual disabilities in large facilities in June 2002 than there were in June 1998.

Between 1991 and 2002 populations of persons with moderate and severe intellectual disability decreased slightly more rapidly than large state facility residents as a whole. The proportion of large state facility populations with profound intellectual disabilities increased substantially from 1977 to 2002, from 45.6% residents to 63.0% of all residents, but between 1996 and 2002 that proportion decreased (from 65.9% to 63.0%).

Despite the general increases in the proportion of residents with profound intellectual disabilities between 1977 and 2002, their actual numbers decreased by more than 41,100 people, from 68,907 to an estimated 27,762 people. In the 15 years between June 30, 1987 and June 30, 2002 the number of large state facility residents with profound intellectual disability decreased by almost 32,000 people or 53.5%. Between June 1996 and June 2002 residents with profound intellectual disability decreased by about 10,700 persons.

Figure 1.7 shows the same basic statistics as those in Table 1.14 with the addition of 1964 and 1982

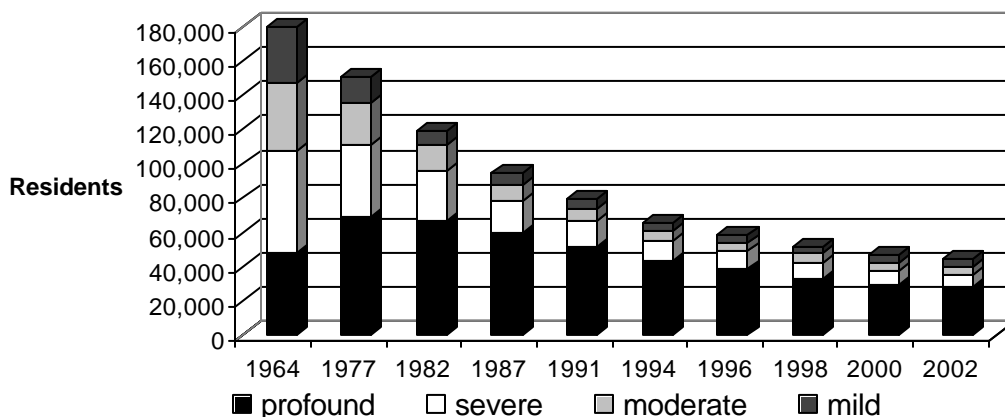
surveys (Scheerenberger, 1965, 1983). It shows that between 1964 and 1977, while large state facility populations decreased by about 38,500 residents, the number of residents with profound intellectual disabilities actually increased by about 20,000. During the same period the number of large state facility residents with mild, moderate, severe or no intellectual disabilities decreased by nearly 50,000 people from 131,100 to 82,000. However, since 1977 and more notably since 1987, persons with profound intellectual disabilities have been decreasing among large state facility populations at rates similar to, indeed slightly faster than, persons with less severe intellectual impairments.

Functional Characteristics

Table 1.14 also shows the percentage of residents of large state facilities reported to have functional limitations in various important activities of daily living. In this study, each of the large state facilities surveyed was asked to report the number of their residents who: 1) "cannot walk without assistance or supervision," 2) "cannot communicate basic desires verbally," 3) "cannot use the toilet without assistance or supervision," 4) "cannot feed self without assistance or supervision" and 5) "cannot dress self without assistance or supervision." National statistics for 2002 are shown in Table 1.14 with comparable statistics from 1977, 1987, 1996, 1998, 2000, and 2002.

Between 1987 and 1996 there was an increasing proportion of large state facility residents with functional limitations requiring assistance. Between 1996 and 2002 the proportions of residents reported to require assistance with activities of daily living remained quite stable. In 2002, 37.0% of large state facility residents were reported to need assistance or supervision in walking and 58.1% to be unable to commu-

Figure 1.7 Level of Intellectual Disability of Residents of Large State ID/DD Facilities on June 30 of Selected Years, 1964-2002



nicate basic desires verbally. Over half (56.1%) of large state facility residents were reported to be unable to use the toilet independently without assistance or supervision. Half (51.4%) were reported to be unable to feed themselves without assistance or supervision. More than three-fifths (62.6%) of residents were reported to need assistance or supervision in getting dressed.

In the 15 years between 1987 to 2002 there were increases in the percentage of residents with substantial limitations in toileting themselves (46.6% to 56.1%), feeding themselves (37.8% to 51.4%), and dressing themselves (60.5% to 62.6%). Again, however, the proportion of residents with limitations in these areas were lower in June 2002 than in June 1998. As will be shown subsequently, there was considerable interstate variation around these averages.

Age by Level of Intellectual Disability

Table 1.15 shows the distribution of residents of large state facilities by age and level of intellectual disability. Facilities housing 77.2% of all residents on June 30, 2002 reported this distribution. Clearly older residents less often had profound cognitive limitations than residents who were relatively younger. Only 57.8% of residents 63 or older and 61.2% of residents 55 years or older had profound intellectual disabilities as compared with 63.5% of all residents 54 years or younger. The youngest residents tended to have more severe cognitive impairments. Over two-

thirds (74.2%) of large state facility residents 9 years and younger had profound intellectual disabilities. On the other hand, there was a notable increase in the number of adolescents and young adults (15-21 years) with mild or moderate intellectual disabilities between June 1998 and June 2002, from an estimated total of 695 (adjusted for non-reporting) in 1998, to 804 (adjusted) in 2000, to 876 (adjusted) in 2002.

One of the most remarkable demographic statistics is that a substantial majority of large state facility residents (56.1%) are non-elderly adults (ages 22-62 years) with profound intellectual disabilities. Over three-quarters (75.1%) of large state facility residents are adults between 22 years and 54 years old.

State-by-State Resident Characteristics

State-by-state statistics on resident characteristics are based on aggregated data on all reporting large state facilities in each state. State breakdowns are provided only for states in which the reporting facilities for any specific characteristics housed at least 50% of all large state facility residents.

Gender of Residents

Table 1.16 shows the distribution of large state facility residents by gender. In all states, the majority of residents were male. Nationally, 62.8% of residents were male, with states ranging from lows of 53% in Arizona, Pennsylvania and Wyoming to more than 75% in Colorado, Florida, Idaho, Michigan, and Minnesota. The proportion of male large state facility

Table 1.15 Distribution of Residents of Large State Facilities by Level of Intellectual Disability and Age on June 30, 2002

Level Intellectual	Chronological Age in Years							Total
	0-9	10-14	15-21	22-39	40-54	55-62	63+	
Mild +	1 (0.0%) [3.2%]	43 (1.3%) [23.2%]	420 (12.3%) [33.3%]	1,394 (40.9%) [13.7%]	1,027 (30.1%) [7.1%]	273 (8.0%) [7.4%]	252 (7.4%) [8.4%]	3,410 (100.0%) [10.4%]
Moderate	3 (0.1%) [9.7%]	31 (1.0%) [16.8%]	234 (7.2%) [18.5%]	1,109 (34.2%) [10.9%]	1,202 (37.0%) [8.3%]	349 (10.8%) [9.5%]	317 (9.8%) [10.5%]	3,245 (100.0%) [9.9%]
Severe	4 (0.1%) [12.9%]	30 (0.5%) [16.2%]	174 (3.2%) [13.8%]	1,564 (28.4%) [15.4%]	323 (42.2%) [16.0%]	709 (12.9%) [19.2%]	704 (12.8%) [23.4%]	5,508 (100.0%) [16.7%]
Profound	23 (0.1%) [74.2%]	81 (0.4%) [43.8%]	434 (2.1%) [34.4%]	6,114 (29.5%) [60.1%]	9,987 (48.2%) [68.7%]	2,361 (11.4%) [63.9%]	1,741 (8.4%) [57.8%]	20,741 (100.0%) [63.0%]
Total	31 (0.1%) [100.0%]	185 (0.6%) [100.0%]	1,262 (3.8%) [100.0%]	10,181 (30.9%) [100.0%]	14,539 (44.2%) [100.0%]	3,692 (11.2%) [100.0%]	3,014 (9.2%) [100.0%]	32,904 (100.0%) [100.0%]

Note: The percentage in parentheses indicates the distribution of persons by age with different levels of mental retardation. The percentage in brackets indicates the distribution of persons by levels of mental retardation within the different age categories. Statistics are based on the reports of state facilities housing 32,904 of 44,066 (74.4%) residents of state facilities on June 30, 2002.

Table 1.16 Gender Distribution of Residents of Large State Facilities by State on June 30, 2002

State	Gender of Residents		Total
	Male	Female	
AL	63.7%	36.3%	100.0%
AK	NA	NA	NA
AZ	53.2%	46.8%	100.0%
AR	65.9%	34.1%	100.0%
CA	63.7%	36.3%	100.0%
CO	81.7%	18.3%	100.0%
CT	57.7%	42.3%	100.0%
DE	DNF	DNF	100.0%
DC	NA	NA	NA
FL	76.1%	23.9%	100.0%
GA	60.2%	39.8%	100.0%
HI	NA	NA	NA
ID	79.2%	20.8%	100.0%
IL	64.1%	35.9%	100.0%
IN	63.0%	37.0%	100.0%
IA	68.9%	31.1%	100.0%
KS	69.4%	30.6%	100.0%
KY	64.3%	35.7%	100.0%
LA	62.0%	38.0%	100.0%
ME	NA	NA	NA
MD	65.3%	34.7%	100.0%
MA	65.8%	34.2%	100.0%
MI	79.2%	20.8%	100.0%
MN	75.6%	24.4%	100.0%
MS	57.3%	42.7%	100.0%
MO	64.0%	36.0%	100.0%
MT	60.8%	39.2%	100.0%
NE	58.4%	41.6%	100.0%
NV	66.6%	33.4%	100.0%
NH	NA	NA	NA
NJ	53.8%	46.2%	100.0%
NM	NA	NA	NA
NY	65.3%	34.7%	100.0%
NC	58.0%	42.0%	100.0%
ND	DNF	DNF	100.0%
OH	62.4%	37.6%	100.0%
OK	72.2%	27.8%	100.0%
OR	73.5%	26.5%	100.0%
PA	53.0%	47.0%	100.0%
RI	NA	NA	NA
SC	60.8%	39.2%	100.0%
SD	73.0%	27.0%	100.0%
TN	56.5%	43.5%	100.0%
TX	59.3%	40.7%	100.0%
UT	59.0%	41.0%	100.0%
VT	NA	NA	NA
VA	60.3%	39.7%	100.0%
WA	59.4%	40.6%	100.0%
WV	NA	NA	NA
WI	60.9%	39.1%	100.0%
WY	52.8%	47.2%	100.0%
U.S. Total	62.8%	37.2%	100.0%

NA = not applicable (state without large state facilities)

DNF = data not furnished or insufficient reporting (50% or fewer of residents included)

residents has slowly increased in recent years (57.0% in 1977, 57.4% in 1982, 59.0% in 1989, 58.5% in 1991, 59.3% in 1994, 60.0% in 1996, 60.4% in 1998, 61.0% in 2000, and 62.8% in 2002).

Age Distribution of Residents

Table 1.17 presents the state-by-state age distribution of residents in large state facilities on June 30, 2002. The table shows the great variability across states in the ages of residents. Differences were particularly notable in the number of children and youth (0-21 years) and the number of older residents (55 years and older). Nationwide, 4.5% of all large state facility residents were 21 years or younger.

Six states reported 10.0% or more of their large facility residents as being in the 0-21 year age range (the same number in 2000, but fewer than the number in 1991). In the 11 years between 1991 and 2002, 47 states reporting statistics for at least 60% of the total large state facility population in both years. In all but 6 of these states there was a reduction in the proportion of residents 21 years and younger or total closure of large public facilities. There was an actual decrease in the number of residents 21 years and younger in all states.

Nationally 20.4% of large state facility residents were 55 years and older, as compared with 14.9% in 1996, 16.8% in 1998 and 18.4% in 2002. Individual states ranged from more than a quarter of all residents being 55 years and older in six states to less than 10% of all residents in this age range in 10 states.

On June 30, 2002 large state facility residents between 40 and 54 years of age made up 44.2% of all residents, a proportion that increased from 26.2% in 1991 and 35.5% in 1996. In the same year period (1991-2002) the proportion of all residents 40 years or older increased from 39.5% to 64.6% of large state facility residents nationally. The proportion of large state facility residents who are 40 years or older is substantially greater than the 44.2% of the general U.S. population in this age range, but it is clearly being influenced by the same demographic trend, the aging of the "baby boom" generation.

In contrast, children and youth (birth to 21 years), made up about 31.0% of the U.S. population, but only 4.5% of the large state facility population. One reason for the disproportionately low rates of large state facility placements among children and youth are the relatively low overall rates of out-of-home placement of children and youth. In 1997 it was estimated that

Table 1.17 Age of Residents of Large State Facilities by State on June 30, 2002

State	Age of Residents in Years						Total
	0-14	15-21	22-39	40-54	55-62	63+	
AL	0.0%	1.4%	37.6%	46.0%	7.5%	7.5%	100.0%
AK	NA	NA	NA	NA	NA	NA	NA
AZ	0.0%	0.0%	5.8%	68.8%	19.5%	5.8%	100.0%
AR	2.1%	5.0%	48.2%	36.7%	6.8%	0.8%	100.0%
CA	0.8%	4.9%	34.3%	44.3%	9.0%	6.7%	100.0%
CO	0.0%	9.1%	42.3%	38.2%	9.7%	0.8%	100.0%
CT	0.0%	1.3%	45.0%	34.7%	11.1%	7.9%	100.0%
DE	DNF	DNF	DNF	DNF	DNF	DNF	DNF
DC	NA	NA	NA	NA	NA	NA	NA
FL	0.0%	1.4%	38.1%	44.0%	9.7%	6.6%	100.0%
GA	1.6%	4.7%	32.5%	42.5%	12.2%	6.5%	100.0%
HI	NA	NA	NA	NA	NA	NA	NA
ID	6.4%	18.2%	34.5%	31.8%	2.7%	6.4%	100.0%
IL	0.0%	2.2%	36.0%	45.1%	10.7%	6.0%	100.0%
IN	0.0%	3.7%	57.4%	31.6%	6.0%	1.3%	100.0%
IA	2.9%	11.3%	29.8%	40.3%	9.6%	6.1%	100.0%
KS	0.5%	6.7%	40.3%	44.3%	3.1%	2.3%	100.0%
KY	0.0%	2.4%	32.8%	49.7%	12.2%	2.7%	100.0%
LA	0.1%	2.8%	42.1%	34.1%	12.2%	8.7%	100.0%
ME	NA	NA	NA	NA	NA	NA	NA
MD	0.0%	3.8%	29.8%	48.0%	11.6%	6.8%	100.0%
MA	0.0%	0.2%	11.5%	44.3%	20.9%	23.1%	100.0%
MI	0.0%	9.8%	50.3%	30.6%	5.2%	4.0%	100.0%
MN	0.0%	24.4%	46.3%	29.3%	0.0%	0.0%	100.0%
MS	3.4%	9.1%	41.0%	32.6%	8.2%	5.7%	100.0%
MO	0.7%	6.1%	41.3%	39.1%	7.9%	4.6%	100.0%
MT	0.0%	2.8%	44.4%	41.1%	5.6%	3.3%	100.0%
NE	1.0%	3.1%	21.2%	50.3%	13.5%	11.0%	100.0%
NV	2.2%	17.7%	51.3%	20.6%	7.5%	0.6%	100.0%
NH	NA	NA	NA	NA	NA	NA	NA
NJ	0.0%	0.5%	19.6%	52.9%	15.6%	11.4%	100.0%
NM	NA	NA	NA	NA	NA	NA	NA
NY	0.4%	8.1%	40.5%	31.8%	10.5%	8.7%	100.0%
NC	0.3%	1.3%	31.3%	48.2%	9.9%	9.1%	100.0%
ND	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OH	0.0%	1.8%	27.1%	46.8%	13.2%	11.1%	100.0%
OK	0.0%	2.8%	42.4%	49.3%	4.2%	1.4%	100.0%
OR	0.0%	0.0%	20.4%	49.0%	10.2%	20.4%	100.0%
PA	0.0%	0.0%	12.3%	47.7%	15.8%	24.2%	100.0%
RI	NA	NA	NA	NA	NA	NA	NA
SC	1.3%	8.3%	36.5%	36.9%	12.5%	4.5%	100.0%
SD	5.8%	19.6%	34.4%	27.0%	9.0%	4.2%	100.0%
TN	0.4%	1.7%	23.8%	50.1%	13.3%	11.5%	100.0%
TX	0.5%	4.9%	36.5%	39.7%	9.6%	8.8%	100.0%
UT	0.0%	2.1%	43.2%	46.2%	5.6%	3.0%	100.0%
VT	NA	NA	NA	NA	NA	NA	NA
VA	0.2%	2.5%	37.0%	43.8%	8.7%	7.8%	100.0%
WA	0.0%	2.2%	50.9%	35.2%	7.8%	3.9%	100.0%
WV	NA	NA	NA	NA	NA	NA	NA
WI	0.8%	3.2%	31.1%	47.8%	11.3%	5.7%	100.0%
WY	0.0%	1.9%	28.3%	36.8%	17.9%	15.1%	100.0%
U.S. Total	0.7%	3.8%	30.9%	44.2%	11.2%	9.2%	100.0%

NA = not applicable (state without large state facilities)

DNF = did not furnish data or insufficient reporting (50% or fewer of residents included)

only 7.7% of all persons with ID/DD in public and private out-of-home placements were between birth and 21 years (Lakin, Anderson & Prouty, 1998).

A more specific factor with respect to large state facilities is the concerted effort by most states to restrict the admission of children to them. This is particularly evident at the younger ages. Thirty-one states had no large state facility residents younger than 15 years and in 10 additional states children 14 years or younger make up less than 1% of all residents. Nationwide, 21.4% of the population is made up of persons 14 years and younger, but only 0.7% of large state facility populations and 8.0% of all admissions to large state facilities in FY 2002 were persons 14 years and younger. In 1965 the majority of persons admitted to large state facilities were 11 years of age or younger (NIMH, 1966).

Persons 63 and older made up about 15.0% of the U.S. population, but only 9.2% of the large state facility population. A primary reason for the lower proportion of persons 63 years and older in large state facilities than in the general population is the continued high use of nursing facilities for the long-term care of older persons with a primary diagnosis of intellectual disabilities and developmental disabilities. The estimated 4,100 persons 63 years and older in large state facilities in 2002 was considerably less than the 10,700 persons 63 and older with a primary diagnosis of intellectual disabilities in nursing facilities based on the total 2002 nursing facility residents in this survey and the estimated 37% of nursing home residents with a primary diagnosis of intellectual disability who were 63 years or older as estimated in the 1985 National Nursing Home Survey (Lakin, Hill, and Anderson, 1991).

Level of Intellectual Disability

Table 1.18 presents the state-by-state distributions of residents of large state facilities by reported level of intellectual disability. Forty states are reported; 9 states are not included because they operated no large state facilities at the time of this survey. In two states reporting large state facilities had only half or fewer of the total state facility populations.

In Table 1.18 persons reported not to have intellectual disabilities have been included in the "mild" intellectual disabilities group. Nationally 63.0% of large state facility residents were indicated to have profound intellectual disabilities. In all but 12 states a

Table 1.18 Level of Intellectual Disability of Residents of Large State Residential Facilities in 2002

State	Level of Mental Retardation (%)				Total
	Mild +	Moderate	Severe	Profound	
AL	10.0	9.6	17.6	62.9	100.0
AK	NA	NA	NA	NA	NA
AZ	2.6	10.4	36.4	50.6	100.0
AR	7.4	11.5	23.8	57.4	100.0
CA	22.6	10.3	12.5	54.5	100.0
CO	31.3	23.9	9.1	35.6	100.0
CT	4.0	8.8	24.9	62.4	100.0
DE	DNF	DNF	DNF	DNF	DNF
DC	NA	NA	NA	NA	NA
FL	DNF	DNF	DNF	DNF	DNF
GA	4.3	10.5	20.3	64.9	100.0
HI	NA	NA	NA	NA	NA
ID	42.7	9.1	11.8	36.4	100.0
IL	10.3	12.4	15.6	61.7	100.0
IN	39.8	16.0	12.2	32.0	100.0
IA	22.2	16.7	17.3	43.8	100.0
KS	14.9	9.9	14.4	60.8	100.0
KY	8.2	11.9	17.8	62.0	100.0
LA	10.2	9.0	12.2	68.6	100.0
ME	NA	NA	NA	NA	NA
MD	9.6	8.4	15.2	66.8	100.0
MA	16.2	15.3	21.9	46.7	100.0
MI	44.5	16.2	15.6	23.7	100.0
MN	80.5	12.2	4.9	2.4	100.0
MS	11.8	12.0	14.7	61.5	100.0
MO	18.1	19.6	20.4	41.9	100.0
MT	19.4	11.1	1.7	35.6	67.8
NE	12.2	9.4	7.9	71.4	100.0
NV	23.6	17.5	25.5	33.4	100.0
NH	NA	NA	NA	NA	NA
NJ	2.9	2.3	11.0	83.8	100.0
NM	NA	NA	NA	NA	NA
NY	34.6	11.6	11.6	42.8	100.0
NC	1.8	5.9	14.8	77.5	100.0
ND	DNF	DNF	DNF	DNF	DNF
OH	3.7	16.2	18.3	61.8	100.0
OK	2.1	3.5	20.8	73.6	100.0
OR	6.1	6.1	8.2	79.6	100.0
PA	3.7	8.5	23.4	64.5	100.0
RI	NA	NA	NA	NA	NA
SC	3.3	8.6	12.7	75.3	100.0
SD	49.2	10.1	9.5	30.2	100.0
TN	4.7	5.5	10.9	78.9	100.0
TX	10.8	10.7	20.3	58.4	100.0
UT	6.8	3.4	6.0	83.8	100.0
VT	NA	NA	NA	NA	NA
VA	3.5	10.4	17.9	54.9	86.7
WA	2.5	6.0	25.1	66.5	100.0
WV	NA	NA	NA	NA	NA
WI	3.1	4.6	19.9	72.4	100.0
WY	2.8	3.8	9.4	84.0	100.0
U.S. Total	10.4	9.9	16.7	63.0	100.0

NA = not applicable (state without large state facilities)

DNF = data not furnished or insufficient reporting (50% or fewer residents included)

majority of the large state facility residents were reported to have profound intellectual disabilities. In more than one-half of reporting states more than 60% of large state facility residents were reported to have profound intellectual disabilities.

A great deal of variability was also found in states' use of large state facilities to house persons with mild and moderate intellectual disabilities. Nationwide, 20.3% of residents were reported to have mild or moderate intellectual disabilities. In 13 states, persons with mild or moderate intellectual disabilities made up more than a quarter of large state facility populations; in 4 states less than 10%. As shown in Table 1.13 the proportion of residents with mild intellectual disabilities has been increasing modestly nationwide in recent years, related in part to the increasing proportion of residents indicated to have psychiatric disorders. In 2002 47.0% of large state facility residents were reported to have psychiatric disorders, an increase from 31.0% in 1996.

Selected Additional Conditions

Table 1.19 presents the reported prevalence of selected secondary conditions of large state facility residents.

Blind. Nationwide, 13.5% of large state facility residents were reported to be functionally blind in June 2002 (defined as having little or no useful vision). This compares with 12.6% in 1991, 15.3% in 1996, 16.2% in 1998, and 16.0 in 2000. Eight states reported 20% or more residents to be functionally blind; 18 states reported less than 10% of large state facility residents were blind.

Deaf. Nationally, 6.6% of large state facility residents were reported to be functionally deaf (having little or no useful hearing). This compares with 5.6% in 1991, 7.4% in 1996, 8.4% in 1998 and 6.8% in 2000. Prevalence rates varied from more than 15% in 2 states to less than 5% in 18 states.

Epilepsy. Nationwide, 45.0% of large state facility residents were reported to have epilepsy. This compares with 44.6% in 1991, 46.1% in 1996, 46.4% in 1998 and 44.7% in 2000. Twenty-six of 40 states reported prevalence rates for seizure disorders among large state facility residents of between 40% and 60%.

Cerebral Palsy. Nationwide, 19.4% of large state facility residents were indicated to have cerebral palsy. This compares to a reported rate of 21.6% in 1991,

22.6% in 1996, 23.5% in 1998 and 21.9% in 2000. The reported prevalence of cerebral palsy varied from state to state. In 18 states the prevalence of cerebral palsy among large state facility residents was indicated to be less than 15% and in 5 other states it was indicated to be greater than 30%.

Behavior Disorder. Individual large state facilities were asked to report the number of their residents with behavior disorders. *Behavior disorder* was defined simply as "behavior that was sufficiently problematic as to require special staff attention." The absence of a definition expressed in behavioral terms of frequency or severity may account for some of the deviation among states from the national average of 52.4%. In 10 states, 60% or more of large state facility residents were reported to have behavior disorders; in 5 states less than 30% of the large state facility residents were reported to have behavioral disorders. The reported prevalence of behavioral disorders has increased from 40.7% to 52.4% between 1987 and 2002.

Psychiatric Condition. Individual facilities were also asked how many of their residents have *psychiatric disorders* defined as "requiring the attention of psychiatric personnel." Nationwide, 45.7% of large state facility residents were reported to be receiving psychiatric attention for psychiatric conditions. This statistic was first collected in 1994 when a prevalence of 30.6% was reported. It has steadily increased in each survey since: 31.0% in 1996, 34.3% in 1998, 42.0% in 2000 and 45.7% in 2002, 65% of reported states reported rates between 35 % and 65%.

Multiple Conditions. In all 47.0% of large state facility residents were reported to have two or more of the above conditions in addition to intellectual disabilities. Nine states reported 60% of large state facility residents as having multiple conditions; 8 reported 35% or less.

Selected Functional Assistance Needs of Residents

Table 1.20 presents selected functional limitations of residents of large state ID/DD facilities.

Walking. Nationwide, 37.0% of residents of large state facilities were reported to need assistance or supervision in walking. This was relatively similar to the 32.4% reported in 1991, 33.4% in 1994, 35.7% in 1996 and 35.4% in 2000. Reported rates varied from 0.0% in Minnesota to more than two-thirds of residents in Montana and Oklahoma. In 7 states more than half of the large state facility residents were

Table 1.19 Selected Additional Conditions of Residents of Large Facilities by State on June 30, 2002

State	Blind (%)	Deaf (%)	Epilepsy (%)	Cerebral Palsy (%)	Behavioral Disorder (%)	Psychiatric Disorder (%)	Two or More Conditions (%)
AL	6.2	7.2	36.4	11.1	48.2	43.0	36.3
AK	NA	NA	NA	NA	NA	NA	NA
AZ	13.0	13.6	52.6	29.2	30.5	30.5	23.4
AR	4.0	4.1	42.2	22.6	47.9	56.6	53.0
CA	32.1	12.5	46.3	28.8	54.6	46.0	56.6
CO	6.3	4.1	28.6	DNF	69.5	69.0	68.9
CT	7.4	7.7	48.9	31.2	64.1	38.1	33.5
DE	DNF	DNF	DNF	DNF	DNF	DNF	DNF
DC	NA	NA	NA	NA	NA	NA	NA
FL	8.5	3.2	28.8	4.4	42.4	34.8	35.2
GA	14.5	7.8	51.1	12.1	32.7	25.9	41.4
HI	NA	NA	NA	NA	NA	NA	NA
ID	7.5	7.5	39.6	10.4	75.5	63.2	67.0
IL	12.7	9.0	44.4	16.7	61.4	38.7	38.9
IN	2.6	1.1	33.4	11.3	81.2	79.6	72.7
IA	7.0	2.1	38.4	4.6	46.0	75.8	63.9
KS	8.7	1.0	58.6	50.6	59.0	22.4	22.1
KY	13.7	2.4	55.9	13.3	68.2	44.6	52.4
LA	9.2	4.0	40.0	21.6	42.4	28.2	37.9
ME	NA	NA	NA	NA	NA	NA	NA
MD	22.4	7.3	48.7	24.4	4.1	36.6	26.9
MA	13.7	1.7	41.0	23.2	40.9	47.7	50.8
MI	5.8	9.2	33.5	0.6	19.7	66.5	66.5
MN	0.0	2.4	17.1	2.4	19.5	100.0	80.5
MS	9.0	4.6	30.6	14.0	34.4	40.4	32.4
MO	10.4	5.1	47.2	22.7	54.4	60.7	55.3
MT	8.6	2.7	58.5	4.3	43.5	56.1	44.3
NE	30.3	5.6	52.6	14.8	35.2	36.0	35.9
NV	8.2	7.1	44.6	11.6	52.7	69.2	77.0
NH	NA	NA	NA	NA	NA	NA	NA
NJ	22.9	9.1	44.5	27.0	47.2	36.0	35.5
NM	NA	NA	NA	NA	NA	NA	NA
NY	12.2	6.0	29.4	19.1	61.2	42.6	63.7
NC	23.7	9.8	52.7	26.7	54.9	28.1	31.6
ND	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OH	13.7	5.8	43.6	12.5	71.0	56.1	58.4
OK	11.1	2.8	66.0	4.2	51.4	51.4	36.1
OR	10.2	4.1	38.8	8.2	61.2	53.1	53.6
PA	9.2	1.5	44.4	19.4	28.9	56.8	43.5
RI	NA	NA	NA	NA	NA	NA	NA
SC	26.0	16.0	59.5	14.9	58.7	32.3	37.3
SD	0.5	1.1	33.3	3.7	100.0	93.1	93.1
TN	18.6	3.5	58.3	50.1	29.7	40.4	16.9
TX	15.1	5.3	51.3	24.1	48.7	46.4	49.4
UT	42.3	24.4	71.4	31.2	49.6	50.4	47.9
VT	NA	NA	NA	NA	NA	NA	NA
VA	14.0	9.7	51.2	20.1	56.7	34.4	39.0
WA	22.4	17.3	52.9	16.9	40.4	39.0	41.7
WV	NA	NA	NA	NA	NA	NA	NA
WI	13.6	7.0	54.5	31.1	51.9	55.1	51.0
WY	9.4	2.8	56.6	16.0	40.6	17.9	32.1
U.S. Total	13.5	6.6	45.0	19.4	52.4	45.7	47.0

NA = not applicable (state without large state facilities)

DNF = data not furnished or insufficient reporting (50% or fewer of residents included)

reported to need assistance walking. In 8 states less than a quarter of large state facility residents were reported to need assistance walking.

Dressing. Nationwide, 62.6% of large state facilities residents were reported to need assistance or supervision in dressing. This compares with 61.1% in 1991, 69.9% in 1998 and 65.3% in 2000. In 18 states two-thirds or more of large state facility residents were reported to need assistance dressing. Only eight states reported less than 50% of their large state facility residents in need of assistance or supervision in dressing.

Eating. Nationwide, 51.4% of large state facility residents were reported to need assistance or supervision feeding themselves. This compares with 50.9% reported to need assistance in feeding themselves in 1996 and 48.4% in 2000. Twelve states reported that 60% or more of their large state facility residents needed help or supervision in eating while 11 states indicated that 40% or less of their large state facility populations needed assistance or supervision eating.

Understanding. Nationwide, 31.3% of large public facility residents were reported not to be able to understand simple verbal requests. States ranged from 0.0% (Minnesota) not understanding to 63.0% (Nebraska). Eleven states reported less than 20%; six states more than 50%.

Communicating. A total 58.1% of large state facility residents were reported to be unable to communicate their basic desires verbally. This compares with 59.4% in 1996, 59.6% in 1998 and 59.4% in 2000. Nine states reported more than 70% of their large state facility residents could not communicate verbally; 12 states reported less than 50% of their large state facility residents could not communicate their basic desires verbally.

Toileting. Nationwide, 56.1% of large state facility residents were reported to need assistance or supervision with toileting. This was an increase from the 46.6% reported in 1987, but similar to the 55.9% reported in 2000. Ten states reported more than two-thirds of large state facility residents needing assistance with toileting; 9 states reported less than 40% of large state facility residents needing assistance or supervision with toileting.

Residents in Movement

New Admissions by Age and Level of Intellectual Disability

Table 1.21 presents the distribution of persons newly admitted to large state facilities in FY 2002 by their age and level of intellectual disability. Data reported in Table 1.21 were supplied by large state facilities with 86.0% of reported admissions. As shown in Table 1.20 persons newly admitted to large state facilities in FY 2002 presented a different profile from the general large state facility population on June 30, 2002. In general they were considerably younger and less severely cognitively impaired than the general population. For example, 4.5% of the total large state facility population was 0-21 years old as compared with 31.1% of the new admissions. While 3.8% of the general large state facility population was made up of persons 15-21 years, 24.8% of new admissions were in this age group. In contrast, while persons 40 years and older made up 64.6% of the large state facility populations, they made only 27.0% of the new admissions. Of course, the relatively higher proportion of young people in the new admission category as compared with general facility population reflects the fact that most people entering residential programs do so in adolescence or young adulthood. In general, over the 15 years between 1987 and 2002, the proportion of children and youth (0-21 years) among new admissions has not changed appreciably, ranging between 31%-35%. Newly admitted middle aged and older residents (40 years and older) have also remained quite stable between about 23% and 27% of all new admissions.

Newly admitted large state facility residents in FY 2002 were much more likely to have mild intellectual disabilities or no intellectual disabilities and considerably less likely to have profound intellectual disabilities than the general large state facility population. Persons with mild or no intellectual disabilities made up 43.2% of new admissions as compared with 10.4% of the general large state facility population. Higher proportions of persons with mild intellectual disabilities among new admissions has been a notable trend in recent years (43.2% in 2002, 42.0% in 2000, 37.8% in 1998, and 31.1% in 1996). This contributed to the increasing proportion of persons with mild intellectual disabilities among general large state facility populations.

Persons with profound intellectual disabilities made up only 19.9% of new admissions as opposed to 63.0% of the total large state facility population.

Table 1.20 Selected Functional Needs of Residents of Large State Facilities by State on June 30, 2002

State	Functional Limitations (%)					
	Needs Assistance/ Supervision Walking	Needs Assistance/ Supervision Dressing	Needs Assistance/ Supervision Eating	Cannot Understand Simple Verbal Requests	Cannot Communicate Basic Desires Verbally	Needs Assistance/ Supervision Toileting
AL	16.7	51.8	37.6	11.8	34.4	41.7
AK	NA	NA	NA	NA	NA	NA
AZ	46.8	70.8	64.3	58.4	71.4	64.9
AR	19.5	55.3	27.2	24.2	54.0	42.6
CA	30.6	56.6	39.4	24.8	49.1	56.2
CO	31.4	6.9	0.0	0.0	17.2	13.8
CT	33.3	84.7	49.9	29.2	69.2	85.3
DE	DNF	DNF	DNF	DNF	DNF	DNF
DC	NA	NA	NA	NA	NA	NA
FL	15.0	43.0	31.2	17.7	46.9	28.0
GA	40.9	79.8	64.7	38.1	79.5	62.2
HI	NA	NA	NA	NA	NA	NA
ID	28.3	39.6	45.3	19.8	46.2	38.7
IL	37.5	57.9	45.5	31.0	47.9	39.9
IN	20.7	42.5	52.0	31.6	33.1	38.6
IA	28.7	64.0	58.7	19.1	57.9	42.1
KS	35.2	68.3	51.4	17.2	66.5	57.5
KY	44.2	68.1	68.0	16.2	64.9	66.0
LA	47.7	65.3	60.5	33.5	58.3	59.9
ME	NA	NA	NA	NA	NA	NA
MD	45.6	78.2	72.9	51.6	62.6	64.8
MA	41.5	59.2	51.6	33.5	54.7	54.9
MI	17.9	35.8	27.2	22.5	38.2	33.5
MN	0.0	0.0	0.0	0.0	4.9	0.0
MS	38.3	62.2	39.8	21.0	58.2	51.6
MO	53.9	69.2	59.3	21.0	57.9	68.4
MT	66.7	69.7	71.3	52.0	63.3	77.2
NE	45.7	65.8	35.5	62.8	69.1	59.4
NV	13.9	30.1	18.9	10.2	43.6	26.5
NH	NA	NA	NA	NA	NA	NA
NJ	34.3	62.7	28.1	7.8	70.9	47.4
NM	NA	NA	NA	NA	NA	NA
NY	25.7	51.0	41.1	32.1	34.6	50.1
NC	53.0	83.6	72.3	53.1	77.8	76.6
ND	DNF	DNF	DNF	DNF	DNF	DNF
OH	34.6	68.3	52.9	34.9	63.5	56.1
OK	69.4	72.9	43.8	52.8	70.8	66.0
OR	14.3	30.6	22.4	8.2	83.7	40.8
PA	54.2	77.9	61.5	42.6	48.0	74.2
RI	NA	NA	NA	NA	NA	NA
SC	48.5	66.6	61.5	37.4	64.5	69.3
SD	DNF	DNF	DNF	DNF	DNF	DNF
TN	47.2	40.7	34.5	28.9	62.8	37.6
TX	38.4	61.2	49.1	35.2	66.4	53.5
UT	37.2	80.8	64.1	41.5	71.8	63.7
VT	NA	NA	NA	NA	NA	NA
VA	32.5	81.1	75.4	42.1	62.3	74.6
WA	42.0	76.2	82.2	44.3	83.0	77.9
WV	NA	NA	NA	NA	NA	NA
WI	55.1	82.4	74.2	46.6	69.6	72.0
WY	64.2	78.3	77.4	37.7	83.0	78.3
U.S. Total	37.0	62.6	51.4	31.3	58.1	56.1

NA = not applicable (state without large state facilities)

DNF = data not furnished or insufficient reporting (50% or fewer of residents included)

Persons with profound intellectual disabilities made up 18.9% of new admissions in FY 2000, 24.5% in 1998, and 28.7% in 1996.

Children and young adults (birth to 39 years) with mild or no intellectual disabilities made up 35.6% of all new admissions in FY 2002. This was an increase in the proportion of children and young adults in new admissions from 2000 (33.9% of all new admissions), 1998 (31.0% of all new admissions) and 1996 (25.7%). As will be seen in Table 1.23, children and young adults also make up a higher proportion of discharges, indicating that large state facilities continue to function as relatively short-term entry and/or "crises response" points for state residential services systems.

Readmissions by Age and Level of Intellectual Disability

Table 1.22 presents the distribution of persons readmitted to specific large state facilities in FY 2002 by their age and level of intellectual disability. The large state facilities reporting data for Table 1.22 had 84.2% of all reported readmissions. The profile of readmissions shown in Table 1.22 is more similar to that of new admissions than of the general population, although, as would be expected, is slightly older than that of the new admissions (e.g., 28.8% as compared with 27.0% being 40 years or older). As with new admissions there was a relatively high proportion of persons with mild or no intellectual disabilities (27.7% as compared with 10.4% in the general large state facility population) and a relatively low proportion of persons with profound intellectual disabilities (42.4% as compared with 63.0% in the general large state facility population). There was a steady increase between 1991 and 2002 in the number and proportion

of persons with profound intellectual disabilities among readmissions (26.5% of readmissions in 1991, 33.9% in 1996, 35.4% in 1998, 37.6% in 2000 and 42.4% in 2002). This reflects the growing numbers of former residents who have moved to community settings as well as the difficulties those settings have faced in successfully meeting their needs.

While persons readmitted were slightly older than new admissions, they tended to be younger than the general large state facility population (e.g., 30.3% vs. 4.5% were 21 years or younger; 2.3% vs. 9.2% were 63 years or older). The proportion of children and youth (0-21 years) among all readmissions increased in recent years, from 19.0% in 1989 to 30.3% in 2002. Still the estimated total number of children and youth readmitted to large state facilities decreased from an estimated 292 in 1989 to an estimated 147 in 2002, as total readmissions were substantially reduced.

Discharges by Age and Level of Intellectual Disability

Age. Table 1.23 presents the age distributions and level of intellectual disabilities reported for 2,132 people discharged from large state facilities in the year ending June 30, 2002. Table 1.23 is based on reports from facilities with 76.4% of all discharges in FY 2002. The age distribution of large state facility discharges was considerably more similar to the age distribution of the general large state facility population than were the persons admitted. Persons between the ages of 22 and 54 made up 68.2% of discharges and 75.1% of the general large state facility population. Persons 55 and older made up 20.4% of the general population and 12.4% of the persons discharged. Like children and youth (0-21 years) admitted to large state facilities,

Table 1.21 New Admissions to Large State Facilities by Age and Level of Intellectual Disability in the Year Ending June 30, 2002

Intellectual Disability	Chronological Age in Years								Total (% of Total)
	0-4	5-9	10-14	15-21	22-39	40-54	55-62	63+	
Mild+	3	1	28	175	269	89	11	3	579 (43.2)
Moderate	0	3	23	71	115	63	11	4	290 (21.7)
Severe	0	6	4	39	86	54	11	3	203 (15.2)
Profound	3	2	12	47	89	79	26	8	266 (19.9)
Total	6	12	67	332	559	285	59	18	1,338
(%)	(0.4)	(0.9)	(5.0)	(24.8)	(41.8)	(21.3)	(4.4)	(1.3)	(100.0)

Note: Statistics on new admissions by level of intellectual disability include 1,338 of 1,567 (85.4%) total new admissions among reporting state facilities in FY 2002. Statistics reported by individual facilities in this table include "transfers" from other large state facilities (see Table 1.24).

the proportion of children and youth being discharged was substantially greater than the proportion of children and youth in the general large state facility populations (19.4% of discharges as compared to 4.5% of the general population). Although large state facilities continue to admit substantial numbers of children and youth, they appear to be generally quick to discharge them.

Cognitive Impairment. The levels of cognitive impairment of persons discharged tended to fall in a range between that of persons being admitted during FY 2002 and the general population of those same large state facilities. Persons with profound intellectual disabilities made up 36.0% of discharges, as compared to 25.9% of combined new admissions and readmissions and 63.0% of the general large state facility population. Persons with mild or no intellectual disabilities made up 30.3% of discharges, 39.1% of combined new admissions and readmissions and 10.4% of the general large state facility population. Overall, persons discharged outnumbered persons admitted (new and readmitted) in the reporting facilities by about 14.8%. Persons with severe and profound intellectual disabilities discharged outnumbered these admitted by 51.5% (388 persons). In notable contrast, there were 7.9% more admissions than discharges of persons with mild and moderate intellectual disabilities during FY 2002.

Persons in Movement in 1989 through 2002

Figure 1.8 compares the number and distribution by level of intellectual disability of newly admitted, readmitted and discharged residents of individual large state facilities in FYs 1989, 1996, and 2002. Admission patterns were generally similar in 1989,

1996, and 2002, although there were steadily fewer persons in each of these categories, in large part because the June 30, 2002 population of large state facilities was 43,348 persons (50.0%) smaller than in June 1989. In 2002, the estimated total of new admissions and readmissions (2,149) was less than half (40.2%) of the number in 1989 (5,337). Discharges in 2002 (2,785) were also less than half (45.5%) of those in 1989 (6,122). This general pattern of decreasing movement into and out of large state facilities has been evident for many years. For example, the combined new admissions and readmissions in 2002 (2,149) were just 19.3% of the total in 1980 (11,141); discharges in 2002 (2,785) were just 20.4% of the discharges in 1980 (13,622).

In 1989, 26.9% of combined new admissions and readmissions had mild or no intellectual disabilities as compared to 39.1% in 2002. In FY 2002, 25.9% of new admissions and readmissions had profound intellectual disabilities as compared to 34.7% in 1989. Among discharges there has been a trend for persons with profound intellectual disability to make up a decreasing proportion: 49.1% in 1996, 40.8% in 2000 and 36.0% in 2002.

Previous Placement of New Admissions

Table 1.24 summarizes the previous place of residence of persons admitted to large state facilities for the first time in FY 2002. Statistics are provided for FYs 1985, 1989, 1994, 1998, 2000, and 2002. As was evident in each of the years shown, a very frequent place of immediate prior residence for persons admitted to one large state facility was another large ID/DD facility (13.8% of 2002 new admissions). However, this percentage was notably lower than in previous years, reflecting the cumulative

Table 1.22 Readmissions to Large State Facilities by Age and Level of Intellectual Disability in the Year Ending June 30, 2002

Intellectual Disability	Chronological Age in Years								Total (% of Total)
	0-4	5-9	10-14	15-21	22-39	40-54	55-62	63+	
Mild+	0	0	1	22	70	30	5	6	134 (27.7)
Moderate	0	1	3	15	29	12	5	1	66 (13.6)
Severe	0	3	6	10	24	26	9	1	79 (16.3)
Profound	2	24	25	35	75	31	10	3	205 (42.4)
Total	2	28	35	82	198	99	29	11	484
(%)	(0.4)	(5.8)	(7.2)	(16.9)	(40.9)	(20.5)	(6.0)	(2.3)	(100.0)

Note: Statistics on readmissions by level of intellectual disability include 484 of 582 (83.2%) total readmissions among reporting state facilities in FY 2002. Statistics reported by individual facilities in the table include "transfers" from other large state facilities (see Table 1.25).

Table 1.23 Discharges from Large State Facilities by Age and Level of Intellectual Disability in the Year Ending June 30, 2002

Level of Intellectual Disability	Chronological Age in Years								Total (% of Total)
	0-4	5-9	10-14	15-21	22-39	40-54	55-62	63+	
Mild+	1	1	16	133	308	137	30	20	646 (30.3)
Moderate	0	3	19	63	138	95	17	10	345 (16.2)
Severe	1	6	13	31	135	126	40	22	374 (17.5)
Profound	7	27	32	61	222	292	88	38	767 (36.0)
Total	9	37	80	288	803	650	175	90	2,132
(%)	(0.4)	(1.7)	(3.8)	(13.5)	(37.7)	(30.5)	(8.2)	(4.2)	(100.0)

Note: Statistics on discharges by level of intellectual disability include 2,131 of 2,785 total discharges among reporting facilities in FY 2002. Statistics reported by individual facilities in this table include "transfers" to other large state facilities (see table 1.26).

effects of facility closures, consolidations and depopulation. On the other hand, in 2002 the combined new admissions from other large ID/DD facilities (16 or more residents) and psychiatric facilities made up 24.4% of all new admissions. Since 1987 this proportion has remained in the range of about 38% to about 45% of all new admissions. In 2000 and again in 2002, more of the newly admitted residents came from psychiatric facilities than from large state ID/DD facilities.

In 2002 the proportion of newly admitted persons coming directly from their family homes continued a sustained decrease (from 39.2% from 1985 to 18.5% in 2002). A primary factor in this reduction has been the decrease of placements of children and youth in the large state facilities.

FY 2002 saw continuation of slight increases in the proportions of new admissions coming from community foster/host family homes, group homes or semi-independent and supported living settings (21.7% as compared with 14.9% in 1989, 18.2% in 1996, 18.6% in 1998 and 21.0% in 2000). It should be noted, however, that the actual numbers of people admitted from these community residential arrangements decreased between 1989 and 2002 as total admissions decreased (i.e., from about 510 in FY 1989 to about 340 in FY 2002).

Previous Placement of Readmissions

Table 1.25 presents the previous place of residence of persons readmitted to large state facilities from 1985 to 2002. Persons readmitted to large state facilities in FY 2002 most frequently came from community residential settings (40.5%), including group homes with 15 or fewer residents (27.3%) foster

or host homes (6.5%), semi-independent or supported living arrangements (5.5%) or board and care homes (1.2%). A notable trend between 1985 and 1991 had been the decrease in persons readmitted from their family home or the home of a relative (36.8% in 1985, 29.1% in 1987, 19.6% in 1989, 14.1% in 1991). Since 1991 there has been a substantial reversal of this trend. For example, in 1994, 26.7% of readmissions came from the homes of family members (29.7% in 1996, 33.8% in 1998, 31.5% in 2000, and 28.2% in 2002). It is not clear why this proportional increase has occurred; however, it may reflect the use of large state facilities as temporary crisis placements. Despite the growing proportion of readmissions from family homes, the total numbers have been quite steady. Between 1991 and 2002 the actual number of people readmitted from family homes decreased as total readmissions decreased by more than 60%.

New Residence of Discharged Residents. Table 1.26 shows the new place of residence of people leaving large state facilities in FY 2002, and, for comparative purposes, in FYs 1985, 1989, 1994, 1998 and 2000. In 2002, 57.7% of all persons discharged from large state facilities for whom subsequent placement was reported (i.e., excluding unknown/other) went to live in group homes, foster/host family homes, semi-independent supported living arrangements or board and care homes of 15 or fewer residents. Another 13.8% of discharged residents whose placement was known went to the homes of family members. In 2002 the pattern of slight increases in the percentage of discharged residents moving to their parents' or relatives' homes continued (from 7.2% in 1991 to 9.2% in 1994 to 10.8% in 1998 to 11.8% in 2000 to 15.1% in 2002), but remained

Figure 1.8 Distribution of New Admissions, Readmissions and Discharges of Large State Facilities by Level of Intellectual Disability in Fiscal Years 1989, 1994, 2000, and 2002.

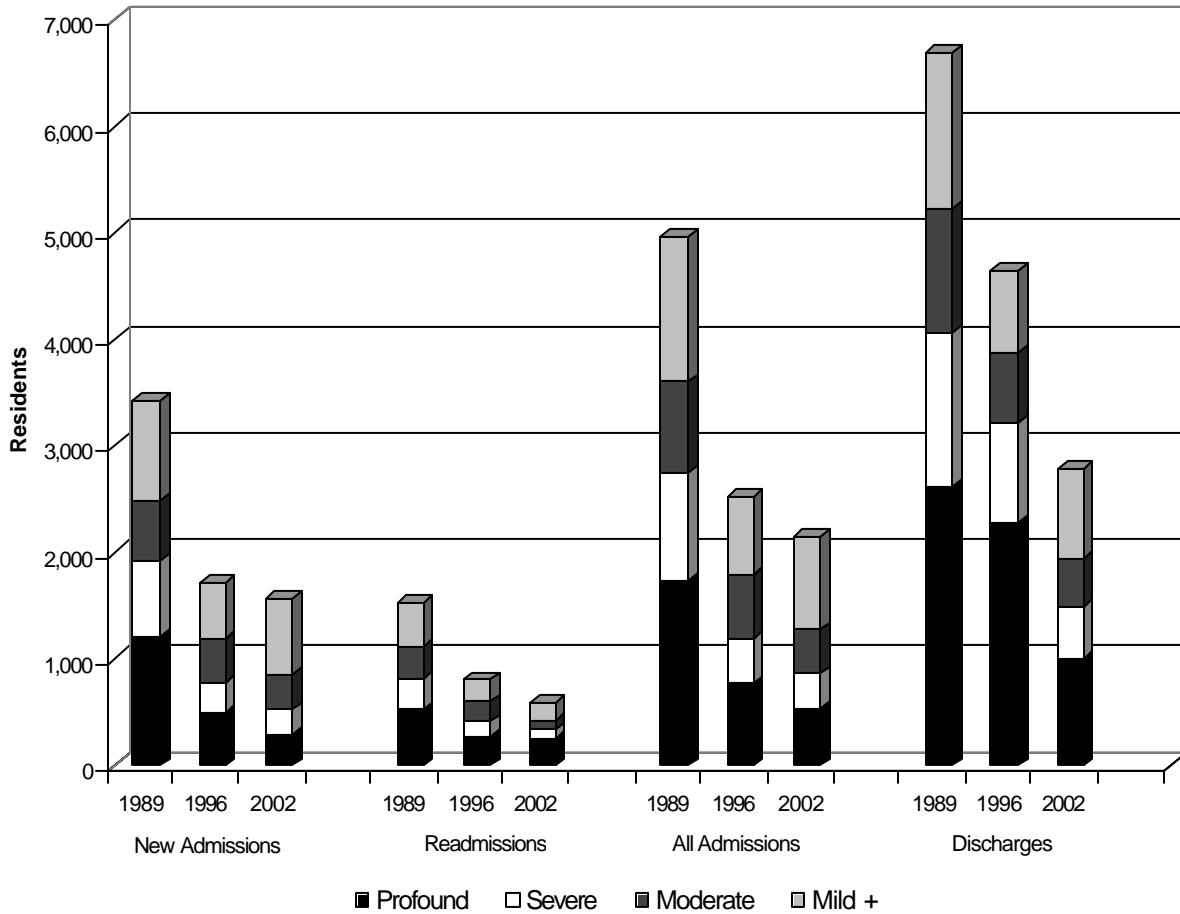


Table 1.24 Previous Place of Residence of Persons Newly Admitted to Large State Facilities in Fiscal Years 1985 through 2002

Previous Place of Residence	Fiscal Years					
	1985	1989	1994	1998	2000	2002
Home of parents or relative	39.2%	28.5%	19.1%	20.9%	20.6%	18.5%
Foster/host family home	3.5	5.2	2.9	2.3	3.4	2.6
Group home (15 or fewer res.)	5.6	8.4	14.1	14.4	14.3	16.4
Group facility (16-63 res.)	3.5	4.0	3.1	3.8	3.8	3.0
Nonstate facility (64+ res.)	1.8	0.0	5.4	2.1	1.8	5.0
State facility (64+res.)	20.6	18.5	23.1	25.3	15.3	13.8
Boarding homes/Board and care	0.5	1.7	0.6	0.5	0.7	0.4
Nursing facility	1.6	2.7	2.1	1.7	1.2	1.4
Semi-ind./ Ind. supported living	1.0	1.3	2.1	1.9	2.6	2.7
Mental health facility	13.6	16.3	15.9	12.0	21.2	16.4
Correctional facility	2.3	3.0	4.3	10.3	7.9	12.6
Unknown/Other	6.7	7.2	7.3	5.9	7.1	6.7
Total	100.0	100.0	100.0	100.0	100.0	100.0

Note: Statistics on previous placements for new admissions in Fiscal Year 2002 are based on the reports of large state facilities reporting 1,369 of 1,566 (87.4%) new admissions.

Table 1.25 Previous Place of Residence of Persons Readmitted to Large State Facilities in Fiscal Years 1985 through 2002

Previous Place of Residence	Fiscal Years (%)					
	1985	1989	1994	1998	2000	2002
Home of parents or relative	36.8	19.6	26.7	33.8	31.5	28.2
Foster home	7.1	9.3	5.4	5.9	6.2	6.5
Group home (15 or fewer res.)	19.7	22.9	30.1	31.3	23.5	27.3
Group facility (16-63 res.)	4.1	2.4	5.1	2.5	5.8	2.8
Nonstate facility (64+ res.)	2.5	2.9	1.8	0.8	1.1	1.4
State facility (64+res.)	7.4	13.5	8.7	4.5	4.3	4.5
Boarding homes/Board and care	1.2	0.9	0.6	0.2	0.4	1.2
Nursing facility	2.0	3.1	1.8	2.7	3.8	3.6
Semi-ind./ Ind. supported living	0.6	1.3	2.5	4.4	6.0	5.5
Mental health facility	8.5	12.8	8.1	8.9	14.5	8.3
Correctional facility	0.0	0.9	3.1	2.5	2.6	4.2
Unknown/Other	7.9	0.1	0.1	0.1	0.3	6.5
Total	100.0	100.0	100.0	100.0	100.0	100.0

Note: Statistics on previous placements for readmissions in Fiscal Year 2002 are based on the reports of large state facilities reporting 505 of 583 (86.6%) of all estimated readmissions.

below the 17.1% in 1985. Post discharge placement patterns were fairly stable between 1985 and 2002 in terms of proportional distributions. But, FY 2002 was notable in the substantial increase in the number of people leaving large state institutions only to go to other large public or private institutions. In FY 2002, an estimated 12.1% of persons discharged went to other large ID/DD or psychiatric institutions. In actual numbers, the estimated 1,373 discharges to community group homes increased from the estimated 1,240 in 2000, but remained fewer than the estimated 3,269 in 1989, 3,081 in 1994, 2,563 in 1996, and 1,503 in 1998. Nursing home placements

(an estimated 125 people and 4.2% of discharges in 2002) were substantially less than the 354 and 4.4% people of all discharges in 1987, the year in which the OBRA nursing home reforms were enacted. (See Section III for a description.) In 2002, the discharge rate to nursing homes (4.2%) continued its steady growth above the 2.0% to 2.7% range that has maintained since the passage of the OBRA 1987 nursing home reforms, perhaps reflecting an aging population of large state facilities. Although the growing proportion of discharges to nursing facilities is still fewer in total number than previous years, it is worthy of attention.

Table 1.26 New Place of Residence of Persons Discharged from Large State Facilities in Fiscal Years 1985 through 2002

New Place of Residence	Fiscal Years (%)					
	1985	1989	1994	1998	2000	2002
Home of parents or relative	17.1	12.4	9.2	10.8	11.8	13.8
Foster/host family home	7.1	7.4	8.6	6.3	3.7	3.9
Group home (15 or fewer res.)	40.4	48.8	55.6	50.9	41.9	46.3
Group facility (16-63 res.)	7.4	5.3	4.3	3.7	5.6	2.0
Nonstate facility (64+ res.)	3.8	2.6	2.4	0.7	4.4	1.2
State facility (64+ res.)	10.1	10.2	8.8	6.1	9.6	6.7
Boarding homes/Board and care	3.2	2.3	1.4	3.1	0.7	0.5
Nursing facility	4.1	2.0	2.6	2.6	3.3	4.2
Semi-independent/Supported living	1.4	1.9	4.6	9.2	10.4	7.0
Mental health facility	1.4	1.4	0.9	1.5	2.1	2.2
Correctional facility	0.2	1.3	0.4	0.0	1.6	2.5
Unknown/Other	3.7	4.3	5.8	5.0	5.0	8.8
Total	100.0	100.0	100.0	100.0	100.0	100.0

Note: Statistics on new placements for people discharged in Fiscal Year 2002 are based on large state facilities reporting 2,229 of 2,785 (80.0%) total estimated discharges.

ALL PEOPLE CAN BE SUPPORTED IN THE COMMUNITY

One common argument for keeping institutions open is that there are some people who cannot be supported in the community. Typically, these include people who have significant and complex medical needs, behavioral issues, and psychiatric disabilities, and people who have grown old in the institution. How can advocates respond to these concerns?

First of all, people with these needs live in states that have closed or drastically reduced the population of their public institutions, as well as in states that rely on institutions to serve them. By 2001, 125 public institutions had closed across the country. The states of Alaska, Hawaii, Minnesota, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia, and the District of Columbia, have closed all of their public institutions. Arizona, Colorado, Maine, and Michigan have very few people still living in public institutions by that year. These states have developed successful strategies for supporting people with significant needs in the community.

Second, many people with extensive support needs, similar to or more intensive than the needs of those now living in institutions, are living in the community today. Many of these people have never lived in an institution. Many others have moved from institutions into the community.

People with Challenging Behavior

In the last decade, studies of people who have moved from institutions have consistently found improvements (or no deterioration) in adaptive and challenging behavior after they move into the community. Many states have developed systems of behavioral support and crisis prevention/response, and many states have shifted from group settings to individualized, person-centered support services, thus reducing the provocations that may trigger difficult behavior. Many people with behavioral issues, now living in environments that interest and satisfy them, learn how to express themselves in other ways. States need not rely on institutions to serve people with challenging behavior.

People with Significant and Complex Medical Needs

People who rely on feeding tubes and ventilators, who have difficult-to-control diabetes or seizures or other potentially dangerous conditions, who need suctioning and frequent positioning, or who have other medical conditions requiring sophisticated medical expertise and technology, are living in the community in most states. For every person with such needs in institutions, there are many with the same or more complex needs living in the community, going to school, going on family vacations, going to a workplace, and generally having as normal a life as possible. Their medical services are provided by community doctors, nurses, personal care assistants, provider agency staff persons, and trained family members. At times, specialized medical services must be created or packaged in order to meet needs: medical

equipment might be brought into a home, or round-the-clock nursing assistance, to enable the person to live as normally as possible. According to the studies that we could find, it is clear that this group of people is a small percentage of people with developmental disabilities, and the data about their health outcomes is very limited. That is, some data shows that most people's health improves with a move to the community, and other data shows that health outcomes for people with the most severe disabilities are slightly worse. It should be evident that where careful planning and implementation is done, those with complex medical conditions have better outcomes.

The latest information from The Council on Quality and Leadership (Gardner, 2003) states, "In organizations participating in The Council's accreditation program with the Personal Outcome Measures, there is no tradeoff of health and wellness, freedom from abuse, or safety in the pursuit of greater outcomes in the areas of community affiliation, choice or self determination. The data show no negative relationship between outcomes related to quality of life and social capital and those of basic assurances. People can make choices associated with where to live and work, and what to do during the day without compromising health and safety. Promoting choice and connections to the community and relationships, in fact, help to promote and sustain these basic protections."

The fact is that as a field, we know how to support people with complex medical needs in the community, and to do so in a manner that maintains their health and happiness. States need not rely on institutions to serve people with complex medical needs.

People with Psychiatric and Developmental Disabilities

The states that have closed their public institutions for people with developmental disabilities have also learned how to support people with psychiatric disabilities (so-called "dually diagnosed" individuals) in the community. In fact, far more people with both diagnoses are living in communities all over the country than in public institutions. States need not rely on institutions to serve people with both psychiatric and developmental disabilities.

Older People with Developmental Disabilities

It is sometimes said that people who have grown old in a public institution should not be moved into a home in the community, because "the institution is the only home they have ever known." However, individuals who have moved out after growing old in institutions are frequently very happy with the move. States need not keep institutions open just for the older residents of such institutions.

People Involved with the Criminal Justice System

When a person with a developmental disability is charged with or found guilty of committing criminal offenses, decisions about his or her future placement are under the jurisdiction of the courts and the

criminal justice system. Some states have developed services for this group of people, but the issue of whether or not they can be served in the community is for the courts to decide, ideally in collaboration with the developmental disability service system. Institutions should not be kept open for them, because there are other alternatives the courts can utilize.

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Serving Persons with MR/DD Who Are Involved with State Criminal Justice Systems

While the vast majority of people with life-long cognitive disabilities are law-abiding and productive citizens, a small percentage find themselves involved in the criminal or juvenile justice systems. Some states have begun programs aimed at assisting these individuals. Generally such programs focus on transitioning persons with mental retardation or a related developmental disability (MR/DD) out of the justice system and into education and/or community support systems that respond to their needs and behaviors in ways that reduce the likelihood of recidivism. These programs often operate side-by-side but separately from community crisis response programs. This article describes three such programs operating in three substantially different states.

The North Carolina Model

Recognizing that limited attention has been given to individuals with MR/DD within the justice system, the North Carolina Council on Developmental Disabilities (DD Council), the Division of Developmental Disabilities Services (DDS), and the North Carolina Center on Crime and Punishment have collaborated to assess the status of people with developmental disabilities in the criminal and juvenile justice systems. Based on the work of the Justice Task Force comprised of staff from MR/DD services, the DDS and justice professionals, a special report, entitled *In Pursuit of Justice: A Report on the Justice System's Response to People with Developmental Disabilities*, was developed to serve as a guide for creating new supports and services for persons with MR/DD involved with the criminal justice system. The task force found that the majority of persons with developmental disabilities in correctional facilities also were diagnosed with mental retardation, and, in

general, found that of the offenders with mental retardation studied:

- Each had a juvenile record;
- There was no mention in probation and parole reports that staff were aware of the offender's disability (i.e., identification of the disability did not occur until the offender entered the Division of Prisons); and
- Most were viewed as "willful and non-compliant" because of a lack of understanding in the corrections system of their disability. Consequently, they often failed to meet the conditions of probation and parole.

The task force also found that there was no communication among human service agencies including mental health, developmental disabilities, and substance abuse, and the criminal justice system. Furthermore, it noted that most mental health, developmental disabilities, and substance abuse professionals were often uncomfortable with offenders possibly due to a lack of knowledge and training about the criminal justice system.

Based on each of the service deficits identified, corrective recommendations were developed by the task force. Currently, the state DD services agency and the state DD Council are working on three separate initiatives based on the report recommendations. First, the DD Council funded a "bench and bar" training to county and local judges, prosecutors, public defender offices, and law enforcement officials. Held in Fall 1999, the training was intended to sensitize judicial and law enforcement officials to the needs of persons with developmental disabilities and educate them about the state's MR/DD service system. Secondly, the state DD services agency convened a statewide meeting composed of North Carolina Department of Correc-

tions social workers, MR/DD case managers, DD agency staff, and Department of Prisons staff. Topics included: a) definitions of services for transition protocol in and out the prison system; b) an overview of the MR/DD system and corrections system – including recent changes in sentencing structure; c) a discussion of victims services; d) case staffing issues; and e) the development of a sex offenders task force (anecdotal estimates by North Carolina officials indicate that as many as 30% of incarcerated persons with MR/DD who were convicted of a felony committed a sexual offense). Thirdly, the Justice Task Force plans on beginning a pilot project on community services for offenders with MR/DD in the eastern part of the state, based on Pennsylvania's Lancaster model.

The Oklahoma Plan

The State of Oklahoma has a statutory requirement that state courts refer offenders with MR/DD to the Oklahoma Department of Human Services. These laws are intended to divert people with cognitive disabilities, mental illness or substance abuse from the criminal justice system into treatment and/or support programs. The Developmental Disabilities Services Division (DDSD) has a cooperative agreement with the Department of Mental Health and Substance Abuse Services concerning the population diverted from the state court system. Under this agreement, offenders with cognitive disabilities, or a mental illness and substance abuse are referred to the Robert M. Greer Center, a state facility for persons with MR/DD and/or mental illness operated by DDSD. Since 1996 Oklahoma has also maintained a Habilitation Center in the Joseph Harp Correctional Facility. Begun with a funds from the Oklahoma Developmental Dis-

abilities Council and now operated by the state Department of Corrections (DOC), the center was established to provide services to offenders with cognitive disabilities that will “help each participant to function at his optimal level in a law abiding manner.” Referrals are made from DOC or by court order and are then reviewed by an interdisciplinary team responsible for developing an Individual Habilitation Plan (IHP).

Offenders who exhibit behavior dangerous to themselves or others, who have received maximum security status, or who are diagnosed with acute mental illness requiring inpatient treatment are excluded from eligibility. The program is intended to aid participants in improving adaptive skills in major life areas as identified in assessments. Offenders take part in community living skills, vocational and academic training, and work towards goals and objectives set out in an IHP that documents progress towards eventual graduation from the program. Upon completion of the program, the offender may receive services in another unit or another facility with regular contacts by center staff; find placement in a non-correctional program; or continue enrollment in the Harp Center. Annually, data is gathered to evaluate effectiveness based on achievement of goals and objectives by participant offenders, work performance of graduates (i.e., pay, performance evaluations, tenure) and return to a correctional facility.

The New York System

The State of New York has structured its correctional programs with the intent that persons with mental disabilities charged with crimes or convicted of crimes not be treated in the same manner as persons without disabilities based on the following findings: a) persons with MR/DD may not understand their rights; b) they have tendency to respond to questions in the manner they believe is expected of them; c) individuals with MR/DD may have difficulty communicating with their legal counsel; d) they

are frequently abused by fellow inmates; and e) there is a lack of appropriate diversion or alternative treatment programs for persons with MR/DD who are incarcerated. New York penal law and criminal procedure law codifies sanctions for those judged not responsible for their actions by reason of mental disability. Aimed at identifying individuals with mental illness and cognitive disabilities, these provisions are intended to divert them from further criminal processes, and ultimately provide care outside correctional settings for those who are not found criminally responsible for their actions.

In New York, following a clinical evaluation, if the court determines that the defendant is “incapacitated (one who as a result of mental disease or defect lacks capacity to understand the proceedings against him or to assist in his own defense),” he or she is committed “to the custody of the commissioner [of mental retardation and developmental disabilities or mental health] for care and treatment in an appropriate institution....” In the case of a misdemeanor and a finding of mental disability, criminal action is ceased with follow-along as appropriate. If the charge is a felony, however, the law requires greater consideration by the courts. The state code stipulates that the appropriate commissioner must “...designate an appropriate institution, operated by the department of mental hygiene in which the defendant is to be placed.”

New York has offenders with MR/DD in three corrections programs. The programs offer vocational, educational, and recreational training. Six months following release, offenders with MR/DD may participate in a community linkage program or receive community support services through the New York Office of Mental Retardation and Developmental Disabilities.

Nationwide Progress

These and other states continue to strive for better methods of: a) training and preparing justice, law enforcement, and health and human services personnel to assist persons with MR/DD involved with the justice system; b) identifying offenders with MR/DD; and c) targeting points of diversion for offenders with MR/DD from the standard adjudication track once in the court system. Meanwhile, Congress has passed the America’s Law Enforcement and Mental Health Project Act (S.1865). It amends the Omnibus Crime Control and Safe Streets Act of 1968, authorizing the attorney general to make grants to states, state and local courts, or units of local government for programs that involve: a) continuing judicial supervision, including periodic review, over offenders with mental illness, mental retardation, or co-occurring disorders who are charged with non-violent offenses; and b) the coordinated delivery of services, including specialized training of law enforcement and judicial personnel to identify and address the unique needs of offenders with mental illness or mental retardation. The programs include voluntary outpatient or inpatient mental health treatment that carries with it the possibility of dismissal of charges or reduced sentencing upon successful completion of treatment, centralized case management involving the consolidation of all cases of defendants with MR/DD or mental illness, and the coordination of all mental health treatment plans and social services, including life skills training. These funds will be blended with current state efforts to improve identification of and services for persons with MR/DD who become entangled in the justice system.

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The Final Stages: Community Services for People Considered the Most Difficult to Serve

by Tom Fitzpatrick and K. Charlie Lakin

Minnesota is in the final stages of public institution operation for persons with developmental disabilities. Between June 1990 and June 1995, Minnesota state institution populations were reduced by 63%, from 1,410 to 524 people. It is clear that those state institutions that have not already been closed or converted to other uses, or are in the process of conversion, soon will be. As this future is anticipated, the Residential Services Division of Minnesota's Department of

In closing institutions, states often face ethical and fiscal questions in deciding how and where to serve individuals with developmental disabilities and behavioral concerns that impact on public safety.

Human Services has considered it important to examine the current uses of Minnesota's state institutions, both in terms of function (e.g., short term emergency placements) and clientele (e.g., persons with records of assaultive behavior), to identify alternative services that will be needed to fulfill functions currently fulfilled by the state institutions.

One step in this process has been to interview officials and service providers in states that have undertaken similar examinations, especially with respect to services for persons whose behavior is particularly difficult to accommodate in community residential programs because it has been threatening to others, criminal in nature or viewed as potentially dangerous to others or self. Thirteen states were selected for extensive interviews on the basis of: 1) having closed all state operated institutions; 2) having developed plans to close all institutions and greatly reduced the number of persons living in state institutions; 3) being under court order to close a state institution without transferring people to other institutions; and 4) having developed programs of relevance for the populations noted above. The states were California, Connecticut, District of Columbia, Maine, Massachusetts, Michigan, Nevada, New Hampshire, New York, Oregon, Rhode Island, Utah, and Vermont.

■ Common Themes

In reviewing the state interviews, there were a number of common themes that emerged:

- States that are successful in final stages of closing state institutions have developed ways to virtually eliminate

admissions to those institutions. Such states admit individuals to state institutions only in extreme situations, if at all. They allocate resources and develop programs to respond to crisis events and to offer special support to particularly challenging people in community settings, replacing the role traditionally given to state institutions.

- Some successful states have decided to retain state-operated programs, but in community rather than institutional settings, and only for certain specific situations or groups of persons. In states in which provider communities have traditionally exercised relative freedom (or license) to reject difficult-to-serve people through demissions or non-acceptance, there appears to be a stronger tendency toward developing or expanding such state-operated services.

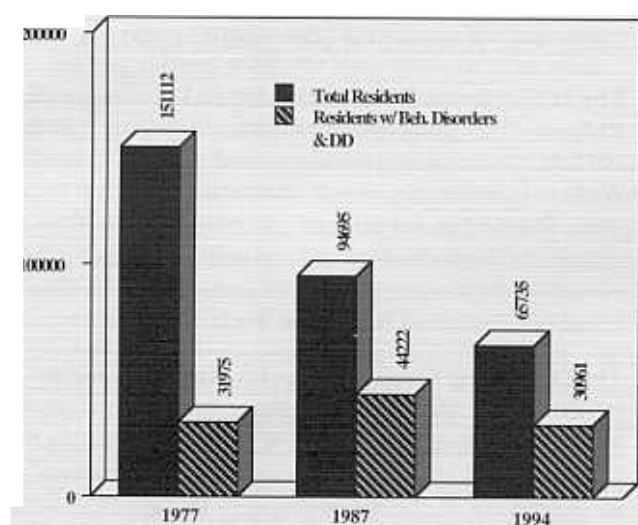
A growing number of states have developed or are considering statewide crisis prevention and crisis intervention systems. Several states have developed programs that feature training, prevention and 24-hour response services. The emphasis of these programs is to provide necessary supports to allow individuals to remain in or return to current living situations, or to serve as a non-institutional transition to more suitable arrangements.

- Several states have improved access to more experienced, higher quality psychiatric services for persons with "dual diagnosis" (i.e., both intellectual and psychiatric disabilities). Some of these states have recruited highly regarded psychiatrists to provide consultation and individual treatment in efforts to improve services for such people.
- Sex offenders with developmental disabilities are commonly viewed as the most difficult population for state programs to serve. States feel particular pressure and obligation to address public safety concerns. A number of programs for sex offenders have been located in rural areas with special security and staffing considerations.
- A growing number of states have contracted for specialized programs to address unique needs of certain types of persons with assaultive or other dangerous behavior. These programs have high costs to operate because of the wages and benefit costs associated with attracting a highly trained and competent staff, people working under stressful conditions, and high staff-to-resident ratios. Special environmental features of these programs add costs, as well.
- Individual and environmental accommodations are increasingly used to enhance the effectiveness of programs.

Many states are emphasizing environmental accommodations in designing programs for individuals with histories of extremely challenging behavior, including space and privacy accommodations, such as single bedrooms with private bathrooms. Some programs are located in rural settings to allow participants more freedom of movement without jeopardizing public safety. Some programs feature extensive security features, such as inward curving unclimbable fences and personal duress alarm systems. The high cost of repeated failure to make programs work for groups of individuals has increased interest in personal futures and other desired lifestyle planning approaches.

- The commitment of the provider community and the ability of that community and the state to work together are viewed as essential to being able to serve all people in the community. The states that have closed state institutions acknowledge that it could not have been done without the commitment of the provider community. States note that until the private provider community no longer views state institution readmissions as the solution to their

Proportion of Persons with Behavior Disorders and Developmental Disabilities in State Institutions Nationwide



Source: Prouty & Lakin (1995)

problems, it is extremely difficult to close the last resort “safety net” of the state institutions.

■ Recommendations

Four recommendations were drawn from the state interviewees about the lessons learned through experiences in providing community services to persons with developmental disabilities and difficult behavioral challenges:

- In closing state institutions, proceed as slowly as needed to move individuals into the community “one person at a

time.” Several states commented that they moved too many people too quickly. In retrospect, they felt that rapid deinstitutionalization overstressed the provider community, causing problems affecting the quality of care, and that some community placements were made without adequately considering the appropriateness. A corollary was that if people must be moved in groups initially, it is important to avoid situations that are difficult to change.

- Provide effective staff training and continuous staff development. States commented on the importance of training for program effectiveness and staff safety. States also spoke of the importance of supporting staff to maintain consistently good services and to reduce staff stress and burnout. One example was even cited of an inadequately trained staff member being beaten to death by an individual with developmental disabilities who was known to be dangerously assaultive.
- Encourage creativity and flexibility in developing programs to serve challenging individuals. Several states reported that they are “avoiding rules” whenever possible to work with provider agencies to creatively serve individuals with behavioral challenges. There is no one way; creativity and responsiveness to individuals are critical, but being overly naive can also be dangerous.
- Collaborate with the corrections and mental health systems. Many states feel that they have not had adequate working relationships with these systems. As institutions are closed, the states increasingly appreciate the need for such collaboration to properly address the unique needs and circumstances of the small proportion of persons with developmental disabilities who are sex offenders, dually diagnosed, and possess other histories of behavior of serious concern.

As public institutions are closed, states have been successful in serving persons with developmental disabilities and serious challenging behaviors in a variety of community programs. In doing so, they often face ethical and fiscal questions in deciding how and where to serve individuals with developmental disabilities and behavioral concerns that impact on public safety. But none of the states that have faced these challenges and made these commitments expresses any regrets that they are now operating the residential services systems without state institutions.

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Reference: R.W. Prouty & K.C. Lakin (Eds.) (1995). *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 1994*. Minneapolis: University of Minnesota, Center on Residential Services and Community Living.

During the last three decades the U.S. has witnessed remarkable achievements in reducing the number of persons with intellectual and related developmental disabilities (MR/DD) residing in public institutions (Prouty & Lakin, 2000):

- Between June 1967 and June 1999 the number of persons with MR/DD residing in both state MR/DD and psychiatric institutions was reduced by 78% from 228,500 persons to 50,067.
- When deinstitutionalization was just beginning in 1969, the Master Facil-

Community living is not, in and of itself, an effective method for addressing behavior support and/or crisis prevention and response needs of people with MR/DD.

ity Inventory of the United States showed only 10,350 people with MR/DD living in community residential settings of 15 or fewer residents; by 1999, 278,450 people with MR/DD lived in community settings.

- As a result of state commitments to provide community services to all who can benefit and to eliminate unjustifiably costly services, in the 12 years between 1988 and 1999, 116 state MR/DD institutions and MR/DD units of 16 or more residents within traditional psychiatric institutions were closed.
- Including the 33 state institution closures before 1988, by 1999 only 56% of all state institutions operating in or established after 1960 remained in operation.

- Ten states have effectively closed all state MR/DD institutions.

The most visible product of the deinstitutionalization movement in the U.S. has been the depopulation of institutions, but the most important accomplishment has been the concurrent transfer of the full range of services once available only in institutions to the communities in which people are born and prefer to live. Today the vast majority of service recipients and over two-thirds (72%) of service expenditures are in the community (Braddock et al., 2000). Most people with MR/DD who receive services today do so without ever experiencing a day of institutionalization. Indeed, it is statistically demonstrable that the primary factor in the massive depopulation of state institutions has not been the number of people discharged from state institutions, but has been the reduction in the number of people who entered state institutions. Between 1970 and 1998, annual admissions to state MR/DD institutions decreased 84% (Prouty & Lakin, 2000).

There has been a well-researched association between movement from institutional settings to community living and the acquisition of functional skills. This research makes a very strong case for community living as a powerful, albeit loosely defined, treatment model for adaptive behavior skill growth (Kim, Larson & Lakin, 1999). Studies of the association between community placement and changes in “challenging” behavior have shown much less evidence of statistical association between community placement and lower rates of challenging behavior.

The review by Kim, Larson and Lakin (1999) identified six “comparison group” studies between 1980 and 1999 that directly compared challenging behavior changes over time among per-

sons deinstitutionalized and matched groups of people remaining in institutions and another 18 “longitudinal studies” which monitored change over time in the challenging behavior of people who moved from institutions to community settings. These studies followed thousands of subjects over periods ranging from 6 months to 84 months. Only one of these comparison group studies and five of the longitudinal studies showed statistically significant relative decreases in problem behavior among like persons moving to the community. Ten of the remaining studies showed non-significant tendencies for improved behavioral outcomes associated with community living, but six showed tendencies toward negative outcomes in behavior, and two even showed statistically significant worsening of problem behavior following movement to the community. In short, community living is not, in and of itself, an effective method for meeting the behavior support and/or crisis prevention and response needs of individuals with MR/DD.

A number of factors may be hypothesized to contribute to the lower consistency of association between “maladaptive” behavior change and movement from institutions than has been found between positive “adaptive” behavior change and movement into community settings. These range from community life being a more direct and consistent teacher of the functional skills assessed as “adaptive behavior” to the complications of psychiatric conditions in reducing “maladaptive behavior.” Whatever the explanations, it appears that community living alone is insufficient as a vehicle of behavior support and training to prevent and respond to challenging behavior. But, more importantly, the evidence is clear that institutionalization for the purposes of developing adaptive behavior

and/or reducing maladaptive behavior offers no dependable (i.e., defensible) treatment benefit.

Most states have made substantial progress toward assuring community lives for all citizens with MR/DD, but others have much more to do. Today, the primary predictor of people's access to opportunities and services that can support them as needed in the communities in which they live is the state and community in which they happen to reside. This relative fortune or misfortune and the essential injustice it may represent was a primary motivation of the landmark *Olmstead* suit.

Arguing that restrictions that derive from government's unwillingness to respond to established benefits of community life, as identified and assured by Congress in the Americans with Disabilities Act (ADA), constituted unlawful discrimination, two individuals in Georgia used the civil rights protections under the ADA to pursue their place in the community. In June, 1999, the Supreme Court of the United States issued a ruling in *Olmsted et al. vs. L.C. et al.* of great significance to persons with MR/DD who are or might be institutionalized as a result of behavioral and/or psychiatric service needs.

In the ADA, Congress noted that the isolation and segregation of individuals with disabilities represented a "serious and pervasive social problem" because it was a form of discrimination (42 U.S.C.12101[a][2]), and that such discrimination was reflected in "outright intentional exclusion" and "relegation to lesser services, programs, activities, benefits, jobs, or other opportunities" (42 U.S.C. 12101[a][5]). Congress noted that "the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, economic self-sufficiency for such individuals" (42 U.S.C. 12101[a][8]).

The federal regulations, responding to the intent of Congress, required that

a "public entity shall administer services, programs and activities in the most integrated setting appropriate to the needs of qualified persons with disabilities" (28C.F.R.35.130(d)). The Supreme Court in *Olmstead* considered specifically whether it was a violation of the ADA for a state to deny individuals community placement when community services were available to others, when community services were recommended for the individuals by the state's professionals, and when community services were desired by the individuals.

The majority opinion of the Court concluded that:

The ADA both requires all public entities to refrain from discrimination and specifically identifies unjustified segregation of persons with disabilities as a form of discrimination. The identification of unjustified segregation as discrimination reflects two evident judgements. Institutional placement of persons who can handle and benefit from community setting perpetuates unwarranted assumptions that persons so isolated are incapable and unworthy of participating in community life...and institutional confinement severely diminishes individuals' everyday life activities.

The significance of the *Olmstead* ruling is yet to be determined. It is likely to be most influential in states that have made the least progress in deinstitutionalization, but its implications are by no means limited to such states. It will contribute to the ongoing push to reduce institutionalization and to challenge communities to serve people who in the past have been viewed as appropriately housed in institutions.

A January, 2000, letter to State Medicaid Directors from the Departments of Health and Human Services and Justice in reference to the *Olmstead* decision noted that:

This decision confirms what this Administration already believes: that no one should have to live in an institu-

tion or nursing home if they can live in the community with the right support and that *Olmstead* challenges states to prevent and correct inappropriate institutionalization and to review intake and admission processes to assure that people with disabilities are served in the most integrated setting appropriate.

The fact the petitioners in *Olmstead* were persons with histories of behavioral and psychiatric diagnoses and treatment is significant. In June 1998, 165 state institutions (84.2% of 197 total) reported that 41.4% of their residents had behavior disorders requiring special staffing and 34.3% had psychiatric conditions requiring the involvement of professionals with psychiatric training. *Olmstead* suggests that continued reliance on institutional settings as a primary locus for specialized services for people who present behavioral challenges to community service systems will be under growing pressure. This pressure may be important. During the 1990s as state institution populations decreased 41% nationally, in the one-third of states with the slowest rates of deinstitutionalization institution populations decreased by 23%. Fifty-seven percent of all state institution residents were in that slowest one-third of states.

Continuing the designation of public or other types of institutions as "specialized" places for treating people with behavioral and psychiatric disabilities in light of the lack of demonstrated benefit to their problem behavior and the well-demonstrated detriments to their functional skill development – and now the *Olmstead* ruling – seems substantially threatened. *Olmstead* further suggests that traditional uses of larger institutions as the "safety net" for emergencies and crisis will be susceptible to challenges as less segregating community alternatives are designed and demonstrated to be effective.

[Lakin, continued on page 27]

how to see things through the lens of having a better life. They will almost always push for a better balance.

If new conceptual frameworks are to be broadly applied, there needs to be extensive training and support in learning how people want to live and in addressing issues of health and safety in the context of what is important to the person. But there also needs to be recognition that different conceptual frameworks rest on different sets of assumptions. In the old conceptual framework, an often-unstated assumption was that professionals knew what was best and should make decisions for people. When this assumption is explicitly discussed it is rationalized with concepts of generalized incompetence, such as mental age (e.g. "He has a mental age of four, so of course we are going to decide what is best"). In saying that we know better, we ignore the fact that everyone has preferences regardless of cognitive capacity, and we ignore the complexity of intelligence (Gardner, 1993). In a rush to an over-simplified view of self-determination, we hear the equally perverse statement: "I was in charge yesterday but because we now believe in self-determination today you are in charge." The preferences that we have today are largely based on our prior life experiences. Much of what we want depends on what we have tried; an absence of opportunities narrows preferences. For all of us choice has boundaries and control is shared; within this "new" conceptual framework what is true for the typical person is also true for those who use disability services.

In sharing control, the goal is to help the person have as much positive control as is possible. The role of the professionals and members of the person's support team is to look for the best balance between what the person wants, what others want for the person, issues of health and safety, and the use of limited public resources. This is an ever-shifting balance and one that frequently has tensions between competing interests and perceptions. It does require new skills. Some of these have been dis-

cussed but there are others (e.g., the skill of negotiation) that are needed. The experiences of those who are moving down this path also indicates that acting on these concepts and using these skills requires extensive changes in policies, practices, and organizational culture. However difficult all of these efforts may seem, they are easier to accomplish and far more rewarding than seeking compliance from people who do not like where, how, and/or with whom they are living.

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[Lakin, continued from page 3]

The *Olmstead* decision, the advancing state-of-the-art in providing community services, and the accomplishments of "institution-free" states challenge all states to develop and sustain effective, community-based behavior support and crisis response services. For many states this will be difficult because a) they have focused their behavior support resources and personnel in institutions; b) they and their private contractors have often come to view these institutions as the "appropriate" places for people who present behavioral challenges; c) state and private community agencies have often developed a mutually reinforced tendency of accepting that institutions are the place to send people with challenging behavior when they are uncomfortably difficult for community agencies to serve; and d) as a result of limited involvement among states and localities in responding to highly challenging and crisis behavior in the community, many have limited technical and experiential capacity to do so.

There have been, however, a number of states and local agencies that have re-

sponded to these same challenges in developing community behavior support and crisis response programs. These lessons learned in their development include the importance of acknowledging and responding to mental health conditions among persons with MR/DD; valuing and incorporating professionals with different psychological, medical and social perspectives; attending carefully and responding seriously to what people are saying through their behavior; committing to people and their right to live in the community; and building the capacity within community organizations and families to reduce and respond to behavioral episodes without outside intervention. The experience of these states and agencies offers substantial hope that with appropriate community support all persons with intellectual and developmental disabilities, including those with serious behavioral and psychiatric conditions, can be and can remain residents of homes and neighborhoods in typical communities.

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Impact



Most crises requiring behavioral support and system response for an individual with a developmental disability can be anticipated. They should not come as a surprise. Those who present complex behavioral “problems” are people who are usually already known – often well-known – to the system. Those who receive services and complain with their behavior about those services, are typically familiar to those who oversee and manage the services. It is often the case that when the individuals first came to the attention of the system they were not listened to, and instead efforts were made to have them comply with the rules of the agencies, programs or residential settings. The efforts did not work. As the individuals escalated their “complaints” about the services and circumstances, there was typically an escalation in the interventions, leading to people being “discharged” and becoming a “crisis.” They were moved to new settings or service providers, and the cycle began again.

For most of the people with developmental disabilities in this situation, there is time for careful planning, for reflection. Part of the reason that the planning does not occur is that we’ve created a culture of chronic crisis. The officials who make decisions about where people live are typically told of someone who needs a new place to live with little lead-time because an agency has decided to “discharge” them, a psychiatric hospital has someone who should not be admitted, or an aging parent has been hospitalized. In these circumstances, the person needs a place to sleep that night. Looking

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at how someone “wants to live” necessarily takes a “Maslowian” back seat to having shelter. But the temporary shelter often becomes a permanent place to live, at least until that person informs us with their behavior that they can no longer tolerate the situation into which they were “placed.” Those who need immediate shelter (with insufficient time for planning) are telling us what is lacking in our system; however, they are only seen as individual “problems” that need a quick solution. There has to be a quick solution because the officials need to move on to the next crisis. In a crisis culture there is no time for thought about real solutions, and the cycle of having today’s temporary solutions adding to tomorrow’s crises is maintained.

The officials who are asked to make the crisis “placements” have the opportunity to break the cycle of crisis. They may have to help the person move “now”, but they don’t have to wait until the quick solution turns into the next crisis. They can require that evaluations be done to learn how the person wants to live and look for alternative frames of understanding the person’s needs, preferences, and behaviors. The goal should be a better balance. Balance implies that the person gets more of what is important to him or her as a unique individual, and that issues of health or safety are effectively addressed within the context of how the person wants to live. One way to look at this balance is to ask those involved the following questions:

- Is there a good balance between how the person wants to live and staying healthy and safe? Is the person (and those who know and care about the person) satisfied with the balance?
- Where there is dissatisfaction, where things are not working, are there other ways of interpreting or understanding the issues affecting the individual and the meanings of the person’s behaviors?

- Do any of these alternate ways of understanding the individual’s issues and behavior suggest positive actions that could result in a better balance?
- If these alternative ways of understanding are acted upon, how will people know if the changes work?

Just as learning to analyze behavior using a behavioral frame is a skill, so is learning to listen to how a person wants to live. For those who practice “positive behavioral supports” it is a clearly overlapping skill, but it is sufficiently different to warrant separate training. It is a way of listening that uses a somewhat different framework, and applying that framework requires practice. It is about listening carefully and intently. This intense kind of listening has been called *active listening* (Farston, 1996), and it has been described as a “mindful” activity (Langer, 1989). Too often there is an assumption that professionals already know how to do this. There is an expectation that a professional can go to a day-long workshop providing an overview of three kinds of person-centered planning training, look at a couple of sample “person-centered” plans, and then go forth and effectively learn how other people want to live. My experience and that of my colleagues is that it is a rare person who can pick up this new skill without extensive structured practice. It is even more challenging to apply this skill when there is a crisis. In a crisis, there is no time for reflection, for puzzling something through. In a crisis there is pressure for a quick solution. Applying a skill that is still being developed in a crisis setting is a recipe for distortion and disaster. Only those already skilled can effectively respond.

When officials engage in an analysis of multiple crises they often identify deficits in system capacity. For example, they often see a need for training in the frames of understanding that we have labeled “person-centered planning.” Or they may find a need for mental health professionals who are able to effectively evaluate and treat people with cognitive impairments. Quite often a need is iden-

tified for support services that permit people to have a place they call home and opportunities to contribute to communities. The best officials see the challenges of those in crisis as symptoms of system deficits. These “best” officials also see development of new capacity as one of their core responsibilities.

For those whose crisis arises because they can no longer live with their families, an important opportunity has been lost. In such situations, the system typically waits until people are in crisis before offering support, and then it is too late. As a result people move out of the family home and the system begins all over again to try to build community for people who have lost community due to its delayed response. The time to learn what is important to the person is while they are living with their family. Many parents are happy to develop plans with their sons and daughters and to begin to act on what is being learned while they are active and able. Parents who do not have the energy to take the lead in planning still have extremely valuable information about the person. When we wait until the parents are disabled, deceased or defeated, we have lost the information and the opportunity for building community that could have occurred.

There are ways pre-crisis planning can occur other than the funding of a large number of new service coordinators. Among the alternatives is to recruit parents who are interested in acquiring the skills needed to help other parents plan, and then to pay them to help other parents develop and implement plans. Self-advocates are another neglected resource. Increasing numbers of self-advocates are being helped to develop plans on themselves. Many of them are interested, capable, and willing to assist others in developing their own plans. Parents and self-advocates may not always have the specialized clinical knowledge needed for some people to be healthy or safe, but they make excellent partners as they almost always know

how to see things through the lens of having a better life. They will almost always push for a better balance.

If new conceptual frameworks are to be broadly applied, there needs to be extensive training and support in learning how people want to live and in addressing issues of health and safety in the context of what is important to the person. But there also needs to be recognition that different conceptual frameworks rest on different sets of assumptions. In the old conceptual framework, an often-unstated assumption was that professionals knew what was best and should make decisions for people. When this assumption is explicitly discussed it is rationalized with concepts of generalized incompetence, such as mental age (e.g. "He has a mental age of four, so of course we are going to decide what is best"). In saying that we know better, we ignore the fact that everyone has preferences regardless of cognitive capacity, and we ignore the complexity of intelligence (Gardner, 1993). In a rush to an over-simplified view of self-determination, we hear the equally perverse statement: "I was in charge yesterday but because we now believe in self-determination today you are in charge." The preferences that we have today are largely based on our prior life experiences. Much of what we want depends on what we have tried; an absence of opportunities narrows preferences. For all of us choice has boundaries and control is shared; within this "new" conceptual framework what is true for the typical person is also true for those who use disability services.

In sharing control, the goal is to help the person have as much positive control as is possible. The role of the professionals and members of the person's support team is to look for the best balance between what the person wants, what others want for the person, issues of health and safety, and the use of limited public resources. This is an ever-shifting balance and one that frequently has tensions between competing interests and perceptions. It does require new skills. Some of these have been dis-

cussed but there are others (e.g., the skill of negotiation) that are needed. The experiences of those who are moving down this path also indicates that acting on these concepts and using these skills requires extensive changes in policies, practices, and organizational culture. However difficult all of these efforts may seem, they are easier to accomplish and far more rewarding than seeking compliance from people who do not like where, how, and/or with whom they are living.

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[Lakin, continued from page 3]

The *Olmstead* decision, the advancing state-of-the-art in providing community services, and the accomplishments of "institution-free" states challenge all states to develop and sustain effective, community-based behavior support and crisis response services. For many states this will be difficult because a) they have focused their behavior support resources and personnel in institutions; b) they and their private contractors have often come to view these institutions as the "appropriate" places for people who present behavioral challenges; c) state and private community agencies have often developed a mutually reinforced tendency of accepting that institutions are the place to send people with challenging behavior when they are uncomfortably difficult for community agencies to serve; and d) as a result of limited involvement among states and localities in responding to highly challenging and crisis behavior in the community, many have limited technical and experiential capacity to do so.

There have been, however, a number of states and local agencies that have re-

sponded to these same challenges in developing community behavior support and crisis response programs. These lessons learned in their development include the importance of acknowledging and responding to mental health conditions among persons with MR/DD; valuing and incorporating professionals with different psychological, medical and social perspectives; attending carefully and responding seriously to what people are saying through their behavior; committing to people and their right to live in the community; and building the capacity within community organizations and families to reduce and respond to behavioral episodes without outside intervention. The experience of these states and agencies offers substantial hope that with appropriate community support all persons with intellectual and developmental disabilities, including those with serious behavioral and psychiatric conditions, can be and can remain residents of homes and neighborhoods in typical communities.

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“BUT AREN’T THERE SOME PEOPLE...?” DISPELLING THE MYTH

Nancy Rosenau

A myth is an imaginary story that lives in the minds of people that tell it, working as a set of instructions for how things are or should be. In the case of the story, “Some People Really Need an Institution,” if we sift facts from fiction we can see that the story works to perpetuate a myth.

The fact is there are people who have significant health issues that are complex, need a trained eye to evaluate, require specialized intervention, are sometimes chronic, and sometimes critical. The fiction is the leap to the conclusion that they need a special kind of building to live in and to share with others with similarly complex needs.

Let’s critique this leap. There is readily available evidence to refute the conclusion. For every person for whom an institution is suggested, there is a “functional twin” with exactly the same needs who lives successfully in a home in a community.

But functional twin evidence is not enough (apparently) to sway those who skeptically pose the question. Their worry is not eased by such evidence but rather is built on beliefs fueled by imagination. Dispelling the myth requires confronting that imagination and unbundling its elements to find our way from the imagined to the actual, and ultimately, to a different imaginable conclusion.

When the myth is raised around health care issues, it usually references notably fragile conditions, complex technologies or medical interventions. The list seems daunting and evokes the feeling that surely “These People” are the ones for whom institutions are necessary.

The other side of the myth/coin details attributes of institutions. This description usually highlights professional credentials. The credentials seem as impressive as the conditions are daunting, and evoke the inference that maybe “These People” need those people and their expertise.

And the Leap is made. “A” needs “B,” therefore A should live where B is. It is at this juncture that we can further expose the errors in logic. We can ask the question differently. Rather than asking “Doesn’t A have to live where B is available?”, we can instead ask, “Can B be available where A lives?” Posing the question differently is much more than an argument to expose illogic; it is a methodology to work through. Sometimes this reversal and its serious

exploration can result in a person having the opportunity to live in his/her community rather than being forced into an institutional setting (though sometimes not, an issue I will come back to).

First we need to push deeper to get to the bottom of imagination that fosters the Leap. Whether the proposed institution is a hospital, nursing home, mental retardation facility, or group home, “special” places for “special” people are really nothing more than two elements.

1. The physical environment
2. The peopled environment

Let’s look at each more closely.

1. The physical environment. Any residential setting is a set of rooms in a building with walls and ceilings and hallways. Some of the rooms have particular features. Some have cooking equipment, some have medical equipment (e.g., oxygen), some are configured to separate people from each other (e.g., isolation for infection control), some are configured to have people congregate (e.g., day rooms, dining rooms, lounge rooms).

If we look at any single individual it is hard to conclude that This Person *needs* cafeteria dining arrangements; or This Person *needs* to share a residence with 5, 25, or 300 other people; or This Person *needs* a roommate with equally complex needs.

When we closely examine what This Person does need, we find it is oxygen, not the fact that is piped in from a line in the wall; or medications, not the fact that they are stored in the pharmacy downstairs; or nursing, not the fact that they park in the employees lot. Ironically, we might find it is the fact that This Person needs to be protected from contagion from other residents that necessitates the isolation room he “needs.” On close examination, the physical space does not offer something that cannot be replicated (or improved on) in another building with fewer rooms and fewer roommates. Something like, say, the size and scale of a family home.

What This Person *does* need, however, is other people and their expertise. This takes us to the second element of any residential arrangement, that is, the configuration of people and their activities within the physical building space.

2. The peopled environment. Any residential facility is a set of people. Often a critical issue for individuals with complex medical needs is access to the expertise of people. The peopled environment boils down to logistics and numbers, that is, people with time, energy, expertise, and availability.

Let's look more closely at the peopled environment needed by individuals with severe disabilities or complex medical needs. An argument often made for institutional care is that there is a physician available. But where is that actually true? It is true in an acute care hospital. It is not true in most nursing homes, mental retardation facility medical units, or specialized group homes.

Usually, a physician is available only on some days or some shifts or is "on-call" for phoned-in intervention rather than a face-to-face contact. In the rare setting where a physician is actually present 24 hours a day, 7 days a week, we can examine how many hours of a 24-hour period the physician spends with This Person. The answer will be measured in minutes, not hours.

The credential most often referenced for people with complex medical needs is a nursing license. An argument often made for institutional care is that there is a nurse (or nurses) available 24 hours a day, 7 days a week.

Again we can examine how many hours of the 24-hour day the nurse actually spends with This Person. In many specialized settings, it is not a nurse who provides most care, but rather an aide with a modest amount of training. If there is a nurse available, he is passing medications, adjusting equipment, observing, or intervening for particular kinds of care for short periods of a 24-hour day.

For very few individuals does a nurse provide the bulk of the direct care. And for those individuals, the nurse could apply his expertise in other buildings, like those of the size and scale of a family home. Or alternatively, the nurse may be able to delegate to a regularly available parent or other family member certain care which he would not delegate to a roster of interchangeable staff of a facility.

What we find when we break down the peopled environment is that the need for institutional care is not located in This Person, but is located in the way we've organized needed assistance into a limited number of settings. We find This Person does not need an institution, but, rather, we have configured the delivery of services so that the only place that offers people with the needed time, energy, expertise, and proximity are congregated in a building that is not the person's home. These logistics are alterable.

Without a doubt, logistics are no small feat. Getting enough people with time, energy, and expertise into the homes of people who need them is a managerial challenge. Sometimes it is successfully met, and, unfortunately, sometimes it is not.

If we frame the problem as located within the individual, then we stop short of finding answers because the individual's characteristics may not be modifiable. If we frame the problem as logistical, we can find logistical answers to create home life because logistics *are* modifiable. We need to shift our thinking to see that the problem doesn't lie within the person with the complex medical issues--it lies in the arrangement of our services configuration.

So the question, "Do some people need institutional care?" can be reframed as, "Have we organized our care arrangements in such a way as to provide them in a person's home?" When push comes to shove, these decisions are less often about what individuals *need* and are more often about economics.

Defense of institutions invokes "economy of scale" arguments that say we need to put individuals with like needs together in physical spaces to be able to afford the caregivers that are needed. This argument reveals that it's not that individuals need institutions but that institutions need multiple residents to share the helper-people in order to make the economics work. If we can't figure out how to reconfigure our service arrangements, let's at least stop saying people need institutions--let's say institutions need people.

Of course, to reduce the problem to logistics is too simplistic. It will not resonate with skeptics that all we have to do is manipulate staffing schedules. In truth, a much bigger task to tackle is the imagination. It's not the intellectual exercise of reason but the emotional exercise of imagery and imagination that stymies our efforts.

Across this special issue of *TASH Connections*, you will read about states, agencies, and individuals who have worked out better ways to organize their physical and peopled environments. You will find examples of policies, practices, and funding, but what it looks like on-the-ground is the imaginable that most sparks change.

For many years I have worked to help children growing up in nursing homes to find their way to family homes. To be sure, changing the pathway from residential care to family homes requires policy and funding changes. It also requires systematically tackling each and every child and family on their own terms and figuring out arrangements that work. Those arrangements vary from schedule modifications to home modifications, from on-call systems to ambulance

arrangements, from back-up generators to back-up nurses, from willing-and-able birth families to willing-and-able alternate families.

Along the way we met complex kids like Tiffany. Born with a rare syndrome, she needed a tracheostomy and ventilator to breathe, a tube in her stomach for nourishment, a wheelchair for mobility, and caregivers who knew how to judge her breathing, adjust her vent settings, do her tube feedings, suction her airway, and position her in her seating equipment. Her birth family was too frightened of the equipment and the imagined difficulty of learning to care for her at home. They were unwilling to have strangers intrude on their home to do it for them. But another family in their community was willing.

We helped the birth family to make the loving decision to enable their daughter to enjoy the important need of childhood for “a safe, secure environment that includes at least one stable, predictable, comforting, and protective relationship with an adult, not necessarily a biological parent, who has made a long-term, personal commitment to the child’s daily welfare and who has the means, time, and personal qualities needed to carry it out” (Greenspan, 1997).

In every institution, we found children like Tiffany--with the kind of needs that scare a lot of us. We also found people like Luis, whose condition was equally scary to a lot of us. Luis had been in a coma for two years due to injuries from a car accident. A coma conjures up images of being so medically fragile that surely an institution is required. But a careful examination of Luis’ care revealed he needed positioning and skin care, tube feeding and trach care. His family had overcome their imagination of that kind of care and became very skilled, with the nurses blessing, at providing it on their daily visits.

What kept Luis in a nursing home was not his coma/condition, but the fact that his family home and car were not accessible. These logistical challenges were surmountable. By arranging housing, transportation and a nurse to make several home visits a week and be available by phone, the family was able to take Luis home. When we rearranged the people he needed, we found there was nothing about the nursing home that Luis required. It had only helped “efficiently” arrange his care.

Neither Luis or Tiffany *needed* the nursing home. What they really needed was to live with people who loved them and had enough support to thrive as a family. I am not saying that solutions are *readily* available; I am saying they are feasible. It took a year to get Luis home, and

funding to get Tiffany a family, but asking “What will it take?” raises more surmountable problems than asking “Don’t those people need that place?”

Some of the mythology about people whose needs are “too” severe arises from letting our imagination go unchallenged. The imagined “too”-ness can be dissipated by unpacking its underlying details and shifting to imagining what it would take.

If we look at a minute-by-minute analysis of what the care in most “special” settings really consists of we can replicate it (or improve on it). We can pull back the curtain and see it is only people in buildings. Once you look at the actual details, they can be broken down into “who” rather than “where” in a process that allows an alternative to become imaginable, and then, ultimately, doable.

The good news is that methodically unbundling logistics can sometimes, in and of itself, address the most feared aspects of our imagination. The very process of examining the logistics can dispel the imagery and break down the imagined difficulties. This is as true (often more true) for us planners as it is for individuals and their families or loved ones. The logistics can be confronted as challenging but (re)arrangeable given enough ingenuity and a committed group of co-conspirators.

The bad news is that too often the problem isn’t the theoretical feasibility of (re)arranging the peopled environment or finding funding, but the trustworthiness of the arrangements. We find competent parental caregivers in a family home who aren’t scared about the care; they’re afraid about what will happen to their loved one if something happens to them. And the something that might happen imminently is their dropping from exhaustion. They either have not had people-help--the kind with energy, time, and expertise--or the promised help didn’t show up, or weren’t on-call when called, or weren’t as expert as their credentials suggested. But, as unfortunate as this is, it is no less true in facilities that struggle with turnover, no-shows, and too few staff across too many residents.

In truth, we don’t find flimsy arrangements for families compared to quality facilities but, rather, flimsy arrangements for facilities as well. If we are going to spend the money and work out the logistics to adequately support facilities, we might as well go back to the drawing board and work out arrangements to support people in their own homes.

But the myth that prevents the work is stubborn. I was recently talking to an attorney who serves as the guardian for a young man living in a nursing home who was paralyzed and uses a

ventilator following an accident. After meeting him and learning about what he needed, she imagined him living in a home in the community (albeit with complex accommodations). Even as she fought for home-life for him, she asked me the mythical question, “But aren’t there *some* people who really need an institution?” She didn’t say it in a way that made it sound like a question, but rather as an assumed answer. She hadn’t yet met Those People and hadn’t yet worked through the details of what they needed, like she had with the young man she was supporting. She let her unchallenged imagination assume such imaginary people.

If we confront our fictional imagination and dissect the actual facts, we can find our way to answering the mythologized question, “Nope.”

Greenspan, S. (1997). *The Growth of the Mind*. Reading, MA: Addison-Wesley Publishing.

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TRENDS IN INSTITUTION CLOSURE

National Trends

The trend toward institutional closure began in the 1970s and continued throughout the 1980s and 1990s. Between 1970-1984, 24 institutions in 12 states were closed. By 1988, 44 institutions in 20 states had been closed. And, by 2000, there were 125 closures, or planned closures, in 37 states. A number of factors contribute to this trend toward institution closure. One is that as states have further developed their community services system, they have less need or desire for institutions. Second, due to rising costs of institutionalization, states are relying less on institutional services.

State Trends

In 1991, New Hampshire closed the Laconia State School and became the first state to close all of its public institutions. Since that time, The District of Columbia, Vermont, Rhode Island, Alaska, New Mexico, West Virginia, Hawaii, and Minnesota have also closed all of their public institutions. In contrast, states which continue to use institutions for a significant number of people include: Arkansas, Louisiana, Mississippi, North Carolina, and Virginia.

Issues

- A number of states have not closed any public institutions. These states include: Arkansas, Delaware, Idaho, Iowa, Louisiana, Mississippi, Montana, Nebraska, Nevada, North Carolina, Utah, Virginia, Wisconsin, and Wyoming.
- States which continue to support "an extensive network of public institutions" include: Arkansas, Louisiana, Mississippi, North Carolina, and Virginia.
- In some instances, institution closure has been achieved through transfer of significant numbers of individuals to other institutions.
- One of the major challenges to institution closure is the economic impact on and resistance from local communities and public employee unions.

INFORMATION IN THIS SECTION IS BASED ON THE FOLLOWING:

Braddock, D. (Ed.). (2002). *Disability at the dawn of the 21st century and the state of the states*. Washington, DC: American Association on Mental Retardation.

Lakin, K. C., & Prouty, R. (1995/96, Winter). Trends in institution closure. In M. F. Hayden, K. C. Lakin, & S. Taylor (Eds.), *IMPACT: Feature Issue on Institution Closures*, 9(1), 4-5. Minneapolis: Institute on Community Integration, University of Minnesota.

OTHER RESOURCES:

Braddock, D., & Heller, T. (1985, August). The closure of mental retardation institutions I: Trends in the United States. *Mental Retardation*, 23(4), 168-176.

Scheerenberger, R. C. (1987). *A history of mental retardation: A quarter century of promise*. Baltimore: Paul H. Brookes Publishing Co.

INCLUDED WITH THIS SECTION AS BACKUP DOCUMENTS:

Braddock, D., Hemp, R., Rizzolo, M. C., Parish, S., & Pomeranz, A. (2002). Table 2.5: Completed and in-progress closures of public institutions. In D. Braddock (Ed.), *Disability at the dawn of the 21st century and the state of the states* (pp. 93-94). Washington, DC: American Association on Mental Retardation.

Lakin, K. C., & Prouty, R. (1995/96, Winter). Trends in institution closure. In M. F. Hayden, K. C. Lakin, & S. Taylor (Eds.), *IMPACT: Feature Issue on Institution Closures*, 9(1), 4-5. Minneapolis: Institute on Community Integration, University of Minnesota.

Table 2.5
COMPLETED AND IN-PROGRESS CLOSURES OF PUBLIC INSTITUTIONS

State	Institution	Year Built/ Became MR	Original Use	# Residents, Closure Announcement	Year of Closure	Alternate Use
Alabama	Glenn Ireland	1986	MR Facility	20	1996	To be sold
Alaska	Harborview	1964	MR Facility	45	1997	Undetermined
Arizona	Phoenix	1974	MR Facility	46	1988	Pending Sale: Commercial
	Tucson	1972	MR Facility	13	1997	Outreach Offices
California	Camarillo	1935	MR Facility	497	1998	University
	DeWitt	1942/1947	Army Hospital	819	1972	Placer County Recreation
	Modesto Unit	1943/1948	Army Hospital	1,394	1969	Modesto Co. Comm. College
	Napa	1875/1967	Asylum for MR/MI	30	1988	MI Use Only
	Stockton	1852	Asylum for MI	414	1996	University
Colorado	Pueblo	1935	MI/MR Facility	163	1989	Pueblo Regional Center
Connecticut	John Dempsey Center	1964			1998	Undetermined
	Mansfield	1906/1917	Epileptic Colony	146	1993	Corrections/U. of Connecticut
	New Haven	1964	MR Facility	56	1994	Job Corps
	Seaside	1961			1996	Administrative Offices
	Waterbury	1963/1972	Convent	40	1989	Administrative Offices
D.C.	Forest Haven	1925	MR Facility	1,000	1991	Private Rehab/PH Infirmiry
Florida	Orlando	1929/1959	TB Hospital	1,000	1984	Unoccupied: asbestos
	Tallahassee	1928/1967	TB Hospital	350	1983	Unoccupied: asbestos
Georgia	Brook Run	1969	MR Facility	364	1997	Undetermined
	Rivers' Crossing	1969	MR Facility	37	1994	Undetermined
Hawaii	Kula Hospital (privatized)	1984			1999	
	Waimano	1921	MR Facility	96	1999	Undetermined
Illinois	Adler	1967	MI/MR Facility	16	1982	Water Survey Offices
	Bowen	1965	MR Facility	105	1982	Corrections
	Dixon	1918	MR Facility	820	1987	Corrections/New MR Facility
	Galesburg	1950/1969	Army Hospital	350	1985	Head Start/Community Programs
	Meyer	1966/1970	MI Facility	53	1993	Women's Prison
Indiana	Central State	1848	MI/MR Facility	83	1994	Undetermined
	New Castle	1907	Epileptic Village	200	1998	Corrections
	Northern Indiana	1943	MR Facility	53	1998	Undetermined
Kansas	Norton	1926/1963	TB Hospital	60	1988	Corrections
	Winfield	1888	MR Facility	250	1998	Undetermined
Kentucky	Frankfort	1860	MR Facility	650	1972	Demolition
	Outwood	1922/1962	TB Hospital	80	1983	Demolition/New Campus
Maine	Levinson	1971			1999	
	Pineland	1908	MR Facility	265	1996	Undetermined
Maryland	Victor Cullen	1908/1974	TB Hospital	79	1991	Private Juvenile Facility
	Great Oaks	1970	MR Regional Center	273	1997	Private Senior Retire. Community
	Henryton	1928/1962	TB Hospital	312	1985	Undetermined
	Highland Health	1870/1972	General Hospital	88	1989	Sold to Johns Hopkins University
Massachusetts	Belchertown	1922	MR Facility	297	1992	Vacant
	John T. Berry	1900/1963	TB Sanitarium	101	1995	Undetermined
	Paul A. Dever	1940/1946	P.O.W. Camp	294	2001	Undetermined
Michigan	Alpine	1937/1959	TB Hospital	200	1981	Notsego County Offices
	Caro	1914			1998	
	Coldwater	1874/1939	Orphanage	113	1987	Corrections
	Fort Custer	1942/1956	Army Hospital	1,000	1972	Back to U.S. Dept. of Defense
	Hillcrest	1905/1961	TB Hospital	350	1982	Demolition
	Macomb-Oakland	1967/1970	CDA	100	1989	Reverted to Community Dev.
	Muskegon	1969	MR Facility	157	1992	Vacant
	Newberry	1896/1941	MI Facility	39	1992	Vacant
	Northville	1952/1972	MI/MR Facility	180	1983	Revert to MI Use
	Oakdale	1895	MR Facility	100	1991	Vacant/County Negotiating
	Plymouth	1960	MR Facility	837	1984	County/State Offices
Minnesota	Southgate	1977			2001	
	Brainerd	1958			1999	
	Faribault	1879	MR Facility	501	1998	Portion Used by Corrections
	Fergus Falls	1969			2000	
	Moose Lake	1938/1970	Psychiatric Hosp	34	1993	Corrections
	Owatonna	1895/1947	Orphanage	250	1970	Abuse
	Rochester	1879/1972	MI Facility	150	1982	Federal Corrections
St. Peter	1968			1996		
Willmar	1973			1996		

Table 2.5 continued

State	Institution	Year Built/ Became MR	Original Use	# Residents, Closure Announcement	Year of Closure	Alternate Use
Missouri	Albany	1967	MR Facility	4	1991	Administrative Offices
	Hannibal	1967	MR Facility	3	1989	Administrative Offices
	Joplin	1967	MR Facility	5	1992	Administrative Offices
	Kansas City	1970	MR Facility	12	1993	Administrative Offices
	Kirksville	1968	MR Facility	4	1988	Administrative Offices
	Poplar Bluff	1968	MR Facility	50	1993	Administrative Offices
	Rolla	1968	MR Facility	2	1984	Administrative Offices
	Sikeston	1969	MR Facility	40	1993	Administrative Offices
	Springfield	1967	MR Facility	12	1990	Administrative Offices
New Hampshire	Laconia	1903	MR Facility	4	1991	Corrections
New Jersey	Edison	1975/1981	Corrections	70	1988	Sold at Public Auction
	Johnstone	1955	MR Facility	239	1992	Corrections
	North Princeton	1898/1975	Epileptic Colony	512	1998	Undetermined
New Mexico	Fort Stanton	1964	Army Apache Outpost	145	1995	Skilled Nursing/Respite
	Los Lunas	1929	MR Facility	252	1997	Undetermined - State Use
	Villa Solano	1964/1967	Missile Base	82	1982	Housing
New York	J.N. Adam	1912/1967	TB Hospital	180	1993	Undetermined
	Bronx	1977	MR Facility	217	1992	Plans Not Final
	Craig	1896/1935	Epilepsy Hospital	120	1988	Corrections
	Gouverneur	1962	MR Facility	N/A	1978	Leased site
	Letchworth	1911	MR Facility	704	1996	Undetermined
	Long Island	1965	MR Facility	682	1993	Undetermined
	Manhattan	1919/1972	Warehouse	197	1991	OMRDD Office
	Newark	1878	Custodial Asylum	325	1991	Community College
	Rome	1825/1894	County Poorhouse	638	1989	Corrections
	Sampson	1860/1961	Naval Base	695	1971	Office of Mental Health
	Staten Island	1942/1952	Army Hospital	692	1987	OMRDD & Community College
	Syracuse	1851/1972	MR Facility	409	1997	Undetermined
	Valatie	1971	MR Facility	N/A	1974	Private Holdings and ICFs/MR
	Westchester	1932/1979	MI Facility	195	1988	Office of MH
	Wilton	1960	MR Facility	370	1995	Sold to Private Industry
North Dakota	San Haven	1922/1973	TB Hospital	86	1987	Vacant
Ohio	Broadview	1930/1967	TB Hospital	178	1992	City Administration Building/Retirement
	Cleveland	1855/1963	MI Facility	149	1988	Vacant/Negot. with City of Cleveland
	Orient	1898	MR Facility	800	1984	Corrections
Oklahoma	Hissom	1967	MR Facility	451	1994	Corrections/Educational
Oregon	Columbia Park	1929/1963	TB Hospital	304	1977	College
	Eastern Oregon	1929/1963	TB Hospital	240	1984	Corrections/Opened New MR Facility
	Fairview	1907	MR Facility	327	2000	Undetermined
Pennsylvania	Cresson	1912/1964	TB Hospital	155	1982	Corrections
	Embreeville	1880/1972	County Poorhouse	152	1998	Undetermined
	Holidaysburg	1974	MR Facility	60	1976	Revert to MI Use
	Laurelton	1920	MR Facility	192	1998	Undetermined
	Marcy Center	1915/1974	TB Hospital	152	1982	Vacant
	Pennhurst Center	1908	MR Facility	179	1988	Veterans' Medical Center
	Philadelphia	1983	MI/MR Facility	60	1989	Vacant
	Western	1962		133	1999	
Woodhaven	1974	MR Facility	N/A	1985	Became Private Institution	
Rhode Island	Dix Building	1945/1982	WPA	80	1989	Corrections
	Ladd Center	1907	MR Facility	292	1994	Undetermined
South Carolina	Clyde Street	1973	mothers	20	1995	Administrative Offices
	Live Oak	1987	Nursing home	50	1999	To Be Sold
South Dakota	Custer	1964	TB Hospital	76	1996	Boot Camp for Delinquent Boys
Tennessee	Winston	1979			1998	
Texas	Forth Worth	1976	MR Facility	339	1995	Undetermined
	Travis	1934	MR Facility	585	1997	Undetermined
Vermont	Brandon	1915	MR Facility	26	1993	For Sale, Local Realty
Washington	Interlake School	1946/1967	Geriatric MI	123	1995	Other State Agency
West Virginia	Colin Anderson	1920s	MR Facility	85	1998	Possible Juvenile Corrections
	Greenbrier	1801/1974	Women's College	56	1994	Community College
	Spencer	1893	MI/MR Facility	150	1989	Vacant/Possible Corrections
	Weston	1864/1985	MI/MR Facility	99	1988	Revert to MI Use

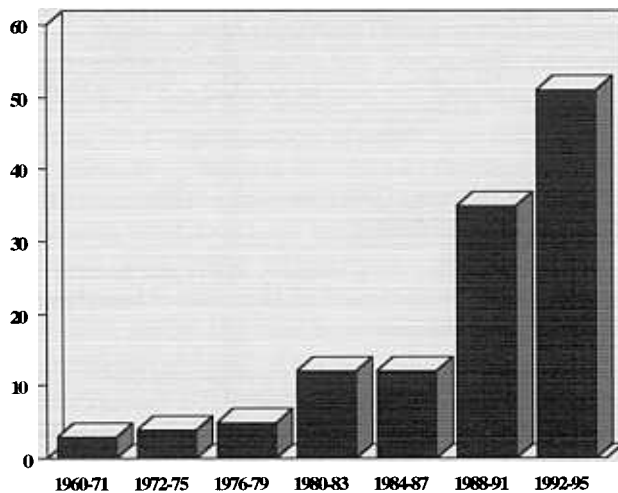
Trends in Institution Closure

by K. Charlie Lakin and Robert Prouty

In the past decade, there has been a remarkable increase in the number of closures of state mental retardation/developmental disabilities (MR/DD) institutions in the United States. Figure 1 shows the number of large state MR/DD facilities, and MR/DD units in large state facilities primarily serving other populations, that have closed since 1960. As shown, between 1960 and 1971 only three large state MR/DD facilities were closed, an average of .25 per year. Between 1972 and 1975 there were four closures, an average of one per year. In every subsequent four-year period, closures have occurred at an increasing rate. There were 5 closures between 1976 and 1979 (an average of 1.25 per year), 12 between 1980-1983 (an average of 3 per year), and 12 between 1984-1987 (an average of 3 per year). Between 1988 and 1991 closures increased rapidly to 35 (an average of 8.75 per year). In the Fiscal Years 1992-1995, there were 51 closures (an average of 12.75 per year).

Today, four states (District of Columbia, New Hampshire, Rhode Island, and Vermont) no longer operate large

Figure 1: Number of Large State MR/DD Institutions and Units Closed Between 1960-1995

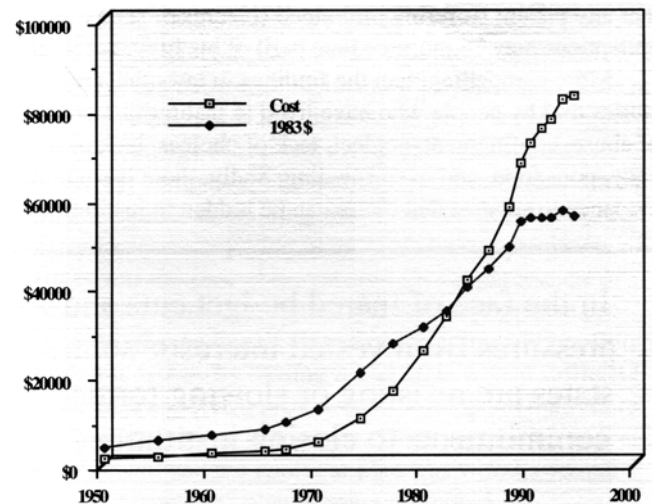


state MR/DD institutions. A number of other states are currently developing plans for total or very significant reductions in the number of large state operated MR/DD residential facilities. For example, Michigan and Hawaii anticipate operating no state institutions by the end of the century.

A number of factors contribute to states' decisions to close institutions. One is simply that much less state institution capacity is needed or desired in most states. In June 1994, state institution populations were barely one-third of 1967 populations, decreasing from 194,650 to 65,735 over

the period. A second factor in the recent spate of institution closures has been the rapidly increasing costs of state institutions care. As shown in Figure 2, average annual state

Figure 2: Average Annual Per Resident Expenditures in State MR/DD Institutions, 1950-1994



institution costs in 1994 were about \$82,300 per year. In part, these costs are the result of decreasing occupancy of institutions with high fixed costs. In many cases, costs are high because of physical and program improvements resulting from federal and state court actions. Costs are high because of the high costs of complying with federal standards for participation in the Medicaid Intermediate Care Facility/Mental Retardation (ICF/MR) program. The ICF-MR program provides federal cost-sharing of from 50%-80% of the costs of care in ICFs-MR, which has provided huge subsidies for the rapidly increasing state institution costs since 95% of all state institution residents living in ICF/MR units. However, with impending Medicaid block grants, all state institution costs in effect become state expenditures, and it seems likely that in the face of general revenue restrictions and loss of direct federal subsidies, many states will reevaluate their ability to afford state institution care.

One of the major challenges facing states considering reduction in the number of the institutions they operate is the economic impact on and resistance from local communities and public employee unions. While some states like Rhode Island and New York have responded by developing community services operated by state employees, many states find the wage and benefits costs, union work rules, and the desire to clearly separate the state oversight and service purchasing

Table 1: Alternative Uses of 99 State Institutions Closed or Planned for Closure (1970-2000)

The closed state MR/DD institution became:

• Correctional Facility (includes Juvenile)	17
• Psychiatric Facility (includes MR/DD Units closed)	18
• College/Educational Programs (includes Job Corps)	6
• Rehabilitation/Medical/Skilled Nursing Facility	4
• Facility for Another State/Local Agency (administration or program)	19
• Facility for a Federal Agency (other than Justice)	1
• Unoccupied/Declared Unsafe/Demolished	12
• Use Still Undetermined/ For Sale/Presumed Useful	22

(Source: Braddock et al., 1995. *State of the States* (4th ed.). Washington, DC: American Association on Mental Retardation).

role from the service providing role, leads them to respond to community and union concerns by trying to develop alternative uses for the state institution sites. Table 1 uses information collected by Braddock and colleagues at the University of Illinois at Chicago to show alternative uses for 99 state institutions that have been closed or are projected to close

between 1970 and 1999. As shown, a majority have become correctional facilities, exclusively dedicated psychiatric facilities, or have had the buildings taken over to house other public agencies. Twenty-two facilities were still in the process of exploring alternative uses, while 12 were judged as so outdated, asbestos contaminated or otherwise expensive to rehabilitate that they are considered unusable. Of all alternative uses, it seems at present the one of greatest favor is as correctional facilities. Corrections is a major growth industry in the United States, and offers substantial employment opportunities of similar pay and benefits to persons with backgrounds similar to the direct care staff of state institutions. In the growing number of conversions of state institutions to federal and state prisons it is often hard to overlook the irony that places that will this year be argued to be wonderful homes for persons with developmental disabilities, next year will be argued to be wonderful places in which to incarcerate convicted felons. But so it goes.

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Leaving Institutions: Effects on Those Who Move

Within the past 25 years, many people with developmental disabilities have moved out of large institutions into smaller, community homes. Originally, people with mild or moderate mental retardation moved, while those with severe or profound mental retardation were thought to be better served in larger institutions. However, in recent years people of all ability levels have been shown to benefit from living in community settings. A review of 18 research studies following the movement of over 1,350 people – the majority having severe or profound disabilities – from large institutions to small community settings between 1976 and 1988 found the following:

- All of the studies measured adaptive skills and reported at least some improvement in either overall adaptive behavior or in self-care and domestic skills with movement to small homes.
- The eight studies that compared the adaptive behaviors of those who left the institution and those who stayed found significant improvements in overall adaptive ability on the part of movers, sometimes as soon as nine to twelve months after moving to smaller settings.
- Five of the ten studies that measured people's adaptive skills while living in the institution and after moving to the community found marked improvement in overall

adaptive behavior or in basic self-help and domestic skills. The remaining studies found modest, but not statistically significant improvements in these areas.

In these studies, smaller residential settings had a positive impact on the ability of people with mental retardation, regardless of level of disability, to gain in the areas of self care and domestic skills. Living in smaller settings may be especially beneficial to people with severe and profound disabilities by promoting greater growth and independence in self-help and adaptive behavior skills. But, the benefits of community living go beyond improvement in ability, offering the opportunity to live in the same communities as the general population and to learn to function as a part of those communities.

Contributed by Lynda Anderson, Research Assistant, and Sheryl A. Larson, Research Fellow, with the Center on Residential Services and Community Living, University of Minnesota, Minneapolis. They may be reached at 612 / 624-6024.

Reference: The review of the 18 studies is found in Larson, S.A. & Lakin, K.C. (1989). Deinstitutionalization of persons with mental retardation: Behavioral outcomes. *Journal of the Association for Persons with Severe Handicaps*, 14 (4), 324-332.

TRENDS IN DEINSTITUTIONALIZATION

Background

"Deinstitutionalization as a concept affecting mentally retarded persons gained recognition during the late sixties; acquired greater support during the seventies; and became a national political, professional, and parental goal during the eighties" (Scheerenberger, 1987, p. 241). The population of people with intellectual disabilities in public institutions peaked at 194,650 in 1967. Since that time, there has been a significant national trend toward deinstitutionalization. However, in the past three years, the reductions in population at state institutions have been the smallest in 30 years.

National Trends

By 1977, there were 149,892 individuals in public institutions, and by 2000 there were 47,374. Between 1990 and 2000, the number of individuals in public institutions declined by 44%, from 84,818 to 47,374. In this same time period, the number of individuals in private facilities for 16 or more people declined from 38,883 to 34,410 (26%), and the number of people with developmental disabilities living in nursing facilities declined from 38,960 to 34,743 (23%).

State Trends

All states except Missouri and North Dakota reduced their public institutional populations during 1996-2000. At the same time, there is wide variation between states with respect to trends in deinstitutionalization. The states with the greatest percentage reduction in public institution population between 1996-2000 were: Kansas, Maine, Minnesota, New York, Oregon, and Tennessee. These states reduced the size of public institutions by 40%-86%. During the same time period, several other states only reduced their institutional populations by less than 15%. These states include: Arkansas, Delaware, Florida, Illinois, Iowa, Kentucky, Mississippi, Missouri, Nebraska, Nevada, North Carolina, North Dakota, Ohio, Texas, and Washington.

Issues

- Most recently, there has been a slowing of the trend toward deinstitutionalization nationally. From 2001-2003, there was the smallest rate of reduction in institutional size in 30 years.
- Over the years, some of the figures given for deinstitutionalization of public institutions have been misleading, as significant proportions of people were transferred to other types of institutions including nursing homes.
- Between 1996-2000, the population of people with developmental disabilities in nursing homes increased by more than 100 in six states: Alabama, California, New York, Ohio, Oklahoma, and

Virginia. States with the highest per capita utilization rates of nursing facilities were: Arkansas, Indiana, Mississippi, and Oklahoma.

- There is wide variation within states on use of larger settings. For example, in 2000, in 10 states, Arkansas, Georgia, Illinois, Kentucky, Louisiana, Mississippi, New Jersey, Oklahoma, Texas, and Virginia, 40% or more of all persons living in out-of-home residential placement lived in public and private institutional facilities for 16 or more people.
- In 2000, there were 53,913 individuals with developmental disabilities living in residential settings with between 7-15 people. Although these are not typically counted as “institutional” placements, due to their size as well as daily routines and other aspects of life in these settings, many people with disabilities, family members, and advocates consider them to be mini-institutions within the community.
- Deinstitutionalization must be accompanied by provision of necessary community supports. Over the years, some people have been “dumped” into the community without adequate supports. In response, some have focused their energy arguing against deinstitutionalization, while the need is to focus energy on demanding and establishing adequate community supports.

INFORMATION IN THIS SECTION IS BASED ON THE FOLLOWING:

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OTHER RESOURCES:

Lakin, K. C., Prouty, R., Polister, B., & Coucouvanis, K. (2004, June). States' initial response to the President's New Freedom Initiative: Slowest rates of deinstitutionalization in 30 years. *Mental Retardation*, 42(3), 241-244.

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INCLUDED IN THIS SECTION AS A BACKUP DOCUMENT:

Lakin, K. C., Prouty, R., Polister, B., & Coucouvanis, K. (2004, June). States' initial response to the President's New Freedom Initiative: Slowest rates of deinstitutionalization in 30 years. *Mental Retardation*, 42(3), 241-244.

Trends & Milestones

Edited by K. Charlie Lakin, David Braddock, and Gary Smith

States' Initial Response to the President's New Freedom Initiative: Slowest Rates of Deinstitutionalization in 30 Years

K. Charlie Lakin, Robert Prouty, Barbara Polister, and Kathryn Coucouvanis

On February 1, 2001, President George W. Bush announced The New Freedom Initiative (NFI), promising to promote “full access to community life” through, among other things, “swift implementation of the *Olmstead* decision” (White House, 2001). In the *Olmstead et al. v. L.C. et al.* decision (1999), the Supreme Court ruled that Title II of the Americans With Disabilities Act (ADA) required states to provide the services, programs, and activities developed for persons with disabilities in the “most integrated setting appropriate” because “unjustified isolation or segregation of qualified individuals with disabilities through institutionalization is a form of disability-based discrimination prohibited by Title II of the Americans With Disabilities Act of 1990.” In Executive Order 13217, President Bush committed the Executive Branch of the United States government to the principal findings of *Olmstead* and stipulated that “the United States is committed to community-based alternatives for individuals with disabilities and recognizes that

such services advance the best interests of Americans” (Bush, 2001). He called on federal departments to “work with States to help them assess their compliance with the *Olmstead* decision and the ADA” and to assist them in “removing barriers that impede opportunities for community placement.”

Paradoxically, the announcement of the NFI has been followed by the smallest reductions in state institution residents with intellectual and developmental disabilities (ID/DD) in 30 years, both in terms of numerical reductions and in percentage rates of decline. Figure 1 shows the total size of reductions in average daily populations (ADPs) in 3-year periods beginning in state fiscal year (FY) 1968, the first year in which U.S. state institution populations decreased, through FY 2003. It also shows the decreases in ADPs during each 3-year period as a percentage of the population of the immediately preceding year. As shown, the total reduction in state institution ADPs in the FY 2001–

Table 1 Average Daily Populations of State Institutions and Percentage Changes, 1980–2003

State	Average daily population				Change (%)		
	1980	1990	2000	2003	1980–2003	1990–2003	2000–2003
AL	1,651	1,305	642	377	–77.2	–71.1	–41.3
AK	86 ^a	58	0	0	–100.0	–100.0	NA ^b
AZ	672	360 ^a	166	149	–77.8	–58.6	–10.2
AR	1,550	1,260	1,229	1,123	–27.5	–10.9	–8.6
CA	8,812	6,768	3,879	3,606	–59.1	–46.7	–7.0
CO	1,353	466 ^a	129	104 ^a	–92.3	–77.7	–19.4
CT	2,944	1,799	992	887	–69.9	–50.7	–10.6
DE	518	345 ^a	256	170	–67.2	–50.7	–33.6
DC	775	309 ^a	0	0	–100.0	–100.0	NA
FL	3,750	1,992	1,508	1,521	–59.4	–23.6	0.9

Table 1 continued

Table 1 Continued

State	Average daily population				Change (%)		
	1980	1990	2000	2003	1980-2003	1990-2003	2000-2003
GA	2,535	2,069	1,510	1,333	-47.4	-35.6	-11.7
HI	432	162	0	0	-100.0	-100.0	NA
ID	379	210	110	104	-72.6	-50.5	-5.5
IL	6,067	4,493	3,237	2,952	-51.3	-34.3	-8.8
IN	2,592	1,940 ^a	854	612	-76.4	-68.5	-28.3
IA	1,225	986	674	672	-45.1	-31.8	-0.3
KS	1,327	1,017 ^a	379	368	-72.3	-63.8	-2.9
KY	907	709	628	543	-40.1	-23.4	-13.5
LA	2,914	2,622	1,749	1,682	-42.3	-35.9	-3.8
ME	460	283	0	0	-100.0	-100.0	NA
MD	2,527	1,289	548	421	-83.3	-67.3	-23.2
MA	4,531	3,000	1,306	1,155	-74.5	-61.5	-11.6
MI	4,888 ^a	1,137 ^a	271	164	-96.6	-85.6	-39.5
MN	2,692	139	422	33	-98.8	-97.6	-21.4
MS	1,660	1,498	1,383	1,378	-17.0	-8.0	-0.4
MO	2,257	1,860 ^a	1,286	1,247	-44.7	-33.0	-3.0
MT	316	235	131	115	-63.6	-51.1	-12.2
NE	707	466	401	386	-45.4	-17.2	-3.7
NV	148	170	157	116	-21.6	-31.8	-26.1
NH	578	87	0	0	-100.0	-100.0	NA
NJ	7,262	5,069	3,555	3,218	-55.7	-36.5	-9.5
NM	500	500	0	0	-100.0	-100.0	NA
NY	15,140	7,694	2,466	2,261	-85.1	-70.6	-8.3
NC	3,102	2,654	1,939	1,863	-39.9	-29.8	-3.9
ND	1,056	232	144	147	-86.1	-36.6	2.1
OH	5,045	2,665 ^a	1,996	1,893	-62.5	-29.0	-5.2
OK	1,818	935	391	366	-79.9	-60.9	-6.4
OR	1,724	838	62	50	-97.1	-94.0	-19.4
PA	7,290	3,986	2,127	1,577	-78.4	-60.4	-25.9
RI	681	201	0	0	-100.0	-100.0	NA
SC	3,043	2,286	1,129	1,002 ^a	-67.1	-56.2	-11.2
SD	678	391	196	183	-73.0	-53.2	-6.6
TN	2,074	1,932	948	758	-63.5	-60.8	-20.0
TX	10,320	7,320 ^a	5,431	5,011	-51.4	-31.5	-7.7
UT	778	462	240	230	-70.4	-50.2	-4.2
VT	331	180	0	0	-100.0	-100.0	NA
VA	3,575	2,650	1,625	1,581	-55.8	-40.3	-2.7
WA	2,231	1,758	1,143	1,043	-53.2	-40.7	-8.7
WV	563	304 ^a	0	0	-100.0	-100.0	NA
WI	2,151	1,678 ^a	900	791	-63.2	-52.9	-12.1
WY	473	367	113	97	-79.5	-73.6	-14.2
U.S. total	131,088	84,389	47,872	43,289	-67.0	-48.7	-9.6

^aEstimate. ^bNot applicable.

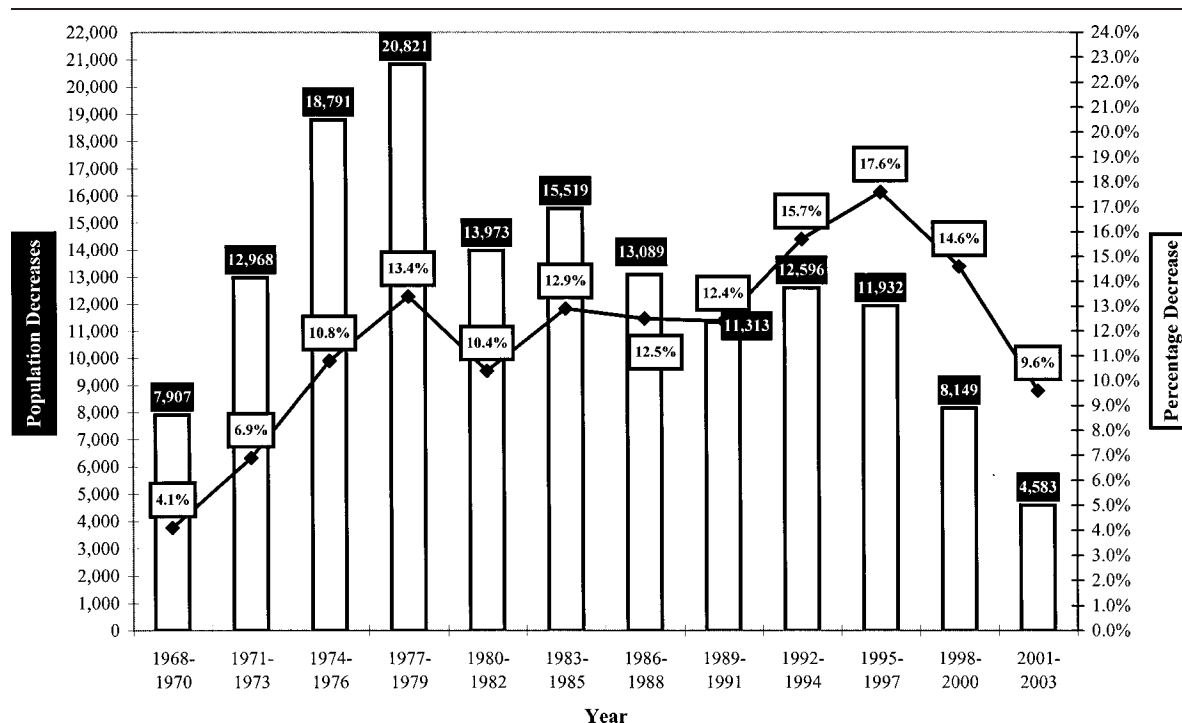


Figure 1 Decreases in state institution average daily populations in 3-years periods, 1968–2003.

2003 period (4,583 people) was by far the smallest of any 3-year period since state institution populations began to decrease in FY 1968, barely one half (58.0%) of the next smallest total for a 3-year period (7,907 in FY 1968–1970). As a proportional decrease, the FY 2001–2003 decrease (9.6%) was smaller than any period since FY 1971–1973 (6.9%), 30 years earlier. Of the individual years in the FY 2001–2003 period, FY 2003 had the smallest decrease in institution residents. The FY 2003 decrease in ADPs of state institutions (1,054) was the smallest since 1968 (960) and the smallest proportional decrease (2.4%) of any year since FY 1972 (1.6%).

Table 1 identifies the relative contributions of individual states to the progress in deinstitutionalization called for in the New Freedom Initiative. It shows state-by-state ADP trends over various periods between FY 1980 and FY 2003, including between FY 2000 and FY 2003. Since FY 1980, there has been a more than two thirds reduction (67.0%) in the ADPs of state institutions nationwide, with 8 states and the District of Columbia ending state institution placements altogether. Between FY 1990 and FY 2003, state institution ADPs were nearly

halved (–48.9%). Between FY 2000 and FY 2003, state institution ADPs decreased by 9.6%, an average of 3.2% per year as compared with 4.3% between FY 1990 and FY 2000. Recent patterns in ADPs suggest that deinstitutionalization will occur at increasingly slow rates without changes in those patterns. The 22 states with ADP decreases below the national average reduced their ADPs by an average of 6.1% between FY 2000 and FY 2003. This compares with an average of 19.0% in all other states. The vast majority of the 22 slowest changing states (16) were below the national average rate of state institution depopulation between FYs 1990 and 2000 as well, a notable exception being New York, which before FY 2001, was well above the national average. As a result of these states’ long-term patterns of generally slow depopulation, by FY 2003 they housed 75.9% of all state institution residents, an increase from 73.0% in FY 2000 and 64.0% in 1990. Clearly, without new priorities, incentives, and/or expectations, the increasing concentration of state institution residents in those states with the lowest rates of deinstitutionalization will continue to impede access to the “community-based alternatives” to which President Bush in the

New Freedom Initiative declared the United States to be committed.

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III. Issues

- a. What's Wrong with Institutions?
- b. Cost/Economic Issues
- c. Quality of Life Outcomes in the Community
- d. Choice
- e. Safeguards
- f. Family Issues

WHAT'S WRONG WITH INSTITUTIONS?

Issue

The idea of providing “human” services in an institution has never worked and will never work. This is because of problems with the nature of institutions. Wolfensberger (1975, p. 69) states: “It seems as if the very model, as we have known it, is unworkable.” Problems with institutions are most powerfully revealed by the stories and experiences of people who have lived in institutions. Tia Nelis, a noted self-advocate, emphasizes the critical need to hear the voices of those who live in or have lived in institutions: “Next time people start talking about closing institutions, make sure you’re asking and listening to the right people—those who live there. They know the truth about these places” (Nelis, 1995/96, p. 27). Problems with institutions are also revealed by research. Themes from personal accounts and research include the following:

- **Abuse and Neglect** - People with intellectual and developmental disabilities are vulnerable to abuse and neglect. These can occur in institutions as well as in the community. However, because of the large numbers of people in institutions and the depersonalization that occurs in large settings, abuse is more common and harder to detect in institutional settings. Experienced advocates talk of a “wall of silence” among institutional staff. Due to inadequate staff and lack of other resources, institutions became places of widespread abuse and neglect. Dick Sobsey, a leading expert on abuse of people with disabilities, says that people who have the best chance of not being abused are those who are fully integrated into the community and surrounded by people who care about them.
- **Dehumanization** - Within institutions, people have been treated in ways that disregard all human dignity and respect. In many ways, people are thought of more like numbers than as humans. As one example, in the past, many people who were buried in institutional cemeteries had markers with numbers rather than their names.
- **Segregation and Isolation from the Community** - Institutions cut people off from the mainstream of neighborhood and community life. Many institutions have been geographically located in rural areas. Even in urban areas, though, institutions have operated on a very self-sufficient basis, with the idea that the institution itself is the “community” for those who live there. Thus, individuals living in institutions have often had little or no opportunity to participate in the life of the community beyond the institution.
- **Lack of Human and Civil Rights** - People have been confined to institutions for years without any legal reason, only because of the label of “mental retardation.” They have been denied privacy, choice, and control in their lives.

- **Lack of Access to Education and Assistive Technology** - People in institutions have had very little opportunities to obtain an education and/or acquire skills and competencies that would promote independence. Instead, institutions have fostered dependency and often loss of skills and competencies.
- **Lack of Individualization in Services** - Institutions do not adapt their services to fit the needs of each individual. Instead, people are forced to fit into the institutional setting.

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COST/ECONOMIC ISSUES

There are many myths about the costs of institutional versus community services. Some insist that a person with significant disabilities cannot be served in the community because it would cost too much. Others insist that community services are always less expensive. In reality, the economic issues related to maintaining institutions, as opposed to deinstitutionalization or closure paired with development of quality community services, are complex. Much depends on decisions made at the state level about issues such as infrastructure, community capacity-building, wages of community workers, and the like. Still, research on the economic consequences of institutional downsizing and closure is available and will be summarized in this cover sheet.

Also, it is crucial that costs be viewed in the aggregate—that is, for a large group of people instead of on an individual basis. Making decisions about whether or not someone should live in the community based on the cost of serving that person is like saying that if a person's services and supports cost more than an arbitrary ceiling amount, he or she is not worth the expense. This goes against everything disability advocates stand for. When costs are aggregated, the average per-person cost is the standard, and it is appreciated that the expenses for some will be higher than the expenses for others.

Considerations Other than Money

Since 1980, 38 research studies have indicated that people who move into communities from institutions show improvements in daily living skills, community participation, frequency of contact with family members and others in the community, greater choice, and satisfaction (Kim, Larson, & Lakin, 1999). Public money is wisely spent when people grow, learn, become more independent, and enjoy their lives, and studies consistently show that people who move to the community are much more likely to do just those things. Conversely, in institutions, tax dollars are paying for services that are shown to produce poor outcomes for the people served. This is poor public policy. In fact, the states that have closed institutions have done so because it is the right thing to do, not because it would save money.

Comparing Costs

In 2002, states spent an average of \$125,746 per public institution resident, as compared with \$37,816 per person served in the community through the Medicaid home and community based waiver (HCBS). However, such comparisons can be misleading, in part because the services differ in many respects, such as the amounts or types of support provided and the characteristics of the people served. Most people still live with families, so the costs of 24 hour supports that are provided unpaid by families can make community services look lower for those people.

In studies that looked more closely at the costs of services provided to similar groups of people served in both types of settings, costs of community services ranged from 5% to 27% less than state institutional services provided to similar people. However, a major reason for that difference was that substantially lower wages and benefits are consistently (across states and providers) paid to direct support workers in community service agencies.

Costs of Closing Institutions

When states close institutions, there is generally a period during closure when more money must be spent. Safety must be ensured in the institution for those who have not yet left, and at the same time there must be expansion of services in the community. Community service expansion should include the costs of building new or enhanced systems for supporting people with significant disabilities (crisis behavioral response systems, housing and work developers, service coordinators, etc.), as well as one-time expenses for start-up (housing deposits, furnishings, appropriate clothing, etc.). Per-person costs in institutions that are closing go up as people move because institutions have many fixed costs that cannot be reduced. After closure, these costs end.

One study (Stancliffe, Lakin, Shea, Prouty, & Coucouvanis, in press) compared per diem institutional costs in states that had dramatically reduced or closed institutions between 1988 and 2000 to per diem costs in states that had very minor declines in institutional populations during the same years. This study found that the high-change states had a greater increase in per-person costs in their institutions than did the low-change states. However, their institutional populations declined rapidly, bringing their overall institutional expenditures down over time. Of course, those states that closed institutions had no institutional per diem after closure and were able to spend all of their annual allocation in the community. Additionally, some states have been able to sell their institutional facilities and land, and to use these proceeds to support more people with developmental disabilities in the community.

Cost Savings?

Recent cost comparisons of community and institutional services do not support the position that there are "economies of scale" associated with institutions or that community settings (especially traditional setting such as group homes and sheltered employment) cost less than institutions. These studies also suggest that costs are associated with a state's traditions as much as with any absolute "cost of service" that can be identified. That is, one state may spend two or three times as much, per person, as another, due to many factors unrelated to the support needs of the individuals being served. It is also important to note that the cost impact of new ways of providing supports, such as consumer-directed services with individual

budgets (often referred to as “self-determination”), is just beginning to be studied. A 2004 [Policy Research Brief](#), *Costs and Outcomes of Community Services for Persons with Intellectual and Developmental Disabilities*, which was recently published by the Research and Training Center on Community Integration, presents evidence about individual budgets, as does the Spring 2004 [IMPACT Feature Issue on Consumer-Controlled Budgets and Persons with Disabilities](#).

States can use their budgets to do what they decide to do. As advocates, our job is to remind them that all people are entitled to life in the community, and that they can make this a reality if they choose to do so.

INFORMATION IN THIS SECTION IS BASED ON THE FOLLOWING:

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Taylor, S. J. (2003, April). The editor's perspective on institutional and community costs. *Mental Retardation*, 41(2), 125-126.

INCLUDED WITH THIS SECTION AS BACKUP DOCUMENTS:

Eidelman, S. M., Pietrangelo, R., Gardner, J. F., Jesien, G., & Croser, M. D. (2003, April). Let's focus on the real issues. *Mental Retardation*, 41(2), 126-129.

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The Editor's Perspective on Institutional and Community Costs

This issue of the *Journal* contains a research review by Walsh, Green, and Kastner (2003) on cost comparisons of institutional and community services. The response that follows by the Developmental Disabilities Quality Coalition-DDQC (Eidelman, Pietrangelo, Gardner, Jesien, & Croser, 2003), a consortium of nine national groups, refers to an Executive Summary that has been widely distributed by Voice of the Retarded (VOR), a group that provided financial support for the research review.

I first became aware of VOR's Executive Summary when I was contacted in July 2002 by several people in Washington, DC, who inquired about whether the Walsh et al. article was forthcoming in the *Journal*. (I confirmed that it was but declined to provide copies.) A copy of this Executive Summary was sent to me, along with "Talking Points and Action Steps" prepared by VOR, in which the summary was described as an advocacy tool to use with policy makers to oppose the "aggressive push towards deinstitutionalization."

I subsequently accepted for publication the following response by the DDQC (Eidelman et al., 2003) to VOR's Executive Summary. This response is *not*, and *should not*, be interpreted to be a critique of the Walsh et al. article published in this issue. The response is directed at the Executive Summary and the advocacy materials distributed by VOR. The authors of this response could not comment on the Walsh et al. article or criticize their methodology and findings simply because the article was not available to them.

The reason I accepted the DDQC response is that VOR's Executive Summary has been disseminated to policy makers and discussed in policy circles. In the materials by VOR, numerous references were made to the fact that the research review was forthcoming in a peer-reviewed journal and implied that this review countered one of the major arguments in favor of deinstitutionalization and community inclusion. The DDQC response provides a different perspective on the relevance of cost in the institution versus community debate.

In VOR's Executive Summary a footnote was

included signifying that "a slightly modified manuscript has been submitted for publication." The manuscript accepted for publication in the *Journal* is *not* a "slightly modified" version of the Executive Summary. The Executive Summary is missing the essential information—the methodology, the list of studies reviewed, the interpretations of the findings of these specific studies—to enable the research and scholarly community to evaluate the research reviewers' conclusions. No single study or research review is ever definitive or conclusive. Readers of this and other journals know that published articles sometimes generate responses or stimulate additional research and analyses in which other researchers come to conclusions opposite to those in the originally published work. This is why authors of peer-reviewed research articles are expected to provide specific descriptions of their methodology.

The contribution of Walsh et al. (2003) in their research review, in my opinion, is that they draw attention to the complexity of cost comparisons and identify some of the major factors that should be taken into consideration. For example, Walsh et al. pointed out that lower costs in community settings often reflect differentials in staffing costs. Staff members at state-operated institutions tend to receive higher wages and benefits than do workers at privately operated community settings. Walsh et al. noted, and I agree, that the lack of parity in wages and benefits between workers at institutions and community settings is not a "desired efficiency," but it is not a foregone conclusion that parity will be achieved in the foreseeable future.

When I made the decision to accept Walsh et al.'s research review, I was not influenced by the potential political implications of publishing the article. I never am when making editorial decisions on manuscripts submitted for peer-review.

Any set of findings or facts can lead to different conclusions and policy implications. If Walsh et al.'s (2003) article suggests that community settings are not inherently less expensive than are institutions, then it also refutes claims that institutions offer "economies of scale" or that the centralization of

services at institutions is more cost-effective. The “institutional bias” of the federal–state Medicaid program, alluded to by Walsh et al., cannot be justified on fiscal grounds.

I consider the Walsh et al. (2003) research review to be a valuable addition to the literature on cost analysis of developmental disability services and hope that readers will evaluate it according to its contribution to the field by identifying factors that should be considered in cost comparisons. It would be unfortunate if people in the field viewed it as ammunition in a political debate. This is not why I accepted this research review for publication, and it is not what I think that we can learn from it.—S.J.T.

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Editor's Note: The American Association on Mental Retardation (AAMR) is a member of the Developmental Disabilities Quality Coalition. Editorial decisions on manuscripts submitted to the *Journal* are made without regard to the position statements of AAMR. The Board of Directors and personnel from the National Office of AAMR have never attempted to influence the editorial decision-making process of the *Journal*. Further, when this response was originally accepted, AAMR was not associated with it.

Let's Focus on the Real Issues

Steven M. Eidelman, Renee Pietrangelo, James F. Gardner, George Jesien, and M. Doreen Croser

This article was written in response to a 4-page paper entitled “Executive Summary: Institutional and Community-Based Systems for People With Mental Retardation: A Review of the Cost Comparison Literature,” which was funded and widely disseminated by the Voice of the Retarded—VOR (2002). In this Executive Summary, which is described by VOR as a “research tool,” an analysis of existing studies of costs of supports and services for people with mental retardation and developmental disabilities is reported. It is noted in the summary that it is a “slightly modified” version of a manuscript submitted for publication. Although we have not reviewed the manuscript submitted for publication and cannot comment on it, the Executive Summary is an example of how research can be turned into a call for poor public policy.

The Developmental Disabilities Quality Coalition (DDQC) is comprised of the chief staff executives of The Arc of the United States, American Association on Mental Retardation, American Network of Community Options and Resources, Council on Quality and Leadership, National Association

of State Directors of Developmental Disabilities Services, American Association of University Centers on Disabilities, National Association of Protection and Advocacy Systems, National Alliance of Direct Support Professionals, Consortium of Developmental Disabilities Councils, and National Association of Developmental Disabilities Councils. Members of this coalition are gravely concerned about the misguided interpretation of this Executive Summary as it relates to the national agenda for full inclusion, choice, and person-centered outcomes for people with mental retardation and developmental disabilities. In addition to the DDQC and numerous other advocacy and disability organizations nationwide, this agenda is supported at the highest levels of public policy by the current Bush Administration through its “New Freedom Initiative” and by the Supreme Court in its *Olmstead* decision.

It is imperative that we place this report in its proper historical context. Deinstitutionalization has been taking place in the United States for the past 3 decades. In the 1990s alone there was a 44% de-

cline in the number of persons in state-operated institutions (Lakin, Prouty, Polister, & Smith, 2002). It is critical to note that these reductions were not driven primarily by potential cost savings. In so many cases, states also “matched” someone leaving the institution with someone at home waiting for services. These institutions closed and others are continuing to close because it is the right thing to do, not because it will save money. The best estimate is that all institutions will be closed somewhere between 2011 and 2025, the later date adjusted for slower progress in Georgia, Illinois, Kentucky, Louisiana, Mississippi, New Jersey, Oklahoma, Tennessee, Texas, and Virginia (Brad-dock, Hemp, Rizzolo, Parish, & Pomeranz, 2002).

The disability field has, over these past 3 decades, learned to separate “level of care” from real estate. They are two separate issues. Where the needed supports for a person take place and the frequency, intensity, and duration of those supports are two separate issues.

There has been a national movement to promote *The Community Imperative* (1979), which every member of the DDQC has endorsed. *The Community Imperative* states, in part:

- All people have fundamental moral and constitutional rights.
- These rights must not be abrogated merely because a person has a mental or physical disability.
- Among these fundamental rights is the right to community living.
- All people, as human beings, are inherently valuable.
- All people can grow and develop.
- All people are entitled to conditions that foster their development.
- Such conditions are optimally provided in community settings.

Note that nowhere in *The Community Imperative*, which is a civil rights and social justice statement, is there any mention of cost. The question of the comparative costs of institutional versus community services is not relevant; it is a non-issue. The real question is: Under what circumstances should or, more important, will the taxpaying public pay for 24-hour wrap-around services for people with disabilities regardless of the setting in which those services are provided? In institutions, the taxpaying public is paying for services that are shown to produce poor outcomes for the people served. Clearly, this is poor public policy.

Discussions of comparative costs have been going on ever since people started mounting serious threats to the existence of institutions. The fundamental question that needs to be addressed is whether or not we, as a society, want to have those among us who have disabilities receive the supports they need in their own local communities, close to families and friends, or do we want to segregate them from the rest of society in congregate settings?

Does it make sense to label and categorize people on the basis of some characteristic and treat them as if the condition they have is the most important thing about them? Is this categorization so important, in fact, that it is a legitimate interest of the state to offer alternatives for the provision of needed care and support that, in fact, force people to trade their human and civil rights for services? Doesn't our nation's Constitution have something to say about this?

If it is agreed that people should not have to actually leave society in order to receive the basic support they need to live their lives, then it does not make sense to offer needed supportive services outside the community setting. Again, this is not an issue of cost; it is an issue of civil rights. Other than the criminal justice system, we cannot think of another situation where such restrictions take place nor one that tolerates the effective control of one group by another.

In specific response to the points noted in the Executive Summary, the DDQC offers the following comments:

1. From the studies reviewed here, it is clear that large savings are not possible within the field of developmental disabilities by shifting from institutional to community placements. (VOR, 2002)

Placements are not the issue. Most people with mental retardation live with their families and have never lived in institutions. Their families provide for them because of love and necessity. The fallacy that those in institutions are somehow different and “more severely challenging or disabled” is not borne out by the research or by common sense. The question is one of fairness and resource allocation; although those in institutions may have numerous services available, many families are supporting their family member who has severe disabilities with little or no public support. There is also the issue of how the funds are spent. Institutions have their own electricians, plumbers, power plant op-

erators, roads, and maintenance personnel. In the community, those things are there for everyone and are part of rent, taxes, or general citizenship. Community programs concentrate on the people, not buildings.

2. The scope of the present literature review did not allow for the simultaneous review of research on the many clinical and quality of life outcomes but noted the importance of including in policymaking consideration [of] a full range of individual outcomes. (VOR, 2002)

The literature review refutes the argument made by some institutional proponents that economies of scale and centralized services make institutions more economical than community services. The research on outcomes overwhelmingly makes it clear that the outcomes for people in the community are better than those for individuals segregated in institutions (Lakin, 1999). In a well-constructed study, investigators would have looked at both issues simultaneously. Good public policy supports good outcomes and human rights, especially when there is no significant cost advantage to either form of service and support.

3. Clear-cut evidence was not found in the studies reviewed to support the unambiguous conclusion that community services are inherently less expensive than institutional settings. (VOR, 2002)

From the studies reviewed here, it is clear that large savings are not possible within the field of developmental disabilities by shifting from institutional to community placements. Again, the issue of note is that most people with developmental disabilities are not now nor have they ever been in an institution, that institutions are inhumane and violate people's rights, and that there is virtually no demand, except from the small membership of VOR, to keep institutions open or to admit people to them. It is also apparent that approaches such as self-determination and individualized budgeting were not analyzed in the Executive Summary, even though these are the issues of utmost importance. Determining resources that provide what people really want and need, as opposed to a rigid package, should be explored. The Intermediate Care Facility (ICF) program and the myth of something called "active treatment" make assumptions about people's deficits and then designs a program within the confines of the active treatment framework to address them. Active treatment was designed in the early

1970s to deal with the lack of anything positive in the environment in institutions—not as a panacea for a way to help people with developmental disabilities lead lives of meaning.

4. . . . public policy should not be generalized statements about cost-efficiency, rather, they should revolve around the individual and his/her needs: "What does this person need?" "Where best to provide for these needs?" and "At what cost?" (VOR, 2002)

We agree with this statement. Person-centered approaches, practicing self-determination, and a solid understanding of a person's needs will lead to the best services and supports. When these are present, the setting will not be an institution. Gross comparisons between costs in institutions and the community oversimplify the costs associated with different ways of supporting people in the community. They also ignore the *benefits*, which study after study have demonstrated is substantially higher in the community.

5. Finally, a factor that has been included only sporadically in the literature or, in some cases, not at all, has to do with the variability in the characteristics of those being served (referred to here as case mix). Individuals with mental retardation and related developmental disabilities are quite heterogeneous with some individuals being nearly indistinguishable from people without disabilities to those who are quite disabled and dependent. Over the period reviewed, it has been typical for a higher proportion of individuals with mild disabilities to live in community settings while people with more complex needs requiring extensive care remained in institutional facilities. (VOR, 2002)

Most people live in the community and always have. Therefore, to compare the cost of most people in the community to a small subset of those remaining in institutions is inaccurate and misleading. The true comparison would be the cost for all people with similar disabilities in the community, including those who receive minimal or no public support.

The DDQC was compelled by moral obligation and commitment to respond to the obfuscation of the real issues generated by the Executive Summary and the subsequent policy interpretations extrapolated by VOR. We are confident that the arguments set forth herein clarify the relevant issues implicit

in today's public policy debate regarding supports and services for people with mental retardation and developmental disabilities.

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Excerpts from *The Economics of Deinstitutionalization*¹

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2004

RESEARCH, POLICY AND EXPENDITURE CONTEXT

Introduction

In the United States policy decisions about deinstitutionalization have been made for a range of reasons related to the well-being of service recipients, litigation, funding, and political considerations. Economic factors have not been nor should they be the primary basis for determining policy on developmentally disability services. However, decisions about institutional downsizing and closure have economic consequences. It is important that research-based information about these consequences is available to policy makers, administrators and advocates, so that deinstitutionalization can be planned and implemented in a rational, economically sustainable manner. This chapter examines the research, policy, and economic context of deinstitutionalization drawing on national data on deinstitutionalization, as well as specific examples of deinstitutionalization in California and Minnesota.

...National Trends in Public Institutional Costs

Public institutions are costly enterprises. In Fiscal Year (FY) 2002 states spent, on average, \$125,746 per public institution resident. In the 20 years between 1982 and 2002, the "real" (inflation adjusted) dollar cost of public institution care more than doubled from \$61,117 (2002=\$1) to \$125,746 (Prouty, Smith & Lakin, 2003).

In the United States rapid escalation in public institution costs began in the early 1970s. Four major factors contributed to this trend. The creation of the Intermediate Care Facility for the Mentally Retarded (ICF-MR) program in 1971 provided, for the first time, federal Medicaid cost

¹These paragraphs are excerpts from R. J. Stancliffe, K. C. Lakin, J. R. Shea, R. W. Prouty, & K. Coucouvanis. (in press). *The economics of deinstitutionalization*. In R. J. Stancliffe & K. C. Lakin (Eds.), *Cost and outcomes of community services for people with intellectual disabilities*. Baltimore: Paul H. Brookes Publishing Co.; adapted with permission by Paul H. Brookes publishing Co. (ISBN 1-55766-718-7; 1-800-638-3775; <http://www.brookespublishing.com/store/books/stancliffe-7187/index.htm>).

sharing of 50%-80% of institutional costs under the condition of facilities meeting specific programs, staffing and physical plant standards. In the decade that followed, 88% of all public institution residents were living in units that met ICF-MR standards and received federal cost share. In the process, annual expenditures per resident increased from \$4,635 in 1970 to \$32,759 in 1982, or in inflation adjusted dollars from \$21,458 (2002=\$1) to \$61,117. This was the decade of the most rapid rate of increase in public institution expenditures since national data were first gathered in 1903.

ICF-MR certification costs were not the only factor in this increase. Beginning in 1968 public institution populations in the United States began to decrease steadily. In the years that followed, public institutions had to spread the fixed costs of operating the institutions (maintenance, administration, utilities, etc.) over fewer and fewer individuals. (This issue is examined in more detail later in the chapter.)

...It is hard to determine the relative impact on cost of any one of these factors because for the most part they were not only simultaneous, but also interrelated. By the mid-1980s public institutions became extremely costly in comparison to the average per person costs of 1970, so much that in inflation adjusted "real dollars" (\$1=2002), the expenditures for state institutions in 1986 (\$7.97 billion) was nearly double the real dollar expenditures of 1970 (\$4.18 billion), even though the number of average daily public institution residents had been nearly halved from 194,650 in 1970 to 100,190 in 1986. Not only were public institutions expenditures in 1986 dramatically greater than they had been in 1970, community residential alternatives were consistently found to be 75% to 92% as costly as public institutions for comparable sets of comprehensive services (Ashbaugh & Allard, 1984; Bensberg & Smith, 1984; Jones, Conroy, Feinstein, & Lemanowicz, 1984; Minnesota Department of Public Welfare, 1979; Toche Ross, Inc., 1980).

...Institutional and Community Services: Relative Costs

As noted, the comparative costs of institutional and community costs differ greatly, with average expenditures of \$125,746 per public institution resident in FY 2002, as compared with \$37,816 per recipient of community services financed by the Medicaid Home and Community Based Services (HCBS). But such comparisons can be misleading as institutional and community services differ in many important respects, such as the characteristics of the populations served,

wages rates and conditions of employment, and the array of services provided. Consequently, the most meaningful comparisons of institutional and community service costs may be found in the deinstitutionalization costs literature where similar groups of service recipients receive a similar array of services in institutional and community settings.

Available US studies of both costs and outcomes of deinstitutionalization reveal a consistent pattern across states and over time of better outcomes and lower costs in the community (Jones, Conroy, Feinstein, & Lemanowicz, 1984; Knobbe, Carey, Rhodes & Horner, 1995; Stancliffe & Lakin, 1998), consistent with US deinstitutionalization literature on outcomes (Kim, Larson, & Lakin, 2001), and cost comparison research showing US institutional services to be more costly than community services (Campbell & Heal, 1995; Schalock & Fredericks, 1990).

It should be noted that a primary factor associated with the difference is the consistently and substantially lower wages paid to direct support staff employed by community service agencies. Nationally in 2000, the average hourly wage of direct support staff in state-operated services was \$11.57 versus an estimated \$8.72 (24.6% less) in non-state community services (Polister, Lakin & Prouty, 2002). Such consistent and substantial wage differentials likely have been noted as a major driver of the lower cost of non-state community services (Campbell & Heal, 1995; Rhoades & Altman, 2001; Stancliffe & Lakin, 1998), especially given that staff costs are the largest component of residential and related services expenditures, generally representing about 77% to 87% of total expenditures (Stancliffe & Lakin, 1998). More detailed discussion of issues related to cost comparisons between institutional and community services may be found in Chapter 1 of the volume (Stancliffe, Lakin & Lewis, in press).

COSTS OF CLOSING INSTITUTIONS

Large, State-Operated Facilities

...As populations of public institutions have continued to fall, increasingly specialized roles have been ascribed to institutions. With ultimate closure of public institutions, states must identify the roles and services that the public institutions are providing, so that alternative sources can be established. This often requires systematic analysis of each institutional admission and readmission. Frequently, the roles/services sustaining the institution have relatively little to do with their life circumstances. For example, many public institutions serve as the one place where there is always an open "bed" in times of crisis (death or illness of the primary care provider; unexpected

and immediate demission from community settings). Identifying such roles/services provided by institutions that will still be needed after their closure is an important aspect of the closure process. Likewise, designing those features into the system of community supports as programs or enhanced capacities is an important aspect of institutional closure and represents an additional cost. Probably the most commonly identified function/service needed in support of public institution closure is community-based behavioral support and crisis response (see Hanson, Wieseler & Lakin, 2002), but the nature of the community service needed depends on the analysis of roles and functions of the specific institution to be closed.

Current and Future Issues

In any analysis of public expenditures, including expenditures for services for persons with ID/DD, it must be recognized that ultimately the resources expended are determined much more by resource allocation traditions than by inherent costs. One might note these traditions the variations in expenditures for highways between two states of similar size. For example, Missouri spent twice as much for highways in 1999 than neighboring Arkansas. Such variations exist with institutional and community services. In FY 2002, attempting modest control for diseconomies of reduced scale, the five states (Georgia, Illinois, Iowa, Missouri, Nebraska) with state institution population reductions from 1980 to 2002 in the range of 42.0% to 48.0% had average daily institution costs in FY 2002 that ranged from \$235 (Missouri) to \$334 (Illinois); nine states (California, Delaware, Montana, New Jersey, Ohio, Tennessee, Texas, Virginia, Wisconsin) with state institution population reductions from 1980 to 2002 that ranged from 50.0% to 62.0% had average daily costs that ranged from \$253 (Texas) to \$589 (Tennessee). (Some "traditions" such as Tennessee's are sometimes recreated in federal courts.) Similarly combining Medicaid ICF-MR and HCBS expenditures for states showed that in FY 2003, states had average combined annual per person expenditures that ranged from less than \$35,000 in nine states to more than \$70,000 in six states. Because there is no "right amount" that services should cost, the amount services do cost are affected by various factors. One set of factors that may well substantially affect expenditures in the next few years is the cost of direct support workers....

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QUALITY OF LIFE OUTCOMES IN THE COMMUNITY

Issue

What quality of life improvements are experienced by people who move from institutions into the community? Much research has focused on certain specified "quality of life outcomes." In order to best understand quality of life outcomes, it is most important to listen to the experiences and perspectives of individuals with disabilities who have lived in the institution and then the community.

What Is Quality of Life

Quality of life is difficult to define; it is different for each person, and depends on personal experience. Goode (1992, p. 3; cited in Taylor, 1994) quotes a definition from the National Institute on Disability and Rehabilitation Research: "the timbre of life as experienced subjectively; one's feelings about/evaluations of one's own life..."

There are many ways that people have tried to capture and frame quality of life. One of the most commonly used and referred to today in the field of developmental disabilities is the five "valued experiences" proposed by John O'Brien and Connie Lyle O'Brien (1987). These include: sharing ordinary places and activities; making choices; developing abilities and sharing personal gifts; being respected and having a valued social role; and growing in relationships.

Research on Quality of Life

For research purposes, many different definitions of quality of life have been used. Research studies have examined quality of life across domains such as interpersonal relations, social inclusion, personal development, physical well-being, self-determination, material well-being, emotional well-being and rights.

- There are numerous studies that document positive changes in adaptive behavior for people who leave institutions and move into the community.
- In addition, research reviews have found documentation of positive changes associated with deinstitutionalization.
- Studies focusing on more subjective aspects of quality of life (e.g., self-determination, autonomy, choice, etc.) have also found positive changes.

Quality of Life and the Individual's Perspective

In order to really understand the difference between quality of life in an institution and in the community, it is necessary to listen to the stories of people who have lived in institutions and in the

community. Time after time, these stories document abuse and lack of privacy, choice, and control in the institutions. The stories tell of struggles in the community, as well. However, there is unanimous agreement about the vast improvement of life in the community over life in the institution. For example, Russ Daniels reflects, "Now, I live like a king. I'm happy, I do what I want, go where I want, I can come back when I want." Similarly, Mark Samis states, "In the past few years, my life has all turned around. Nothing but great things have happened to me since leaving the institution."

INFORMATION IN THIS SECTION IS BASED ON THE FOLLOWING:

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- Wehmeyer, M., & Bolding, N. (2001). Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments. *Journal of Intellectual Disability Research*, 45, 371-383.

RESOURCE:

- Conroy, J. W. (1998, December). *Are people better off? Outcomes of the closure of Winfield State Hospital* [Final Report (No. 6) of the Hospital Closure Project]. Rosemont, PA: The Center for Outcome Analysis.

INCLUDED WITH THIS SECTION AS BACKUP DOCUMENTS:

- Daniels, R., & Samis, M. (1995/96). Inside and out: Former residents reflect on their lives. *IMPACT: Feature Issue on Institution Closures*, 9(1), 10-11. Minneapolis: Institute on Community Integration, University of Minnesota.
- Kim, S., Larson, S. A., & Lakin, K. C. (1999). Behavioral outcomes of deinstitutionalization for people with intellectual disabilities: A review of studies conducted between 1980 and 1999. *Policy Research Brief*, 10(1). Minneapolis: University of Minnesota, Institute on Community Integration. Available: <http://ici.umn.edu/products/prb/101/default.html>

Inside and Out: Former Residents Reflect on Their Lives

Below are the stories of two individuals who were once residents of state institutions. Today, they live in their own homes and are actively working to improve the lives of all persons with disabilities through their involvement with Self Advocates Becoming Empowered, the national self-advocacy group.



■ Russ' Story

My name is Russell Daniels. I was 12 years old when I was sent to a state school. When I left there I was 28 years old. I'm 50 years old now. I went in April of '58. It was a rainy day. I went to the institution because I had problems with going to school and stuff like that. You know, when you don't like school

that's what happens. And that's one reason why I had to go to the institution, because I was a problem child. Everybody, you know, sometimes gets in trouble and they don't like to go to school, and stuff like that.

I wasn't allowed to see my family the first day. They give you a week without seeing them. After awhile they start letting you have visitors. In those days they let you go out for the day but when you came back you would be searched. You couldn't have money, watches, rings, or anything. They'd take everything away because that was the rules and regulations.

I'm really proud to be out and I never want to go back to any institution at all. It was terrible. They treat you like dirt. You don't get treated like a human being. They treat you mean, like, you know, you do something, they slap you. "Do this, and do that. Sit down and don't say a word." So, when I got about 17, something like that, I took off. Packed up my lunch and took off and went into the woods and went on the highway and started walking. Then I got picked up by the police. So they brought me back and put me in seclusion. They put you in a room by yourself for awhile and let you stay there, and later on they let you out. Then you couldn't go anywhere for that amount of time.

I wanted to leave because I didn't like it after that first time. I didn't like it at all. I was scared, and didn't know anybody, and all that. But after awhile I got used to it. I got friendly with everybody. Yeah, it was all right then. Yet, I wasn't given any choices. I wasn't abused, but other people

were. Other people got abused, got pushed around, banged around and stuff like that. I mean it was terrible, you know.

During the day they put you in a room with a bunch of other people and they'd stay there. After I got used to being there I went to school and I had a job. I used to help clean the place up and do dishes and set tables. They didn't pay you. That was a job, and that's what you had to do. For fun they would have movies and dances and stuff like that.

You'd have to get up at six in the morning, get dressed, make sure everybody else is up, make your bed, and then everybody went downstairs in the day hall. They are ready to go down for breakfast at seven o'clock. We all had to be in line. The second shift comes in, they go outdoors and play, you know, play baseball or something like that, lunch-time was about noon, and then they come in about five o'clock. Everybody comes in, washes their face and hands, line up and get a tray and get their food in line and sit down. At night they watched TV until nine, which was bedtime. Everything shut off, the lights off and that's it.

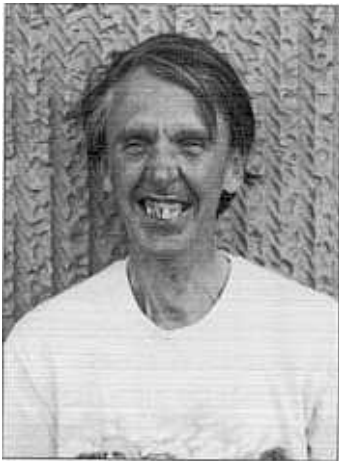
Now, I live like a king. I'm happy I do what I want, go where I want, I can come back when I want. Nobody tells me, "You can't go here, you can't go there." 'Cause that's annoying. I live by myself. I pay my own rent. I pay my bills. I work at the Senior Center. I have been working there for about three years. I'm a janitor. I clean up the place and lock up and help the elderly people out. You know, help them down stairs and stuff. I love it. And they all love me.

I am working on the Self Advocates Becoming Empowered subcommittee, Operation Close the Doors. We passed a petition around for people to sign to show their support. I brought that to some people and they said they wouldn't sign it because they didn't think it was a good idea all places should be closed. So I just looked at them and I said, "Why do you say that?" Because they're not getting the care, treatment like they used to get when they were in an institution. That's what they were saying. When they used to be there, they used to get a dentist, a doctor—everything right there on the campus. Today, doctors may refuse to take a patient with a disability. Like last time I went they took me, but there was another person that used to live in an institution, I know him well, they refused to take him. The next person came in. They took that person and had the other person wait. And I went up there and I said, "This person has been waiting for an hour. It's not right to take the next person when he just walked in the door and this other guy has been sitting there for an hour, and the other guy without a disability that came in, they took him right away. That really bugged me, so I got up there and I told the person. I said, "This is not right for you to do. Have this disability person wait that long and wait on the other person that didn't have

a disability." You know, they said, "Well, you got a point there." So what they did, they listened to me and they took that person and had the other person sit down and wait. Because I got up there and I told them how I felt about it. I told them I used to live in institutions myself and I know how they are when they do something like that.

I have friends that I visit in the institution. They tell me they want to leave because they saw me leaving. They said, "Well, gee, how come this guy is leaving?" So I said, "All you have to do is be patient. You'll be next." There was one person that didn't want to leave the place because he was afraid to go out into the community because he didn't figure he would get the care. I said, "Don't worry about that. You will get the care like everybody else." So, they didn't think he would make it, but he did. He got out, and he made it. I saw him the day I left to come here. He said, "Well, wherever you go, you make sure that you bring up that I made it."

Russ Daniels is a board member of the self-advocacy organization Open Door Club and is active in Operation Close the Doors. He lives in Belchertown, Massachusetts, and may be reached at 413 / 323-6036.



■ Mark's Story

My name is Mark Samis. I was 15 when I went into the institution and I lived there for 12 years. When I entered the state hospital and school back then I was scared 'cause I thought I would never see my family, 'cause there were people up there whose family just put them up there and forgot about their love.

I had no rights. I could not speak up for my rights. If I did, the supervisor or attendants would work me over, flatten me out or things like that. I had no privacy. I could not go to a room to cool down when felt sad about something or didn't want to be bugged, things like that. And I could not sit outside and visit friends of mine who lived on other wards. I could not sit on the merry-go-round, swing set, what have you, to visit with my friends. I had no girlfriend up there. I couldn't talk to my male friends. If I did, an attendant would chase me back. Again, I couldn't say nothing or I'd get slapped up or what have you. A few times they would slap me up for not saying something. They'd use a stick. Like, I could not have friends, they were telling me.

There was this one substitute attendant who would not let me sit at a table, paint-by-numbers, play card games, things like that. He'd force me to watch TV when I didn't want to watch TV 'cause I'm not a soap opera fan. That's all they'd watch. So, if I'm working on this paint-by-numbers

set, he would put his hand on it to smear it up and say, "Nice job." He didn't actually smear it up, though he would have felt like doing it. He just he kept getting on my nerves so I would say something. He was just waiting for me to say something, but I wouldn't play his game. So when he was on, I knew I would just go put away the paint-by-numbers as soon as he walked in the door, and go and watch TV. Sometimes when he was officially on duty he would come over and say, "You're lucky you made this decision. You're over here watching TV." Again, I wouldn't say nothing. He just couldn't get me to play his game, hoping I would say the wrong thing. Then in the evening during prime time when there is programs I wanted to watch, he would not let me watch them.

And they forced me to do things against my will. They intimidated me, put it that way. Now, I would say I was physically and mentally abused. Like speaking up for my rights, my God-given rights, they would slap me up and things like that. They called me every name underneath the sun you can think of. That's how I was mentally abused.

When January 8, 1974 came – the day I was to leave – I wanted to get away from that place. It was the worst experience I ever faced. I don't want nobody to go through that. I felt like I was in a warehouse or something.

Now, I travel telling my story to college students who are being teachers or working in special education and things like that. I just go around and give them a message: Treat people with disabilities as you want to be treated 'cause one day you students might become the parent of a child with disabilities and you would want that child to be treated as anybody else would be treated. I tell them, "Look at a person with disabilities as a person first, not their disabilities. You want respect, so do we people with disabilities want respect."

I also went back to the institution and told my story. The superintendent and I went riding around in these golf carts touring because I wanted to see that building I described where I had no rights. I explained to him what it was like, what this building was like. It's like when survivors of World War II go back to these death camps how they remember this was the gas chamber, this was the barracks and things like that, this is where we ate, things like that – I could remember that building just like it was still there.

Now, in the past few years my life has all turned around. Nothing but great things have happened to me since leaving the institution. Maybe it took awhile. Like they say, patience is always rewarded. So I'm very proud of what I do now. I'm hoping to see these institutions all over the United States close and I don't care what they do with them once they get them closed. As far as I'm concerned they can drop a bomb on them once they get the people out.

Mark Samis is Vice President of People First of South Dakota, Vice Chair of the South Dakota DD Planning Council, a board member of Self Advocates Becoming Empowered, and is active in Operation Close the Doors. He lives in Pierre, and may be reached at 605 / 224-6486.

Policy

Research Brief

RESEARCH & TRAINING CENTER
ON COMMUNITY LIVING

UNIVERSITY OF MINNESOTA

Behavioral Outcomes of Deinstitutionalization for People with Intellectual Disabilities: A Review of Studies Conducted Between 1980 and 1999

This Policy Research Brief reports the results from a review of 38 published studies that measured behavioral outcomes associated with the movement of people with mental retardation from public institutions to community residential settings. The review was conducted by Shannon Kim, Department of Educational Psychology and Educational Leadership, University of Mississippi in University; and Sheryl A. Larson and K. Charlie Lakin of the Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota, Twin Cities.

■ Introduction

Deinstitutionalization as a policy and a practice has produced dramatic changes in the sizes and types of places where individuals with intellectual disabilities live. In the United States, this policy has produced dramatic reductions in the census at large state-operated institutions (from 154,638 people in 1977 to 52,488 in 1998) (Prouty & Lakin, 1999). Similar reductions have also occurred in other institutions serving 16 or more people with intellectual disabilities (declining from 52,718 people in 1977 to 35,247 in 1998). A corresponding trend has increased the number of people receiving residential supports in homes with six or fewer people with intellectual disabilities from 20,400 people in 1977 to 202,266 people in 1998. Four states (WV, RI, VT and DC) have moved all people with intellectual disabilities out of facilities serving 16 or more people. An additional seven states (AK, AZ, CO, HI, ME, MT, NM) serve more than 90% of all persons with intellectual disabilities receiving residential supports in settings with 15 or fewer residents (Prouty & Lakin, 1999). Clearly, the practice of deinstitutionalization has been accepted and adopted widely.

Despite the enormous changes that have occurred over the past 20 years, however, there were in June 1998 still 89,348 people with intellectual disabilities living in private or public residential institutions and an estimated 24,144 living in nursing homes in 1998 (Prouty & Lakin, 1999). This reality has not gone unnoticed by the national self-advocacy organization Self-Advocates Becoming Empowered (SABE), which has begun “Operation Close the Doors” (Nelis & Ward, 1996).

Despite the ongoing movement toward depopulation and closure of institutions, deinstitutionalization continues to be a controversial topic in states that continue to operate institutions. A considerable body of research has examined the relative risks and benefits associated with institutional and community living. Many studies have examined changes in adaptive or challenging behavior associated with movement from institutions to community settings. Summaries of this research noted that, overall, adaptive behavior was almost always found to improve with movement to community settings from institutions, and that parents who were often as a group initially opposed to deinstitutionalization were almost always satisfied with the results of the move to the community after it occurred (Larson & Lakin, 1989; Larson & Lakin, 1991). A recent meta-analysis of 11 studies of specific adaptive behavior skills found that self-care skills — and to a lesser degree communication skills, academic skills, social skills, community living skills, and physical development — improved significantly with

A summary of research on policy issues affecting persons with developmental disabilities. Published by the Research and Training Center on Community Living, Institute on Community Integration (UAP), College of Education and Human Development, University of Minnesota.



deinstitutionalization (Lynch, Kellow & Willson, 1997). A recent literature review examined the outcomes of deinstitutionalization in the United Kingdom and Ireland and concluded that deinstitutionalization was generally, but not inevitably, associated with increases in adaptive behaviors and reductions in observed challenging behavior (Emerson & Hatton, 1996).

This study extends and updates an original report by Larson and Lakin (1989) reviewing all identifiable literature on changes in adaptive and challenging behavior associated with movement from institutional to community residences. It is understood in presenting the findings of this analysis that adaptive behavior and challenging behavior are only two of many important outcomes of residential services. However, considering the continuing debates regarding depopulation and closure of public and private institutions, and the frequent requests we receive for outcomes of studies conducted since our last review, we believe this update may be useful in informing future policy decisions.

■ Method

Selection of Studies

This review includes studies identified through the following methods: (a) a computer search of the *PSYCHINFO* database from 1980 to 1998; (b) a computer search of the *ERIC* database from 1980 to 1998; (c) a computer search of the *Dissertation Abstracts Online* database from 1980 to 1998; (d) a manual review of *American Journal on Mental Retardation*, *Education and Training in Mental Retardation*, *Journal of the Association for Persons with Severe Disabilities*, *Journal of Intellectual and Developmental Disabilities*, and *Mental Retardation* from 1980 to 1998; (e) use of the “ancestry approach,” that is, the manual review of reference lists of relevant research to locate additional studies; (f) direct requests for assistance in identifying relevant studies made to researchers prominent in this area of research; and (g) inclusion of studies cataloged by the authors after publication of the original review.

Over 250 studies were screened for inclusion in this review. The following criteria were applied in selecting studies for inclusion: (a) a minimum of five subjects moved from institutional to community residences after 1974; (b) basic demographic information reported about the sample; (c) exclusive or primary use of adult subjects; (d) baseline data collected while the subjects were residing at the institution or within one month of moving to the community; (e) post-test results obtained after the subjects had resided in the community a minimum of six months; and (f) overall adaptive behavior, overall challenging behavior, and/or specific domains of adaptive or challenging behavior were

measured with the same assessment instruments in the same manner at the times being compared. The authors conferred in applying the criteria to specific studies. These methods yielded a total of 38 studies for inclusion in this study.

Coding Procedures

The 38 studies were reviewed and coded by the authors according to research design, outcomes reported, and direction and magnitude of the findings. Two types of research design were identified: longitudinal designs, which examined changes within a single group over time ($n = 29$ studies), contrast group designs, which compared changes in treatment and control groups over time ($n = 14$ studies), and studies that used both types of design ($n = 5$ studies).

Several different types of outcomes were reviewed and coded. Adaptive behavior outcomes were summarized into nine categories (e.g., overall, academic skills, community living skills, language/communication skills, motor/physical skills, leisure/recreation skills, self-care/domestic skills, social skills, and vocational skills). Challenging behavior outcomes were collapsed into the most frequently cited categories (overall, frequency, severity, external, internal, and asocial behaviors).

The procedure for coding the direction and magnitude of outcomes utilized the baseline (institutional) scores as the point of reference. A (+) was recorded to indicate the subjects' scores improved in the community, but not to a statistically significant degree, and a (++) was used to indicate this difference was statistically significant ($p \leq .05$). Likewise, a (–) was used to indicate scores declined in the community, with a (– –) used to indicate the difference was statistically significant ($p \leq .05$). In cases in which the authors did not test for statistical significance, an asterisk (*) was placed beside the direction indicator. A zero (0) was used to signify that no tendency was found, or that the results were presented in a way that prevented identification of tendencies. In summarizing the findings, blanks were used to indicate a category of outcome was not studied, or that no data were provided.

The decision rules were developed and consulted to resolve potentially conflicting findings. Conflicting findings were apparent when studies reported findings from more than one measure in a single domain. When such findings were in opposite directions, a “0” was recorded to indicate that the findings appeared to cancel each other out and/or that the results could not be interpreted. When the findings were in the same direction, but of different magnitudes (e.g., ++, +, and 0), they were reported to be not statistically significant. When studies used multiple baselines, the last baseline score obtained while the subjects resided in the institution was used as the point of reference. When studies reported results from more than one post-test this review noted the outcome for the longest interval between baseline and follow-up.

■ Results

Contrast Group Studies

Fourteen studies compared people who moved from institutions to small residential settings with a “contrast” group of people who stayed in institutions. All but one of the studies found either a significant improvement associated with community placement or found improvements that did not

reach statistical significance (see Table 1). In terms of overall challenging behavior, only one study reported a difference between stayers and leavers that was statistically significant. In that study, movers stayed the same while the stayers had overall challenging behavior ratings that declined significantly.

The findings regarding outcomes within specific domains of adaptive behavior among the contrast group studies (see Table 2 on next page) showed movers with either statistically significant improvements relative to the stayers, or with

Table 1: Overall Adaptive and Challenging Behavior Outcome: Contrast Group Studies

Study	Location	N ^a (exp, cont)	Age ^b	Level of Mental Retardation ^c	Time (months)	Adaptive Behavior ^d	Challenging Behavior ^d	Instrument ^e
United States								
Bradley, Conroy, Covert, & Feinstein (1986)	NH	160 (80, 80)	AC	B, Mi, Mo, S, P	72	++	–	CDER
Calapai (1988)	NY	106 (53, 53)	NS	Mo, S, P	24	+		DDIS
Conroy, Efthimiou, & Lemanowicz (1982)	PA	140 (70, 70)	A	Mi, Mo, S, P	24	++	+ ^f	BDS
Conroy, Lemanowicz, Feinstein, & Bernotsky (1991)	CT	248 (124, 124)	A	Mi, Mo, S, P	60	++	+	CIER
D'Amico, Hannah, Milhouse, & Froleich (1978)	WV	13 (6, 7)	AC	Mi, Mo, S, P	12	++		CBC
Davis (1990)	PA	66 (33, 33)	A	NS	48	+	+	BDS
Rosen (1985)	AR	112 (56, 56)	A	B, Mi, Mo, S, P	24	++		SSSQ
Schroeder & Henes (1978)	NC	38 (19, 19)	A	MA range 4.0 to 6.8 yrs	12	++		PAC
Williams, Paskow, Thompson, & Levine (1985)	DC	26 (13, 13)	AC	B, Mi, Mo, S, P	15	+	–	ABS
International								
Molony & Taplin (1990)	Australia	57 (26, 31)	A	B, Mi, Mo, S, P	12	++	0	VABS

^a N: numbers in parentheses indicate the number of persons in the experimental and control groups.

^b Age: A, Adults; AC, Adults and Children; NS, Not Specified.

^c Level of Mental Retardation: B, Borderline; Mi, Mild; Mo, Moderate; S, Severe; P, Profound; NS, Not Specified.

^d Results: ++ statistically significant improvement relative to the control group at $p \leq .05$; + improvement relative to the control group, but not statistically significant; -- statistically significant decline relative to the control group at $p \leq .05$; – decline relative to the control group, but not statistically significant; 0, no change or conflicting results relative to the control group.

^e Instruments: ABS, *Adaptive Behavior Scale*; BDS, *Behavior Development Scale*; CBC, *Camelot Behavior Checklist*; CDER, *Client Development Evaluation Report*; CIER, *Connecticut Individual Evaluation Report*; DDIS, *Developmental Disabilities Information Survey*; PAC, *Progress Assessment Chart*; SSSQ, *Street Skills Survival Questionnaire*; VABS, *Vineland Adaptive Behavior Scales*.

^f The experimental group stayed the same while the control group declined.

Table 2: Adaptive and Challenging Behavior Domain Outcomes^a: Contrast Group Studies

Study ^b	Academic Skills	Community Living Skills	Language/Communication Skills	Motor/Physical Skills	Leisure/Recreation Skills	Self-Care/Domestic Skills	Social Skills	Vocational Skills	Challenging Behavior Frequency	Challenging Behavior Severity	External Behavior	Internal Behavior	Asocial Behavior
United States													
Bradley, Conroy, Covert, & Feinstein (1986)								0					
Calapai (1988)	+	+	+	+		+							
Close (1977) ^c						++							
D'Amico, Hannah, Milhouse, & Froleich (1978)	0	++	++	++		++	++	0					
Eastwood & Fisher (1988) ^d	++	++	+			++	++	++					
Fuess (1987) ^e	+	0	+	+		++	0	+			++	+	+
Horner, Stoner, & Ferguson (1988) ^f		+				++	++				++	+	
Rosen (1985)	++	++				++		++					
Schroeder & Henes (1978)			+			+	+						
International													
Molony & Taplin (1990)			++			++	++				+	+	0

Guide: ++, statistically significant improvement relative to the control group; +, improvement relative to the control group, but not statistically significant; --, statistically significant decline relative to the control group; -, decline relative to the control group, but not statistically significant; 0, no change or conflicting results relative to the control group. Statistical significance reflects a p-value $\leq .05$

^a In cases where repeated measures are reported, results from the last time period are used.

^b Complete information on study characteristics can be found in Table 2 unless otherwise indicated.

^c This study was conducted in Oregon with 12 adult subjects (6 per group) who had severe and profound levels of mental retardation. The Developmental Record (DR) was used to assess subjects after 12 months in the community.

^d This study was conducted in the Northeastern United States with 98 adult subjects (49 per group) who had borderline, mild, moderate, severe, and profound levels of mental retardation. The MDPS was used to assess subjects after 60 months in the community.

^e This study was conducted in Ohio with 122 (104, 18) adult subjects who had borderline, mild, moderate, severe, and profound levels of mental retardation. The ABS was used to assess subjects after 48 months in the community.

^f This study was conducted in Oregon with 46 adult subjects (23 per group) who had mild, moderate, severe, and profound levels of mental retardation. The BDS was used to assess subjects after 60 months in the community.

improvements that did not reach statistical significance. As the Lynch, Kellow & Willson (1997) meta-analysis reported, the self-care or domestic skills domain of adaptive behavior showed the most consistent statistically significant improvements. Other adaptive behavior domains that showed statistically significant improvements in at least two separate studies included academic skills, community living skills, language or communication skills, social skills, and vocational skills. Unlike the overall challenging behavior findings which showed little consistency in differences between stayers and movers, externalized challenging behavior (e.g., aggression toward other people and property destruction) improved significantly for movers in two studies relative to stayers and improved, but not significantly so, in the third study.

Longitudinal Studies

General adaptive behavior. A total of 19 studies examined changes in overall adaptive behavior among movers in samples in the United States (see Table 3). Of those studies, 13 reported statistically significant improvements in overall adaptive behavior associated with moving to a small community setting, one reported improvements that were not statistically significant, one reported improvements that were not tested for significance, one reported a decline that was not statistically significant, and two reported significant declines. One international study reported statistically significant improvements in overall adaptive behavior at the longest point measured, one reported improvements that were not

Table 3: Overall Adaptive and Challenging Behavior Outcome: Longitudinal Studies

Study	Location	N	Age ^a	Level of Mental Retardation ^b	Time (months)	Adaptive Behavior Results ^c	Challenging Behavior Results ^c	Instrument ^d
United States								
Apgar, Cook, & Lerman (1998)	NJ	44	A	B, Mi, Mo, S, P	60	++	+	JIF
Bolin (1994)	OK	44	AC	Mi, Mo, S, P	12	++		ADS
Bradley, Conroy, Covert, & Feinstein (1986)	NH	93	AC	B, Mi, Mo, S, P	84	++	-	CDER
Business Services Group (1999)	CA	44	AC	B, Mi, Mo, S, P	12	-	+	CDER
Calapai (1988)	NY	53	NS	Mo, S, P	6	-- ^e		DDIS
Center for Outcome Analysis (1999)	IN	92	AC	Mi, Mo, S, P	6	++	-	ABS
Colorado Division of Dev. Disabilities (1982)	CO	115	AC	Mi, Mo, S, P	12	+		BDS
Conroy (1995)	OK	382	AC	B, Mi, Mo, S, P	60	++		BDS
Conroy (1998)	KS	88	AC	P	12	++	+	ABS
Conroy & Bradley (1985)	PA	383	AC	B, Mi, Mo, S, P	72	++	+	BDS
Conroy, Feinstein, & Lemanowicz (1988)	CT	207	A	B, Mi, Mo, S, P	24	++	--	CIER
Conroy, Lemanowicz, Feinstein, & Bernotsky (1991)	CT	569	A	Mi, Mo, S, P	60	++	+	CIER
Conroy, Seiders & Yuskasuskas (1998)	CA	91	A	Mi, Mo, S, P	36	++	++	CDER
Feinstein, Lemanowicz, Spreat, & Conroy (1986)	LA	158	AC	B, Mi, Mo, S, P	9	++	++	BDS
Fortune, Heinlein, & Fortune (1995)	WY	157	AC ^f	B, Mi, Mo, S, P ^f	72	--	++	ICAP
Hayden, DePaepe, Soulen, & Polister (1995)	MN	190	A	B, Mi, Mo, S, P	12		0	ICAP
Kleinberg & Galligan (1983)	NY	20	A	Mi, Mo, S, P	12		-	ABS
Maisto & Hughes (1995)	NC	42	A	Mo, S, P	12	++		SIB
Rose, White, Conroy, & Smith (1993)	PA	7	A	Mi, Mo	12	++	+	ICAP
Thompson & Carey (1980)	MN	7	A	S, P	24	+		MDPS
Williams, Paskow, Thompson, & Levine (1985)	DC	80	AC	B, Mi, Mo, S, P	15	+	--	ABS
International								
Conneally, Boyle, & Smyth (1992)	Ireland	11	A	S, P	24	++	++	PAC/ABS
Cullen, Whorisky, Mackenzie, Mitchell, Ralston, Shreeve, & Stanley (1995)	Scotland	39	A	B, Mi, Mo, S, P	24	+	++	ABS
Webb, Wells, & Hornblow (1986)	New Zealand	19	A	MA 1-9	12	--	-	ABS

^a Age: A, Adult; AC, Adults and Children, NS, not specified.

^b Level of Mental Retardation: B, Borderline; Mi, Mild; Mo, Moderate; S, Severe; P, Profound; MA, Mental Age.

^c Results: ++, statistically significant improvement after move to the community; +, improvement after move to the community, but not statistically significant; --, statistically significant decline after move to the community; -, decline after move to the community, but not statistically significant; 0, no change or conflicting results after move to the community; *, mean scores not tested for statistical significance. Statistical significance reflects a p-value ≤ .05.

^d Instruments: ABS, *Adaptive Behavior Scale*; ADS, *Adaptive Development Scale*; BDS, *Behavior Development Scale*; CDER, *Client Development Evaluation Report*; CIER, *Connecticut Individual Evaluation Report*; DDIS, *Developmental Disabilities Information Survey*; ICAP, *Inventory for Client and Agency Planning*; JIF, *Johnstone Information Form*; MDPS, *Minnesota Developmental Progress Scales*; PLQP, *Personal Life Quality Protocol*; PAC, *Progress Assessment Chart*; SIB, *Scales of Independent Behavior*.

^e The subjects demonstrated statistically significant gains between 6 and 12 months and between 12 and 24 months. However, tests were not conducted to compare later years' results with baseline findings.

^f Demographics were reported for the entire population of Wyoming service recipients. The authors report the sample to be representative of the population.

^g Sample size declined over the life of the experiment. Only testing periods for which the number of subjects was reported are listed here.

statistically significant, and one in New Zealand reported statistically significant declines associated with movement.

General challenging behavior. Longitudinal studies of changes in challenging behavior showed the same variability reported for the contrast group studies. Eight U.S. studies found improvements in challenging behavior after the move, including three studies in which these changes were statistically significant (after 9, 36 and 72 months). Five U.S. studies reported increased levels of challenging behavior after the move, including two studies that reported statistically significant increases (after 15 and 24 months). Two of the three international studies of challenging behavior reported statistically significant improvements (after 24 months), with the third reporting declines that were not statistically significant. All of the studies published in 1990 or later reporting significant findings regarding changes in challenging behavior reported significant improvements.

Specific domains. Sixteen longitudinal studies examined changes in specific domains of adaptive and challenging behavior (See Table 4). While the contrast group studies found the most consistent pattern of improvement in self-care or domestic skills, among the longitudinal studies social skills showed the most consistent improvement. Eight of the nine longitudinal studies that measured social skills found statistically significant improvements after movement to the community, and the ninth found improvements that did not reach statistical significance. Similarly, consistent improvements were reported for community living skills and motor or physical skills.

Again, patterns within specific domains of challenging behavior were not predictably associated with movement to the community. Two studies reported significant improvements in internal maladaptive behavior (e.g., self-injurious behavior), but another study found statistically significant deterioration. For externalized maladaptive behavior, four studies found improvements that were not statistically significant while one found deterioration that was statistically significant. The only study reporting interpretable findings for social maladaptive behavior reported statistically significant improvement associated with a move to the community.

■ Discussion

Ten years ago when we published our first synthesis of the literature on the outcomes of deinstitutionalization, we concluded that “available research denies support for the assertion that people obtain greater or even equal benefit in adaptive behavior from living in institutions. In fact, this research suggests that those benefits very consistently accrue more to the people who leave institutions to live in small community homes” (Larson & Lakin, 1989). Studies conducted in the subsequent decade continue to support this conclusion. In a few studies, adaptive behavior did not

improve in conjunction with community living, but in more than two-thirds of the studies reviewed, statistically significant improvements were found.

Interestingly, in the area of challenging behavior, all of the findings of decline associated with deinstitutionalization occurred in studies published during the 1980s. The studies of challenging behavior in the 1990s consistently found improvements (some statistically significant, some not) in both overall challenging behavior, and in the specific sub-domains of challenging behavior measured. One possible explanation for these more positive and more consistent outcomes could be improved behavioral supports available to persons in community settings. Increasingly, examples of systems and strategies of community behavioral support can be found in the professional literature and descriptions of innovations in community services. States as large as California and as small as Vermont are developing systems of behavioral support and crisis response for people with challenging behavior outside of the institutional context. Evaluations of community behavior support and crisis response systems show that they can be both effective in addressing challenging behavior and preventing institutionalization, and at the same time cost-effective (Coland & Weiseler, 1995; Rudolph, Lakin, Oslund & Larson, 1998). Perhaps the development and refinement of community supports for people with challenging behavior is now contributing to improved outcomes. Perhaps the greater experience in serving people with challenging behavior in community settings is increasing the effectiveness of those services. Perhaps the substantial shift in the 1990s toward more personalized housing and person-centered services has reduced the stimuli of challenging behavior. Perhaps these and other factors have operated in concert to make movement to community settings more predictably associated with reductions in challenging behavior.

While it is beyond the scope of this manuscript to comprehensively review the literature on other outcomes associated with deinstitutionalization, these and other studies we reviewed examined a wide range of quality-of-life outcomes. For example, Apgar, Cook & Lerman (1998) found that people who moved from institutions not only increased adaptive behavior significantly and reduced challenging behavior, they also improved material well-being and community integration over that of a contrast group of people who remained in institutions. Similarly Conroy, Lemanowicz, Feinstein & Bernotsky (1991) found that movers had adaptive behavior that improved significantly and challenging behavior that declined; they also found that social presence increased significantly when people moved from institutions to community settings, and that movers reported significantly higher overall quality of life, satisfaction, productivity, independence, and integration than a comparison group who stayed in an institution. Conroy (1995) found that 382 Oklahomans who moved from institutions to community homes not only improved

Table 4: Adaptive and Challenging Behavior Domain Outcomes^a: Longitudinal Studies

Study ^b	Academic Skills	Community Living Skills	Language/Communication Skills	Motor/Physical Skills	Leisure/Recreation Skills	Self-Care/Domestic Skills	Social Skills	Vocational Skills	Challenging Behavior Frequency	Challenging Behavior Severity	External Behavior	Internal Behavior	Asocial Behavior
United States													
Apgar, Cook, & Lerman (1998)		+	-	+		++	++				+		
Bolin (1994)									+ ⁱ	+ ⁱ			
Bradley, Conroy, Covert, & Feinstein (1986)								++					
Conroy (1995)										+ + ⁱ			
Conroy (1998)								+ + ⁱ					
Conroy, Feinstein, & Lemanowicz (1988)								++					
Fortune, Heinlein, & Fortune (1995)											+	++	++
Horner, Stoner, & Ferguson (1988) ^c		++				++	++				+	0	
Kleinberg & Galligan (1983)			0		0 ^d	0	+ + ^d	-- ^d					
O'Neill, Brown, Gordon, & Schonhorn (1985) ^e			0			0							
Rose, White, Conroy, & Smith (1993)		++	++	++		++	++				+	++	0
Thompson & Carey (1980)			+ ^f		+ ^f	+ ^f	+ ^f						
Williams, Paskow, Thompson, & Levine (1985)		++		+		--	++				--	--	
State of Wisconsin (1986) ^f	+	++	++			+	++	++					
International													
Conneally, Boyle, & Smyth (1992)			+ + ^g			+ + ^g	+ + ^g	+ + ^g					
Cummins, Polzin, & Theobald (1990) ^g			0	++		++	++						
McKay & MacKay (1989) ^h						--		--					

Guide: ++, statistically significant improvement after move to the community; +, improvement after move to the community, but not statistically significant; --, statistically significant decline after move to the community; -, decline after move to the community, but not statistically significant; 0, no change or conflicting results after move to the community. Statistical significance reflects a p-value ≤ .05.

^a In cases where repeated measures are reported, results from the last time period are used.

^b Complete information on study characteristics can be found in Table 1 unless otherwise indicated.

^c This study was conducted in Oregon with 23 adult subjects who had mild, moderate, severe, and profound levels of mental retardation. The BDS was used to assess subjects after 60–84 months in the community.

^d The MDPS was used as the outcome measure.

^e This study was conducted in New York with 27 adult subjects who had mild, moderate, severe, and profound levels of mental retardation. The *Skill Indicator* (SI) was used to assess subjects after 9 months in the community.

^f The PAC was used as the outcome measure.

^g This study was conducted in Australia with 57 adult subjects who had severe and profound levels of mental retardation. The PAC was used to assess subjects after 12, 17, and 49 months in the community. Results obtained after 49 months are reported here.

^h This study was conducted in Northern Ireland with 11 adult subjects who had mild mental retardation. The ABS was used after 18–84 months in the community.

ⁱ The *Challenging Behavior Scale* (CBS) was used as the outcome measure.

^j Used the *Orientation Toward Productive Activities* scale.

their adaptive behavior significantly, they also enjoyed more opportunities to make choices after they moved.

Another “outcome” of importance is the relative cost of serving people in community versus institutional settings. The average expenditure for state institutions (about \$104,000 per person per year) is substantially greater than the average expenditure for community service recipients (about \$30,000 per year for people supported by services funded by the Medicaid Home and Community Based Services Waiver program; Prouty & Lakin, 1999). Recognizing the differences between “typical” community and institution residents, one recent study used an analysis of covariance in a matched sample of individuals moving from institutions to community settings and those remaining behind (Stancliffe & Lakin, 1998). This study found that controlling for individual differences, the individuals who left institutions used significantly more community places, engaged in significantly more social activities, experienced significantly more personal integration, had significantly more family contacts, and made significantly more choices at an adjusted expenditure that was 66% of that of their counterparts who remained in institutions.

The studies reviewed here demonstrate strongly and consistently that people who move from institutions to community settings have experiences that help them to improve their adaptive behavior skills. The studies suggest that community experiences increasingly provide people with environments and interventions that reduce challenging behavior. And, a growing body of research suggests that people enjoy a better quality of life along dimensions that have been quantified differently by different researchers.

This review has been able to draw on a data set of remarkable size (over 2,600 subjects) and scope (pre- and post-tests over a period of six months to seven years). The findings are not easily dismissed. There are, however, limitations that must be noted:

- While this review examined more than 250 studies on this topic, there are undoubtedly other studies that were not identified by the methods we employed. Although we used many approaches to identify relevant studies, much of this research is contracted evaluation research and is not submitted for publication. Its identification, therefore, is not always successful.
- Maturation effects cannot be ruled out. As people get older they grow and develop skills. In a longitudinal study, people are maturing during the study. The selection criteria attempted to control for this by ruling out studies conducted primarily on children who are most susceptible to “maturation effects.” The congruence between the findings of the “contrast” group and longitudinal studies suggest that the outcomes we noted were not due solely to maturation effects.
- Many studies adapted existing instruments to meet their own purposes. While most studies reviewed reported the reliability and validity of their measures or used measures with reliability reported elsewhere, not all did.
- While all of the studies met basic criteria listed in the methods section, studies varied in their scientific rigor or at least in the degree to which the rigor of the methodology was described.
- The subject selection for the studies may have a positive bias in that some persons who moved to the community and experienced declines in adaptive behavior or increases in challenging behavior were re-institutionalized. Score changes for persons re-institutionalized before follow-up were not generally included in the data sets.
- Although this report differentiates between findings that were statistically significant and those that were not, it does not report indices of effect size, or practical significance for those studies that had statistically significant findings. Effect sizes were rarely reported in the studies reviewed. No study reviewed reported an index of beta, or statistical power. On a positive note in this regard, the one meta-analysis that has addressed research on this topic reported findings that were consistent with those reported in this manuscript (Lynch, Kellow & Willson, 1997).

Despite these limitations, this is a robust array of research whose findings are remarkable for their consistency.

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CHOICE

Issue

In the field of developmental disabilities, the concept of “choice” has been used to justify institutionalization. In contrast, noted self-advocate Tia Nelis states: “From my experiences with institutions and with life “on the outside,” there are some things that I know to be true. I’ve never met anyone who would choose to live in an institution once they have moved out.”

Perversions of “Choice”

The trend in the field of developmental disabilities is toward increasing choice for individuals with disabilities. However, there have been four major perversions of choice:

- 1) Choice has been used to justify institutionalization by parents or family members, without regard to the choices or interests of the person with a disability.
- 2) Choice has been used to justify institutionalization, when the individual who is “choosing” the institution has had no idea what the alternatives would be.
- 3) Choice has been used to justify “dumping” people in the community without adequate supports. This has sometimes led to reinstitutionalization for the person.
- 4) Choice has been used to justify placement in mini-institutions within the community, when the individual was not given any alternative choices.

Strategies for Promoting “Choice”

In light of these perversions, how can family members, friends, advocates, service providers, and others best assist and support individuals to make choices.

- All people should be presumed competent to make choices about their lives.
- Those individuals who have difficulty expressing their preferences need to be surrounded by a core group of people who know them well to assist with making choices.
- Although family members can play an important role in supporting people with developmental disabilities, they are not entitled to substitute their own interests and wishes for those of people with disabilities.
- Individuals with disabilities do not “choose” institutions or mini-institutions when they have real knowledge and experience of alternatives.
- People with disabilities sometimes make bad choices, as do people without disabilities. Disability is not a reason for depriving any person from making the same choices other people have the right to make. At the same time, choice should never be used to justify neglect.

- The best safeguard against bad or harmful choices by people with disabilities is a network of trusting, caring relationships. For all people, choice is not typically a solitary activity. It is typically done within the context of a network of close relationships. However, especially due to institutionalization, people with disabilities have been cut off from such networks.

INFORMATION IN THIS SECTION IS BASED ON THE FOLLOWING:

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http://thechp.syr.edu/on_choice.htm

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http://thechp.syr.edu/on_choice.htm

Revisiting Choice - Part 1

by Michael W. Smull
AAMR's News and Notes

Choice is the most powerful word and the most abused word in the current lexicon of the disabilities services system. For some people choice means that how they want to live has been discovered and carefully supported. For others choice is an excuse or the basis of a bizarre rationalization. Perhaps because choice is the word de jour, it has been used to argue that congregate facilities are needed in order to ensure residential "choice". An even more egregious example is justifying the use of pain to control behavior to allow "choice among a full range of treatment options". (The same argument could be made to retain "bleeding" as a treatment option for the flu.) Other abuses are more subtle. When you look behind the rhetoric of agencies which say "we offer and teach choice", you find places that ask people what they want to wear but not who they want to live with. What appears to be absent is depth of understanding and a sense of balance. A single word is being used for complex concepts. Too often, there is no recognition of the need for an individual balance between honoring choice and ensuring safety.

Preferences, opportunities, and control Choice, as it is being used in current disability discussions, appears to have 3 related concepts embedded in it - preferences, opportunities, and control.

Preferences include not only what someone likes but also their desires and dreams. Preferences includes: who people want to spend time with; what to do during that time; and where to spend their time.

Opportunities are the available array of: people to spend time with; things to do during that time; and places to spend that time. Opportunities should also include being able to spend time by yourself. Preferences reflect what people want while opportunities reflect what is available.

Control is the authority to make use of an opportunity to satisfy a preference.

Looking at preferences, desires, and dreams Any effort to support choice should start with discovering what is important to the people who are being supported. What do people want in their relationships with others? How do people want to spend their time? What do people want to do (and not do)? What kinds of environments in general and what specific places do people want to spend time in or avoid? Do people have dreams about how they would like to live and do they have nightmares about what they are afraid will happen to them? While answers to these questions are sought (with varying degrees of emphasis) in all of the formal processes for person centered planning, careful efforts are required.

Many people lack the life experiences necessary to know what they like and dislike Will something that sounds desirable to a person feel that way when it is experienced? Some people want to try things or live in ways that put their safety or health (or both) at risk Many people need to have a life of their own before they can have a dream of their own. As people try things

(and as they age) their preferences change. In a system that offers real choice, people continuously have opportunities and are continuously supported in expressing their preferences. Supporting choice requires that there be recognition that everyone has preferences and desires regardless of the severity of disability. Supporting choice also requires that we recognize that what we need to know is taught by the people that we support. Some of what my colleagues and I have learned about preferences from the people that we have listened to follows.

We have taught learned helplessness, now we need to teach trust Many people have experienced systematic ignoring of their preferences. This is an unintended consequence of current "individual" planning and professional practice within the disability system. We cope with the poverty of opportunities for the people we support by suppressing their preferences for what is absent. "Learned helplessness" has been taught and many of those we support have learned this lesson well. For these people, what needs to be taught is that we can be trusted.

Trust is "taught" by having those with control listen to all expressions of preference and, where possible (and sensible), to help people get what they want. "Teaching choice" is a poor label. Those who teach must remember that they are not "offering choices" but soliciting preferences and then demonstrating that staff can be trusted to honor the preference expressed. Staff must learn to acknowledge the preferences that people are expressing with their behavior while not asking what people want until there is a commitment to honor their requests.

Shouting (with behavior) has been the only way to be heard Most of us have had the experience of raising our voices in the belief that it is will increase understanding. We shout so that we will be heard. A number of people with disabilities have learned to "shout" with their behavior because it is the only way that they are heard. If you do not like your current job, complaining about it does not produce change. Acting in unacceptable ways does produce change. Complaining about who you live with is unlikely to get you a new roommate, but aggression often works. "Shouting" gets our attention, but rarely gets people what they really want. We need to listen for the preference that is underneath the shouting. Once real preferences are understood (and acted on), the need for "shouting" with behavior is eliminated (although the person may always be someone who has a loud "voice").

Most of what people want is modest What people want is usually modest. When critics say that we cannot afford choice they have typically confounded what is important to people with what might be nice to have. There is also a difference between learning what is important to people and taking someone on a guided fantasy. Careful planning discovers preferences such as: having a say in who helps me; having privacy in the bathroom; being asked not ordered; going for a walk when I want; and (for one person who uses a wheelchair) to be able control the direction in which I face.

A few people's desires are not modest. While the vast majority of people have modest desires, there are a few people who sincerely want frequent trips to the tropics, a car continuously at their disposal, and support staff who take on the role of servants. They may see these as essential to a reasonable quality of life. They are "virtual yuppies", without the income needed to support their desired lifestyle. They are also unusual, as careful planning identifies very few people with these

expensive tastes. Where rational decisions are being made about allocation of resources, these people are disappointed with the outcome.

Some people have reasonable requests that are difficult to afford. The fact that someone wants something, even if they see it as very important, does not mean that it has to be delivered. However, we do have an obligation to respond to sincere requests as we can. For example, there are many people who would like to try living by themselves. The cost of support (in staff and housing) presents a real challenge to those attempting to create a system of support. The demand for living alone is somewhat reduced when there is more careful listening. For example, some people really do not want to live alone but simply do not want to live with other people with disability labels. Other people have always had to share lives (e.g. it is Tuesday so we all go bowling) and have not learned that you can also live with someone where you only share space.

After these situations have been clarified there are still many people who simply want to have the experience of living by themselves. Where people have been able to live by themselves for a year or two many would like to have a roommate for company (but not to share lives with). Some people, however, find that living alone is the only way they wish to live. The support costs for most of these people decline dramatically as behaviors change, skills are learned, and connections to the community are built. However, the cost of support for some people remains high. From the perspective of a system, a small percentage of people can always be supported in relatively expensive lives. The challenge is to not have that percent exceed the resources available.

What people don't want is as important as what they do want. In learning people's preferences, it is important to discover what they dislike. Simple lists are not adequate, we must go beyond a statement that George likes barbecues and dislikes broccoli. We have a significant degree of control over who we spend time with and what we do. We use that control to avoid people and activities that we strongly dislike. People with disabilities have not had that control. In the absence of being able to "vote with your feet" we need to insure that those things that people hate or strongly dislike are absent.

Choice making is not a solitary activity Figuring out what we want is usually not a solitary activity. To tell people that yesterday we made the choices and that today they are in charge is to ignore that few of us make significant choices without discussion. Before we make major decisions, such as changing jobs or changing partners, we have typically discussed the "pros and cons" at some length. We seek advice, support, and people who just listen. We strive to determine what is right for us. We frequently get conflicting advice and pick the advice that agrees with what we want. We reserve the right to make "bad" choices after we have heard the "good" advice. People with disabilities need the same opportunities.

What people ask for may not be what they want People will ask for those things that they know about. One woman who was being assisted in leaving an institution said that she wanted to move to a "group home". One man said that he wanted to live alone. The woman who said that she wanted to live in a group home spoke very little English. She knew that she wanted to leave the institution and the only place away from the institution that she knew of was a "group home". The man who said he wanted to live by himself thought that the only choices that existed were to

live by himself or with other people with disabilities. The woman is living happily in supported living and the man is living in a house that he wanted where he rents rooms to 5 people who have no formal disability labels.

When people express a desire for a job (or anything else) where their disability or circumstances preclude obtaining what is asked for, we need to listen to what lies beneath the surface. One man said he wanted to be a pilot. After a lot of discussion we discovered that while he did want to be a pilot he also just loved airplanes. We could not help him become a pilot but we could help him get a job at an airport.

Some years ago I worked with another man said that he wanted to have a job just like his father's. His father is a well known research scientist with the federal government who determined what projects got funded. Many conversations later we found that the characteristics that mattered to him were that he be treated with the same respect that his father received and that he wear a tie to work. We helped him find a job where he wore a tie and ran a large copying machine at a facility that did scientific research. If you were a scientist who wanted your latest journal article copied you went to his copy center. If you just filled out the form your article would get copied in turn, if you treated him with "respect" he would do your copying while you waited.

Sometimes what people want is not possible A woman I met in the Midwest, Susie, wants to live with her mother. It is so important to her that she sees it as the only acceptable place for her to live. Unfortunately this is not possible. Susie had lived with her mother for several decades and mother had been the person who provided care and support. After a sudden loss of capacity Susie left her home and entered a hospital and then a nursing home. The supports necessary to support Susie in her mother's house are available and affordable. However, Susie's mother would not agree to her return regardless of the supports that could be provided. This is not to disparage Susie's mother. She continues to be deeply caring and intimately involved in Susie's support, but she is "burnt out" as a caregiver.

In these circumstances our obligation is to acknowledge and honor the positions of both Susie and her mother. Honoring her mother's position requires that we not use guilt or otherwise coerce her to support Susie's return to her home. It requires that we support her in developing her new relationship with her daughter. Honoring Susie's position requires that we acknowledge what is important to her and help her get on with her life. We have to avoid the temptation to deny the presence of a preference that cannot be realized. We also have to help Susie deal with a very real loss and to help her begin to develop new relationships. She needs support in her changing relationship with her mother and in developing new relationships.

Helping people be safe and happy requires thought and effort One of the traps of the current system of planning is that we determine how people can be safe before we look at what they require to be happy. We forget that there is no such thing as a risk free life, that risk is relative and has a context. What we need is to begin with an understanding of what is required for the "pursuit of happiness" and then seek to reduce or avoid risk within that context. What is not acceptable is to simply say it was his choice, that is why I stood by while he hurt himself.

Helping people be happy and safe requires thought and creativity. The following stories give some examples of the efforts needed.

A story that I enjoy telling (and writing about) is that of a man who wants to go for walks whenever he wants and who also thinks that, when he crosses a street, traffic should stop for him. The initial thinking was that he needed one to one staffing across all waking hours. The cost of the staffing necessary for a couple of walks each day was an expense that was disproportionate to the result. On the other hand not being able to go for walks on his schedule significantly reduced the quality of his life. Further discussion lead us to realize that this man would be happy to live in a rural setting. He moved to a house on a five acre Christmas tree farm where he goes for walks whenever he wants without having to cross a street.

One man that we did planning with liked to use "found objects" in his art projects. The challenge was that he would "find" objects in stores and leave without paying for them. He understood the concept of money but was remarkably uninterested in it. The people who supported him could have said that it was his "choice" and let him be arrested. Instead they would go to stores with him, with his money in their pocket. (He would give his money away if it was in his pocket.) As they left each store the support staff would ask if he had "found" something in that store and, if yes, the staff would pay for it.

We got a phone call several years ago from a service provider asking for help with someone who was severely injuring himself. This man is now described as a tall, charming, ladies man who does not use words to talk. At the time,. his brother said that he looked like a hockey goalie with the helmet and all of the padding that he wore to keep from injuring himself. There were people who said that he needed a "more restrictive" setting and there were people who said that pain should be used to control his behavior. The service provider could have argued that an institution would be the "safe place" for him to be. Instead we were asked to help the provider "listen" to what this man was asking for.

After listening to what he was saying with his behavior and after listening to what those who loved him knew, we found that there was no single answer. However, there were a host of simple things that we could do. There were many ways in which we were not listening to how he wanted to live. Some examples include that he: needs to close all doors (except for his bedroom door at night) and to line up all shoes; must be able to make and eat his own snacks when he wants them (including raw onions with salt); must not be ignored (even if it is planned); and he must always have a non-glossy magazine to hold onto. His life is not perfect and he still gets upset occasionally. On these infrequent occasions he still needs people who keep him from hurting himself. However, because we have been listening carefully to what he is asking for he is living in his community. He lives (and goes to concerts with his brother)without pads, splints, or a helmet.

Choice requires opportunities and sharing control A preference is something that people want. Unless they have already experienced it they will not know whether or not they like it or not. Many people with disabilities have never had the life experiences necessary to determine how they really want to live. Honoring choice for these people requires opportunities and taking advantage of the opportunities may require encouragement. As people begin to find that their

choices are honored they want control over those choices. Honoring choice requires that control is shared. This is the subject of part 2 of revisiting choice.

Revisiting choice - part 2

Choice, as we are using it, is a simple word that contains 3 concepts - preferences opportunities, and control. Learning people's preferences is a complex and on-going activity. What people want (and the values that underlie their desires) provide a picture of how people want to live. This was the subject of part 1 of "revisiting choice". However, learning how people want to live is only the beginning. It is the necessary foundation but just the foundation. In order to get the life that you want and to maintain it you need opportunities and control.

For people with disabilities the absence of control and opportunities is a devastating combination. Flooding people with opportunities or simply handing over control can be equally devastating. Everyone needs opportunities and everyone needs control but they need them on their own terms. People who have never had opportunities need to sample life in their own way. Some people need to dive in. They do not want and cannot tolerate transitions. Others are most comfortable with first putting a toe in. They want lengthy and careful transitions. Both need the control necessary to change their minds. Some people have been demanding control over significant aspects of their lives and we have seen them as having challenging behaviors. Some have given up hope and we see them as withdrawn or even as compliant. However, regardless of the severity of disability, people want control over parts of their lives.

Providing opportunities, sharing control. Having control is how we maintain a balance in our own lives. Each of us needs control sufficient to keep (or secure) what we value in our lives and to reject (or leave) situations that we cannot stand. One definition of emotional health is that we recognize what a balance is and that we recognize opportunities that enable us to maintain or enhance that balance. That is, we are able to use opportunities to get more of what we value or less of what we dislike. Control is what allows us to try new things and discard them when they do not fit. Control is what we require when we find our lives out of balance and we look for the opportunities that will bring a positive balance. The situations we find the most frustrating are those where we lack control and/or where the opportunities that we need are absent.

Control is a complex concept. Having control means that we have to make decisions and all of us create a set of positive rituals or routines that allow us to get through much of our day without treating each situation as if it were new. Most of us do not want absolute control. We may joke that if we were in charge of the world we could fix things, but most of us want (and welcome) limits to the areas where we have to make decisions. We conform to large sets of societal rules without much thought and only remark on those few areas where we disagree. Those of us who live with others find that we have to share control. Each of us has our own rules that we insist that our partner honor and our partners expect the same of us. Where expectations regarding behavior are not met, or are mutually exclusive, conflict arises. The outcome of a resolved conflict is a mutual agreement on the behaviors expected. Our vision of the best outcome is that our partners will see the error of their ways and the wisdom of our words. A more rational outcome is that each of us will better understand the other and make the compromise that works for the relationship. In

reciprocal relationships control is shared.

If we apply what works for everyone to people with disabilities, then we should be helping people with disabilities to have sufficient control to maintain a balance in their lives and to create their own rituals and routines. We should help them develop relationships (both paid and unpaid) where control is shared. A brief description of what the disability system should be doing is: to discover how people want to live; provide them with the opportunities necessary to get the lives they want; and help them have the control needed to maintain it. Many of the challenges in doing this arise from the disabling environments in which people have lived. We have created these environments with a binary view of control. Either I have control or you have control. The idea that control can and should be shared seems to be an alien concept.

Control, opportunities, and preferences as developmental triplets. Parents support the development of their children by asking the child to choose from alternatives and then honoring the choice the child makes. As children grow in capacity and experience the span of control gets broader. Children may move from what they will wear, to when they will go to bed, to how they spend most of their waking hours. They move from nearly constant supervision to doing what they want within defined (and often disputed) boundaries. Parents transfer control slowly. All parents worry about whether their children are "ready". When a child breaks a rule about the boundaries of behavior the child loses control for a time (smaller children may go to their rooms, older children may be "grounded"). Parents share control with their children while they are transferring it. Typical children go through phases where they rely on their parents control for most things, go through a period where they both want and do not want parental control (teenagers can simultaneously tell their parents that they are ruining their lives while wanting limits to push against), and end up, as adults, with control regardless of their parents desires.

For people with disabilities the analogy with the developmental process that children pass through is both helpful and dangerous. It is helpful in that it provides some guidance as to where someone is and how we might help them move forward in a safe and rational way. The analogy breaks down as the inevitability of autonomy for typical children is not present for people with disabilities. It is dangerous in that we are talking of supporting adults who may have already been trapped by developmental concepts such as mental age.

Control and capacity. How much control we have and what we have control over should be a function of desire and capacity. However, our stereotypes of people with severe cognitive impairments cause us to over look the capacities that are present. I have met a number of people who do not use words to talk but who are good at training staff in listening to their behaviors with regard to what they want. They demonstrate a much greater capacity for (and interest in)controlling their lives than they are given credit for. At the same time we need to recognize that positive control is learned and control should be coupled with a knowledge of consequences.

We need to ask what are people asking for and how can we help them get it without putting them at unnecessary risk. It can be as simple as supporting Rhonda, who uses a wheel chair, in being where she wants to be. Any sunny warm day she will want to go outside and enjoy the sun. Unfortunately she is also very allergic to pollen and needs to be told, on days with a high pollen count, that she would not enjoy the consequences of going outside.

Timing and opportunities. Timing is important in how people respond to opportunities. We tell our friends that we are not ready or that we will do it when we are ready. Opportunities have a developmental sequence, people need to be offered what they are ready to try. What people are ready for and when they will be ready requires judgment. Given the uneven, but generally impoverished, life experiences that people have had they need to be encouraged to try new things. They may need to have an opportunity presented again and again. Judgment is required to determine where encouragement stops and coercion starts. At the same time a lack of experience coupled with uneven deficits in skills and capacities makes people more vulnerable. Opportunities can lead to injury and judgment is again required. There is little growth that comes without risk. People need to be able to fail and to feel hurt. Supporting people in having opportunities so that we will know what they will want tomorrow is as important as it is to learn what people want now.

What opportunities we provide, hold back, encourage people to find, or protect people from depends as much on our values as they do on the preferences and capacities of the people we support. We need to listen to ourselves when we say that someone is not ready or that they should be able to do something simply because it is their choice. Our values influence and often control what we support. We need to talk about what our values are so that we understand the basis on which we are making decisions. We need to remember that the opportunities that are made available depend on the values of those with control.

Looking for control. Most of us seek, and to a large degree achieve, the amount and kind of control that we want over major aspects of our lives. Control is part of what gives us the predictability that we value. One of the more devastating feelings that people report is being out of control or experiencing a loss of control. When we have less control than we desire, increased emphasis is placed on the control that remains. For people with disabilities who live in very controlled settings control is sought where ever it can be found. Some of the behaviors that we want to change around food, aggression, self-injury, and sexuality are a reflection of a lack of desired control over other aspects of life. When people gain positive control over their lives the behaviors that have caused us concern may diminish and with some people vanish.

The difference between sharing control and giving control. Control is not a fixed quantity. It ebbs and flows in our relationships and it can ebb and flow with the people we support. An agency in North Carolina that is supporting people with severe and persistent mental illnesses as well as cognitive impairments sees control as moving toward the person supported whenever possible but also returning to staff when the person supported has an acute episode. Someone with a severe seizure disorder maybe able to do some things when the seizures are under control and should not have the same opportunities when the seizures are not under control.

Rethinking choice. Our recent history is filled with stories of people whose lives were totally controlled who now live in happy interdependence. People who were seen as not competent to select what to wear are now living in their own homes. We are also hearing of the people who have been injured when some one used choice as an excuse to not think. We need to recognize that the people we support are the experts on what they want while we are their partners in helping them get it. We need to have relationships where we share control and continuously

support people in gaining as much control as is possible. Many people, especially those with severe disabilities are only asking for modest control. They want to be able to: control the pace of life (to not be rushed); to be listened to (to only get to bed when they are sleepy); and to have a say in who their staff are (to only be supported by people that they trust).

In our relationships we should help people grow and remember that there is a dignity to risk. At the same time there is no dignity in serious injury. We need to see the key to growth as starting with understanding what people want today and then helping people find opportunities so that they will know what they want tomorrow. We need to recognize that everyone wants and needs control over some aspects of their lives. Our jobs include supporting people in gaining that control.

Baltimore August, 1995

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[GO BACK TO ELP LEARNING COMMUNITY](#)

The Realities of Institutions

by Tia Nelis

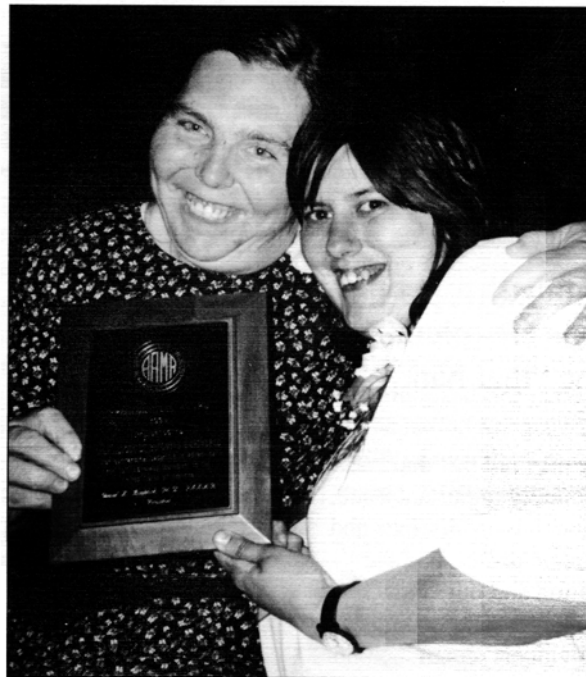
"Should we spend money on institutions or to support people in communities?" As a self-advocate, it bothers me that people are still arguing about this. I'm not quite sure what all the graphs and charts and numbers mean, or what the latest research says, or whose reports to believe. So, I judge by what I know. I listen to the people who live in the institutions.

■ Privacy? What Privacy?

How can you have much privacy when you live on a campus with 100 or more people, in a unit with 10-15 people, and share a bedroom with at least one or two roommates? Struggling college students may need to live under such conditions temporarily, but not a 32-year-old woman with a job. Institutions provide little privacy.

When I visit the institution the staff think I'm another "client", so I get to see the real story. I see shower rooms with the doors open and curtains pulled back. I see staff opening the doors to people's bedrooms without knocking and walking inside. I see people carrying all of their valuables with them – "hoarding behavior" I think it's called by professionals; the truth is that people are afraid their valuables will be stolen when they leave their rooms. No free access to phones. No privacy when caring for personal matters, sleeping, entertaining that special someone, or just plain wanting to be alone. Bedroom doors are never closed or locked; I have noticed locks on nurses' stations, staff lounges and bathrooms, often with a sign that says "staff only" or "knock first." Whose home is this anyway? Administrators and state officials have escorted me through people's homes and invited me into their bedrooms without people's knowledge. I think the picture is very clear: Institutional living allows people very little, if any, privacy.

Realities, continued on page 27



Tia Nelis (right) and Nancy Ward, on behalf of Self Advocates Becoming Empowered, receive an award from the American Association on Mental Retardation recognizing the organization's accomplishments, including efforts to close institutions. See story on page 12.

From the Editors

This issue of *IMPACT* is focused on a critically important step in the honoring of full citizenship of persons with developmental disabilities: the closing of institutions. We dedicate this issue to Roland Johnson, who passed away in August, 1994. Roland's personal experience of living in an institution propelled him to become a leader in the civil rights movement for persons with disabilities. His unwavering conviction that institutions must be closed and that people with disabilities need to live in the community continues to be a driving force behind the advocacy and self-advocacy efforts of many people who knew him.

Roland was one of the founding members of the organization, Self Advocates Becoming Empowered. Pat Gerke, an advisor for the organization, recalls that Roland, in personal conversations, would frequently ask the question, "What are YOU going to do about getting people out of institutions?" She believes that he knew in some way

that he wouldn't be around to see many of the changes he had dreamed of, so he sought to challenge others to understand that people's lives are at stake. With the help of self-advocates who, carrying on in Roland's spirit, worked with us on this *IMPACT*, we present that same challenge to our readers.

CONTENTS

Overview	2
Self-Advocate Experiences	10
Parent Experiences	14
Closure Strategies	16
Resources	26

Realities, continued from page 1

Living “on the outside” as my friends who live in the institution call it, you decide how much privacy you want. If you like people around all the time, you may choose to live with five or six others. If you don’t like noise, then you live with a quiet person. Your phone conversations are private because it’s your phone. Your mail is private because you get it from your own mailbox. When people walk into your home, it’s because you have invited them. It is your home and you make up the rules. It’s called “choice.”

■ Choice...Another Popular Word

People who live in institutions or other large facilities have fewer choices to make because many decisions are made for them, including simple decisions that are made for staff convenience or cost savings. Decisions so important and basic to most people that if we insisted on making these decisions for our friends or families people would think we were nuts. When you are “placed” (my friends and I like to say “incarcerated”) many decisions are taken away, like where you will live and with whom, how you will spend your day, and when you want to eat, sleep, and work. Institutional advocates like to say we can’t make choices, don’t know how to make good decisions, and are not responsible, or that it is easier for us to have them make our choices.

Making choices about our lives gives all of us pride about who we are and what we have done with our lives. I was visiting an institution here in Illinois just last winter. The day staff came in from a shopping spree with new comforters for the 10 people who lived in this “cottage.” One of the men who lived there said he wanted a pink bedroom and the staff laughed. I could hardly believe what I heard – they actually laughed and said pink is for girls. Well, I have a Mickey Mouse comforter and purple walls and I love it because it’s mine. It says something about me. It may not be your choice. In fact, you may think that it was a bad choice, but it’s not your decision to make. It’s mine.

The bottom line about choices is that in the institution you get to make very few choices and the ones you do make are not the big ones. Living in the community you have opportunities to make choices about all parts of your life, from what comforter you may choose to where and with whom you will live. You even get to make bad choices and live with them. It sounds like making choices is a privilege, when it should be the rule.

■ Consumers...The New Buzz Word

I want to get a few things straight about this word “consumer” for all people who receive services. Consumer is a funny word to describe people who use some type of support services. When I first heard of people with disabilities called consumers, it was in a skit put on by professionals.

They showed people with disabilities shopping at a store and choosing different foods depending on what they liked. “We (providers of service) should treat people with disabilities as consumers of our goods and services. Our goal should be to provide quality services that people make choices about.” It sounds good, doesn’t it? But what government agency or service provider is going to say, “If I don’t meet the quality and demand of the services you want, then I will go out of business”? People with disabilities don’t have control over the money nor do they have many choices about what service provider or type of service they receive. The consumer idea is a nice thought, but really just another name to set us apart as being different from the rest of the world.

■ A Few Things I Am Sure Of

From my experiences with institutions and with life “on the outside,” there are some things that I know to be true:

- I’ve never met anyone who would choose to live in an institution once they have moved out.
- Putting people away because they have a disability is wrong, just like segregation is wrong. People should only be locked up if they are dangerous.
- Everyone should be allowed to make mistakes and learn from these mistakes. I’m not talking about putting people’s lives in danger, but about mistakes like spending all your money so you can’t buy snacks for a week.
- People with disabilities want to be friends and neighbors and coworkers with lots of different kinds of people, not just other people with disabilities.
- People who have lived in institutions all of their lives don’t know how to make choices because they are not given the opportunity. We need to teach people how to make decisions and allow them to fail, too.
- Community living is not always easy, perfect or safe, but at least the people who live in the community are free.

Next time people start talking about closing institutions, make sure you’re asking and listening to the right people – those who live there. They know the truth about these places.

Tia Nelis is a member of People First of Illinois, Co-Chair of the national organization Self Advocates Becoming Empowered, and Self-Advocacy Advisor with the Institute on Human Development, University of Illinois at Chicago. She can be reached at 312 / 413-1284.

Choices

I live in America, the land that gives me the right to make choices and speak my mind.

But I have a disability... Nobody allows me to make choices. People tell me all the time what to wear, what to eat, what job to have and who are my friends. Is that fair? I say no!

But I have a disability... people don't listen to me anyway.... why should I give my opinions? I fight so hard for somebody to listen...just someone to listen... and give a damn about what I want.

If people with disabilities can live with everyone else, than why can't I make choices like anyone else...if that's my right as a citizen of the U.S.A?

Liz Obermayer
4/19/04

ON CHOICE¹

By Steven J. Taylor

The concept of "choice" is frequently discussed in the field of developmental disabilities these days. Yet the concept means different things to different people and is used to justify radically disparate visions of the place of people with developmental disabilities in society. This article presents some thoughts on the concept of choice.

Why is choice important?

Historically, people with disabilities and their families were offered few, if any choices over their lives. Families of children with severe disabilities had two options: they could institutionalize their children or keep them at home with no publicly funded assistance or even education. Adults with severe disabilities could be placed at public institutions or live in the community with no services or supports. With the establishment of a federally guaranteed right to education and the expansion of community services, the options available to people with disabilities and their families slowly started to expand. Nevertheless, many people continue to be denied the opportunity to make choices about the most basic aspects of their lives.

What is choice really about?

In my view, choice means that people with disabilities, regardless of severity of disability, should be able to enjoy the *same* choices and options available to other people in society. A *public* commitment to choice means that public funds and programs should support people in making these choices and selecting these options. It does *not* mean that public funds and programs should support lifestyle choices and living conditions other people do not enjoy.

What are some important choices that people should be able to make?

All people should be able to make decisions over various aspects of their lives? For adults, major choices include decisions about

- In which communities and neighborhoods to live.
- Whether to live alone or with others and, in the case of the latter, the specific person or persons with whom to live.
- Friendships and participation in community activities and associations.
- From whom and how to receive personal assistance and support.
- Sexuality and sexual relations.
- Where to work.
- Medical treatment and therapeutic interventions.

¹Taylor, S. J. (2001, February). On choice. *TASH Connections*, 27(2), 8-10. Available: http://thechp.syr.edu/on_choice.htm

Choices about these matters determine the degree to which people can make decisions about day-to-day things such as:

- Meals and mealtime routines.
- Bedtime routines.
- How to spend leisure time.
- Dress and personal appearance.

What public policies and approaches are consistent with choice?

Public policies and service approaches should maximize personal control and choice. The following are some current approaches consistent with this principle:

- **Individualized funding.** Sometimes referred to as "self-determination" or "cash and counseling," individualized funding provides for funds for services and supports to be allocated directly to individuals. A fiscal intermediary and service coordinator may be used to assist people in managing funds allocated to them.
- **Person-directed personal assistance.** Under this approach, people are able to select, hire, supervise, and, if necessary, fire their support staff or personal assistants.
- **Person-centered planning.** This is a planning approach designed to identify people's capacities, needs, and desires.
- **Home of Your Own.** This involves innovative financing schemes to enable people with disabilities to own their own homes as opposed to living in agency operated facilities.
- **Family-center support services.** For children, in particular, families should control the services offered to them.

Are all people capable of making choices?

All people should be presumed competent of making choices about their lives. Some people, however, may be limited in their ability to express their choices. In these instances, every effort must be made to ascertain their preferences and choices by people who know them well. Surrogates—parents, family members, and guardians—will sometimes need to make decisions on people's behalf when it is impossible to determine what they want. The choices that surrogates make in such circumstances should be limited to the range of choices and opportunities available to people without disabilities.

What about people who make bad choices?

People with or without disabilities can make bad choices. Some people pursue unhealthy life styles or spend their money poorly. Disability is not a reason for depriving any person from making the same choices other people have the right to make. Nor is disability a reason for supporting people with disabilities to make decisions (e.g., physician assisted suicide) that persons without disabilities are not entitled to make.

Family members, friends, and loved ones can and do influence the behavior of others. The strongest safeguard on the well-being of any person is to be involved in caring relationships in which people influence each other in non-coercive and non-manipulative ways.

Choice should never be used to justify neglect, poverty, or an absence of realistic options. People do not choose to go hungry or be homeless. To people who might make bad lifestyle or spending decisions, we should be magnanimous.

How has the concept of choice been misused?

Increasingly, choice is used by some individuals and groups as a justification for the continued institutionalization of some people with developmental disabilities. What is usually meant by this is that parents and family members should have the option of deciding where and how their sons and daughters with disabilities should live. Although family members can play an important role in supporting people with developmental disabilities, they are not entitled to substitute their own interests and wishes for those of people with disabilities. The condemnation of institutions by organized self-advocacy groups testifies to the fact that people with developmental disabilities do not wish to be put away.

The phrase "one size fits all" is sometimes quoted by proponents of institution to characterize the policy of community inclusion. Yet it is the institution—with well-documented patterns of "block treatment" and rigidity of routines—that epitomizes "one size fits all." In the community, there is unlimited variety and opportunities to pursue life styles based on individual needs and preferences.

Any adult has the right to decide with whom to associate. Some groups have chosen to segregate themselves from the wider society based on religious, ethnic, and other grounds. Some parents choose to send their nondisabled children to boarding schools where they can be with students of similar ethnic, religious, or economic backgrounds. In a democratic society people have the right to choose segregation—to associate with only those persons presumed to be exactly like themselves. *But society has no responsibility to subsidize segregation.* Public policy toward people with disabilities should support opportunities to make the same choices other people make—nothing more and nothing less.

BULLETINS AND FACT SHEETS RELATED TO CHOICE AVAILABLE FROM THE CENTER ON HUMAN POLICY:

[Policy Bulletin on Safeguards](#) (1993) addresses how safety can be increased by strengthening community and improving the assistance people receive. It also discusses the paradox of regulations. (18 pages)

[Fact Sheet on Self-Advocacy](#) (1999) by Mair Hall briefly defines what self-advocacy is, provides a brief history of the Self-Advocacy/People First Movement, and includes a brief list of resources. (2 pages)

[Fact Sheet: Summary of Self-Determination](#) (1998) by Michael J. Kennedy and Lori Lewin summarizes what self-determination is and is not, the principles of self-determination, the values supported by self-determination, and a call for changes in the system in order for self-determination to truly succeed. (2 pages)

Fact Sheet: In Support of Families and Their Children (2000) by Nancy Rosenau discusses why children belong in families and how to assure families for all children. (2 pages)

Feature Issue on Institution Closures (Winter 1995/96) edited by Mary F. Hayden, K. Charlie Lakin, and Steve Taylor contains national information as well as a variety of articles on closing institutions written from the perspectives of self-advocates, professionals, parents, researchers, and policy makers. This bulletin was published through the Impact series of the Institute on Community Integration at the University of Minnesota in cooperation with the Center on Human Policy.

Fact Sheet: What is "Permanency"? (2000) by Nancy Rosenau describes the importance of permanency for children and discusses strategies to support and implement it. (2 pages)

Fact Sheet: The Community Imperative (2000) In 1979, the Center on Human Policy at Syracuse University wrote *The Community Imperative*, a declaration supporting the right of all people with disabilities to community living. The Center has reissued *The Community Imperative* in 2000 and invites endorsements from individuals and organizations.

Internet Resources Relevant to Choice

Advocating Change Together - <http://www.selfadvocacy.com/>

Self Advocates Becoming Empowered - <http://www.sabeusa.org/>

National Self-Determination Program Office - <http://www.self-determination.org/>

National Home of Your Own Alliance - <http://alliance.unh.edu/>

Institute on Community Integration, University of Minnesota - <http://ici.umn.edu/>

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SAFEGUARDS

People with disabilities are sometimes vulnerable to harm, neglect, or abuse. Thus, there is a need for certain safeguards. However, there are vast differences in ideas about the best kinds of safeguards.

The Faulty Argument of Institutionalization as a Safeguard

Even today, some people argue that some people with disabilities are more at risk in the community, and that institutionalization is the best safeguard. They cite mortality studies as evidence, and use this as grounds to oppose deinstitutionalization. However, this “evidence” is highly disputed within the research community. More importantly, as other researchers assert, “The question of whether mortality rates are higher in institutions than the community is not the right question to be asking today” (Taylor, 2001, p. 27). Instead, focus should be on identifying and addressing the specific circumstances that create risk in the community.

The Limitations of Regulations as a Way of Addressing Risk

In order to address risk, systems tend to impose more and more regulations. However, there are problems with regulations:

- Regulations in the field of developmental disabilities create greater bureaucracy.
- Regulations reflect the abuses of the past, and sometimes the present, but limit the potential of the future.
- Regulations encourage investment unnatural environments.
- Regulations foster compliance.
- Regulations place control and power in the hands of regulators, and not people with developmental disabilities and their families.
- Regulations direct attention to concrete and tangible things, and trivialize the most important things in life.

What Can the Service System Do?

There are various strategies that can be helpful in keeping people safe.

- The best safeguard is personal relationships and social networks beyond the service system. A priority for agency staff and other support workers must be to assist people to build and maintain such community connections.
- People are vulnerable when they have little or no power and control. System reform efforts that enhance people's power and control will contribute to increased safety.

- Within service agencies, the roles and relationships of staff to the people they support and families must be examined. For example, it is important to ensure that there are a few staff who know each person well.
- As an alternative to the current regulatory framework, people with developmental disabilities and their families should be provided with clear-cut rights and due process mechanisms.
- Abuse claims must be independently and vigorously investigated and people who are found to be abusive must be punished.
- Training of staff is a key to preventing abuse. The more staff know about how to best support people, the better off people will be.

INFORMATION IN THIS SECTION IS BASED ON THE FOLLOWING:

Taylor, S. J. (1992, June). The paradox of regulations: A commentary. *Mental Retardation*, 30(3), 185-195.

OTHER RESOURCES:

O'Brien, J., Lyle O'Brien, C., & Schwartz, D. B. (Eds.) (1990). *What can we count on to make and keep people safe? Perspectives on creating effective safeguards for people with developmental disabilities*. Lithonia, GA: Responsive Systems Associates. Available:

<http://thechp.syr.edu/CountOn.pdf>

Taylor, S. J. (2001). The continuum and current controversies in the USA. *Journal of Intellectual & Developmental Disability*, 26(1), 15-33.

Taylor, S. J. (Ed.). (1998, October). Mortality in institutions and community settings [Special issue]. *Mental Retardation*, 36(5).

Taylor, S. J., O'Brien, J., & Hulgin, K. (Eds.). (1993, Winter). *Safeguards* [Policy Bulletin No. 3]. Syracuse, NY: Research and Training Center on Community Integration, Center on Human Policy, School of Education, Syracuse University. Available: <http://thechp.syr.edu/bullsafe.htm>

INCLUDED WITH THIS SECTION AS BACKUP DOCUMENTS:

O'Brien, J., Lyle O'Brien, C., & Schwartz, D. B. (Eds.) (1990). *What can we count on to make and keep people safe? Perspectives on creating effective safeguards for people with developmental disabilities*. Lithonia, GA: Responsive Systems Associates. Available:

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Taylor, S. J., O'Brien, J., & Hulgin, K. (Eds.). (1993, Winter). *Safeguards* [Policy Bulletin No. 3]. Syracuse, NY: Research and Training Center on Community Integration, Center on Human Policy, School of Education, Syracuse University. Available: <http://thechp.syr.edu/bullsafe.htm>

What Can We Count On To Make and Keep People Safe?

Perspectives on Creating Effective Safeguards for
People with Developmental Disabilities

John O'Brien, Connie Lyle O'Brien & David B. Schwartz

Discussion reports in the *Perspectives on Community Building* series summarize group meetings on issues that concern those who are working to increase the presence and participation of people with developmental disabilities in the neighborhoods, workplaces, schools, and associations that constitute community life. Meetings include people with different interests and points of view: people with developmental disabilities, family members, people who provide and manage services, people who make policy and manage service systems, and others who work for stronger, more inclusive communities.

Discussion focuses on deepening understanding of an important theme and creating options for action rather than on making specific plans and decisions. The process emphasizes exploration of different perspectives on complex situations rather than defining consensus positions. So, points in the summary may conflict with one another. Neither the editors nor all participants necessarily agree with each point and the summary does not represent an official position of the group that sponsored the meeting.

Discussions usually happen as events in the context of change efforts; sponsors often schedule them as retreats, search conferences, or reflection days. Participants typically know at least some other people at the meeting, and some participants get involved in planning and following up the meeting.

A facilitator and recorder guide the group's work: negotiating an agenda and discussion groundrules, managing the group process, and recording and summarizing the discussion. The recorder prepares and circulates a written summary from large graphic displays and audiotapes made during the meeting. The summary preserves participant's own words and images and organizes their contributions around themes identified during the discussion. The Perspectives paper is edited from the meeting summary, from participant's comments on the summary, and selections of other materials shared by people present. The editor's introduction and comments are not reviewed by participants.

The discussion summarized here took place at the Annual Retreat sponsored by the Pennsylvania Developmental Disabilities Planning Council on 11-13 November 1988 in Harrisburg. Members of Speaking for Ourselves (a self-advocacy group), activists with physical disabilities, advocates who are family members, disability rights attorneys, people living in intentional community, and people who provide services and manage service systems joined council members to explore options for increasing the security of people with disabilities.

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Contents

The Question.....	5
Quality Assurance in the Asylum.....	6
Concerns that Shaped the Context of the Discussion	8
A Framework for Discussion	11
What Makes People with Developmental Disabilities Vulnerable?	13
What Keeps Joanie Safe?.....	20
How Regulatory Control Expands	23
Contrasting Approaches	25
Administrative Regulation & Related Legal Advocacy.....	26
Lifesharing & Other Personal Commitments	28
Competing Social Tools	30
The Loss of Spirit.....	33
Strategies for Increasing People’s Safety.....	34
Accounting and Reducing the Costs of Regulation	38
Options for Action.....	40
To Make Children Safer.....	40
To Make Adults Safer	41
Minimizing the Costs of Regulation	43

Thanks

To participants in the retreat for their sustained and thoughtful discussion and their willingness to listen to people with different points of view on a complex and difficult issue.

Special thanks to the retreat planning committee —Mark Friedman, Harry Guise, Jerome Iannuzzi, and David Schwartz— who risked the discomfort of an open-ended agenda; to those who prepared reflections on the conference theme—Steve Eidelman, Lucy Hackney, Roland Johnson, Illene Shane, Rud Turnbull, and Helen Zipperlin—for modeling openness, self-criticism, and careful thinking about their deep concerns; and to Chris Barton for setting the whole discussion to music.

Throughout this paper are excerpts from a manuscript, “What really keeps people with disabilities safe in society?” prepared by David Schwartz in September 1988 and selections from other materials sent to participants before the meeting.

The Question

The question—*What can we count on to make and keep people safe?*—frames an important perspective on the continuing work of building communities that offer people with developmental disabilities full and dignified lives. It arises from a realization of the vulnerability to neglect, abuse, and mistreatment risked by people who require substantial, long-term assistance to take and keep their rightful place as citizens. It is shaped by a sober recognition of the shortcomings of unregulated relationships between people with disabilities and their caretakers and the limitations and ironic effects of systematic efforts to keep people safe through professional, bureaucratic methods. Left to their own devices, a frightening number of care providers act inhumanly. But increasing investments in formal means to regulate these relationships don't proportionally increase confidence in people's safety. Indeed formal systems seem to weaken the spirit of commitment necessary for caring relationships to thrive. Discussion is animated by acknowledgement of the desirability and necessity of action to increase people's safety by both strengthening the ties of community and making necessary assistance more relevant and effective.

To increase safety:

- Strengthen community
- Improve needed assistance

“It should be a sobering reminder to us that, when the pioneers of our field undertook their task, despite the greatest good will and thoughtful deliberation they led to the development of modern institutional settings. In offering enormous benefots, their work led to loss of everything important to their beneficiaries.”

—Burton Blatt

As the note on the next page shows, efforts to ensure the safety of people who rely on services have an instructive history. Many of today's approaches to improving quality through policy, training, hands-on management, and external monitoring would be familiar to nineteenth century asylum keepers. Then, as now, their insufficiency raises a troubling issue. Can it be that the very design of well-managed settings that meet every need frustrates our attempts to embody our good intentions? Could it be that the community services we have carefully developed share too many characteristics with earlier, now discredited approaches? And if so, must people with developmental disabilities accept the built-in limits of total environments as the best available compromise in a dangerous world? What strategies offer ways to constructively engage these questions?

Quality Assurance in the Asylum

David B Schwartz

The Willard Asylum for the Chronically Insane was founded in response to a social outcry over the mistreatment of “the insane” in county jails and almshouses in the nineteenth century. Dedicated staff and trustees worked unceasingly to better their condition. Yet barely were the opening celebrations over when Willard found that it was not itself immune to the persistent problems of abuse and neglect. It must have come as a discouraging shock to the idealistic founders.

“Before closing the doors for the night, attendants must see that the patients are comfortably in bed; and it is especially enjoined that they offer gentle and patient assistance to the feeble and aged, and leave all with a kind ‘good night’.”

—Rules for attendants, Willard Asylum, 1869

The institutional planners were not naïve. Practices to maintain the quality of care were built in from the beginning. Designed following the popular “Kirkbride plan”, the asylum was built in two “wings” centered by the residence for the medical superintendent and his family. Knowing that the most “excited” patients were most likely to precipitate mistreatment from staff, it was apparently the practice at Willard to place the ward for that class in the building complex joined to the superintendent’s apartments. It was easy to tour the wards unexpectedly. The Board of Trustees were no less vigilant; in their bylaws they entered the requirement that the facility be visited by a board member weekly. Yet despite these and other monitoring mechanisms, cases of abuse must have begun to occur. The first public sign of this came in an annual report to the legislature only six years after opening. In it an “experiment” was noted in which a “gentleman” of the vicinity had been engaged to tour the male wards daily and to report on the “demeanor of attendants toward patients,” so that he might “provide a wholesome restraint” upon the behavior of attendants.

One must assume that this particular solution proved insufficient, for barely four years later, resort was made to proposing a far more severe remedy. In that report the trustees and the administrator together asked the state legislature to pass a law making it a misdemeanor for an attendant to commit an assault upon a patient. Notice of the law was to be posted on every ward and in the very bedrooms of employees. A year later the annual report noted that the greatest danger to quality of care was still “undue severity” or neglect by attendants. Defending itself against public criticism in the use of physical restraint, the superintendent expressed hope that more thorough training for employees might develop their humanitarian inclinations and thus reduce the frequency to which restraint was resorted. The success of this approach is not known.

Whether in the garb of the New York state’s present Commission on Quality of Care, the State Lunacy Commission, or that anonymous “gentleman” who walked the asylum wards a century ago, a lesson may be that the job of the monitor of quality and human rights is a constant one. It is when society loses interest in peering over the asylum wall that the fruit of inattention is really born. But even more importantly, those early asylum idealists had to learn through their own inevitable failure that, in Andrejs Ozolin’s words: “even if institutions were put in the best working order, they would be intrinsically abusive at their best and their best would be virtually impossible to sustain.” What seemed like the best plan, developed by the best people, had failed to fulfill its dream. Instead of “refuge” the word “asylum: would come in time to be an ultimate symbol of abandonment and despair.

“Even if institutions were put in the best working order, they would be intrinsically abusive at their best and their best would be virtually impossible to sustain.”

–Andrejs Ozolin

Concerns that Shaped the Context of the Discussion

The Pennsylvania Developmental Disabilities Planning Council's retreat planning committee expresses the history of the question in its invitation to a meeting to follow-up on the retreat summarized in this report.

The struggle to improve the lives of citizens of Pennsylvania with developmental disabilities has been a long and difficult one. Each step of progress: to gain admission of children with disabilities to school, to free people from life in institutions, to support people in their own communities, has come only as the result of unceasing work by many committed people.

While gains have often been frustratingly slow, and there are always many more needs to be met, there has usually been a sense of progress being made. People with most disabilities—especially with mental retardation—unquestionably have much better life opportunities than they did thirty years ago... Innovative approaches... [expand] opportunities in new ways only dreamed of a few years ago, such as adoption for children with special needs, flexible and “family-driven” support to families, real employment for people who formerly worked only in sheltered workshops, and many other areas.

In spite of such progress, however, there have been a number of recent signs that serious problems still remain and that new ones are appearing. Among these are:

- People with mental retardation being returned to institutions from community settings.
- Financial and staffing crises in community services.
- Reports of children with disabilities not being given full medical attention in hospitals, and rumors of newborns with disabilities being allowed to die.
- The discovery of high rates of psychotropic drug use in community programs.
- Continuing incidents of abuse and neglect in institutions, and emerging incidents of similar problems in some community residences.

While the picture is still unclear, a disturbing sense of concern about the welfare of people with disabilities seems to be increasingly heard from parents, advocates, government officials, and people with disabilities themselves. Such concerns are not unique to Pennsylvania, and if underlying problems do exist it is clear that they have been developing for some time. It is often easy to place blame, but hard to understand the true dynamics behind the issues involved.

Concern with ensuring security for people with developmental disabilities grows with accomplishment.

Real progress challenges the devaluing notion that people must accept and adjust to second-class status because of their disability. But progress has not freed even those people with disabilities it has reached from heightened risk of abuse, neglect, and mistreatment.

Forty years of vigorous advocacy has shown both the promise and the limits of legislation and litigation. Landmark decisions establish the right to education and create the opportunity for some people to live outside institutions. However, the complex systems that embody these intentions accumulate problems so serious that some observers fear they are close to breakdown. Others note that solutions become barriers as, for example,

they recognize the unintended segregating effects of the current special education system. And the tools for resolving conflict don't always work swiftly or reliably.

As the services have grown larger and more complex, the spirit of reform that shaped the community services system in its early years seems to have given way to more routine formal relationships. State agencies have invested substantially in regulations and enforcement mechanisms; provider agencies have invested substantially in compliance. This pattern of regulation and compliance provides a means of responding to undesirable situations, but it does not work to build better quality services—as Steve Eidelman, Deputy Secretary of Public Welfare for Mental Retardation notes.

The Pennsylvania community mental retardation service delivery system is extremely diverse and highly decentralized. It is administered by 45 separate local government units in partnership with over 300 private agencies serving over 43000 persons annually.

The 1966 Mental Health and Mental Retardation Act places responsibility to set and enforce standards with the Department of Public Welfare. Department of Public Welfare regulations establish minimum standards for the provision of various services.

Though basic health, safety, and minimum program elements are maintained by enforcement of these requirements, it is commonly acknowledged that enforcement does not constitute the most effective method to enhance quality in community mental retardation programs...

Advocates, consumers and their families have historically been instrumental in advocating for the establishment of new and expanded services and have been vigilant overseers of the provision of services. The vitality of Pennsylvania's community mental retardation services system depends on the dynamic interaction between this partnership and an accepting community...

From: Department of Public Welfare (1988). Quality enhancement. *Mental Retardation Bulletin*, #00-88-06, p.2. (Emphasis added)

Despite the growth of investment in services, an increasing number of parents of people with severe disabilities still feel the urgency of the same basic question that animated the pioneers of the parent movement for people with mental retardation: *What will ensure my child's security when I am no longer able to do so?*

A small but growing number of people share their lives and sometimes their homes out of recognition that interdependence among people with socially visible differences offers the best hope of security for everyone in a dangerous world. The more public of these efforts—such as Camp Hill Kimberton Hills, the Orion Communities, and the International Federation of l'Arche—communicate in their daily living together a sense of security and support for every members' development that impresses even those who would not choose such a life for themselves. These set-

tings raise a question about the service system's duty to regulate the safety and adequacy of people with disabilities' home and workplaces, even if they do not accept public funds from the service system. And system interest in regulating these living relationships causes deep concern that the pattern of regulation and compliance will destroy the heart of lifesharing by introducing distinctions of inequality between "staff" and "clients." Finding ways for people who are lifesharing and people with system management responsibility to learn from one another will strengthen both efforts.

Some people have concluded that the pattern of increasing regulation amounts to using the wrong means to desirable ends. In their view, apparent improvements in the system make things worse by undermining the very fabric of community relationships essential to better lives for all people. Moreover, a rising tide of regulation drowns the spirit which must animate efforts to overcome injustice and exclusion.

Responses to the question—What ensures security? — Provides a helpful complement to discussions about how to improve quality in human service systems. Participants in this discussion clearly identify that the qualities that offer people with disabilities security are the same qualities that define a good life: caring relationships, opportunities for participation and association, and power over the conditions of everyday life. The perspective offered here highlights some of the limits and costs of quality assurance systems and describes some of the other kinds of social change and systems change efforts essential to ensuring that people with disabilities have the security offered by a good life in community.

A Framework for Discussion

Wise decisions about how to increase the security of people with disabilities begin with improved understanding of the social conditions that increase vulnerability and careful analysis of the contributions, limits, costs, and conditions for effectiveness of the different types of available instruments. Understanding and analysis suggest possibilities for action.

When concerned people take action without taking time to clarify their understanding and account the possibilities and the limits of their tools, they miss opportunities and increase the chances of getting stuck in the unintended consequences of their action.

Clarence Sundram, Chairman of the New York State Commission on Quality of Care, identifies some of the consequences of acting too quickly on the assumption that more funding, more regulation, and more professional staff will create better environments for people.

Several years ago the Commission was conducting a study of the quality of care provided by community residences serving severely and profoundly mentally retarded persons in the New York City area. Many such residences had been established pursuant to the Willowbrook Consent Judgment and a large number of them had been converted into intermediate care facilities for the mentally retarded in an effort to increase the level of federal funding. One of the expected benefits of converting the residences into ICF-MR's was to enhance the level of clinical staff available to meet the needs of the residents. Yet, as we visited a number of homes, we were struck by the absence of any evident benefit to the residents from this increase in staff. It turned out that much of this newly found clinical staff time was consumed in preparing detailed treatment plans with long-term goals and short-term objectives, performing a variety of assessments, and filling the client's records with a battery of tests and scores and indicators. Many of these procedures and processes were made necessary by Medicaid regulations. In essence, what this sounds like is that we went into the Medicaid program to get more money to hire more clinical staff to fill out the forms that the Medicaid program requires. What does this do to improve client care? When we commented on the paucity of direct services by these clinical professionals to the mentally retarded clients, we were told that the professionals had too much paperwork to be more involved in actually implementing the plans they were writing...

...[There seems to be something fundamentally wrong with the devotion of so much high priced and scarce clinical and professional staff time to the development of treatment plans that no one has the time to implement. For whose benefit are we doing this?

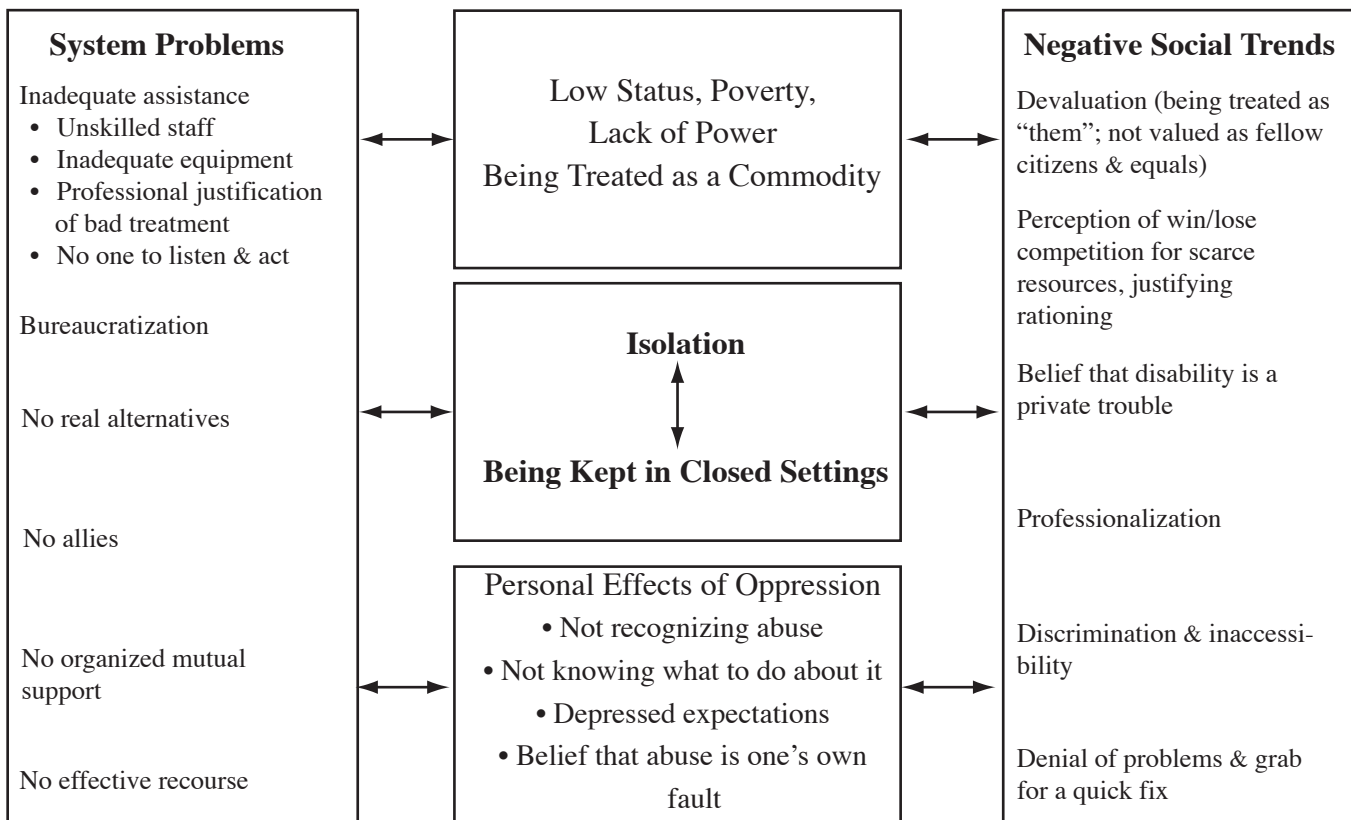
...[E]ffective regulation requires the ability to influence internal behavior with organizations to produce desired outcomes. When regulators do not know how to define the desired outcomes, their strategy often is to take complex problems and break them down into smaller sub-problems and focus on developing detailed regulatory specifications that attempt to control internal behavior of staff without reflection of the effect of these behaviors on outcomes. Both the regulator and the regulated know that the underlying problem is not being addressed but rather that elaborate games are being constructed. If the regulatees are seen by the regulators as always trying to find loopholes, then the duty of the regulator is to plug up such loopholes ahead of time. This leads to myriads of specifications, since regulatees are innovative in finding loopholes. As soon as a pile of specifications becomes high, the regulatees can mount their attack; namely, that they are swamped with regulations and specifications, and paperwork. The regulators in turn will insist that they have no alternative. But over-regulation can miss the target in both directions.

From: Regulation—Have we all gone mad? *Quality of Care*, September-October, 1987, p. 6.

The diagram below summarizes a discussion of the sources of people's vulnerability. It suggests important considerations for those who want to make people more secure:

- No single path leads to great security. Positive action can and should address each condition. Different concerned people may be drawn to work on different conditions; none can claim dominance.
- Problems in one area will hinder efforts to address another. For example, efforts to increase people's options for recourse may be severely limited by the built-in inadequacies of closed settings.
- Focus on just one area can make people less secure. For example, decreasing bureaucratic controls over settings in which people are isolated and powerless is risky. This creates dilemmas.
- Failure to honor the capacity of people with disabilities to influence their own destinies underlies these conditions. Regardless of the focus of work, people with disabilities themselves should be actively involved in decision-making.

What Increases People's Vulnerability?



What Makes People with Developmental Disabilities Vulnerable?

People with disabilities share the same vulnerabilities as everyone else in our society with even less power to deal with them. We are all vulnerable to unsafe streets, air and water pollution, ineffective transport, and a growing number of other threats right up to nuclear war.

Lack of power

No one has the power to control all the threats to safety and well-being. But people with disabilities typically have a much smaller area of power over the environments they live in than the rest of us. At the extreme, some people with disabilities have no time and place which is their own; they are always under someone else's supervision and control. Ironically, our best efforts to insulate people from the threats of the outside world have isolated them. To increase safety we have created places that have closed in upon themselves and deprived people with disabilities of the contacts, information, and power they and their families need to stay as safe as possible. To protect people we have made rules and regulations that effectively undermine staff people's ability to use their common sense. And even all these rules don't guarantee staff will treat people with common decency.

Some risk, some suffering, is integral to our common humanity. It's impossible to defend against it without destroying the fabric of human life. But without vigilant and vigorous protection, people with disabilities are far too often neglected and abused. This is the dilemma we face: How do we collectively protect people without patronizing them or destroying their opportunities?

There are two ways people with disabilities get hurt: actively, when somebody hurts you; and passively, when something you really need isn't there or doesn't work. What you need may be just for you—like a special kind of brace—or it may be something that benefits lots of people—like physically accessible environments.

Isolation

People with disabilities are vulnerable when they are isolated.

Institutionalization

There has been so much talk about deinstitutionalization that some people might think it was finished. We have to keep everyone aware of the continuing reality of institutionalization. Institutions aren't the only bad places, but they are bad and they are still there and their budgets are still growing. All the people aren't out yet; there are still 12 and 13-year-old boys and girls there. And every institution isn't a state institution. People with disabilities are institutionalized in private facilities and nursing homes and jails.

Oppression and its personal effects

Some people with disabilities are abused or neglected and think they deserve no better. People with disabilities are safer when they know for themselves what abuse is and what to do about it. This means more than just information; it means helping people sort out their expectations, taking responsibility for what they can do, and learning to deal with the anger and depression that arise from being oppressed.

Groups like Speaking for Ourselves* can help many people with disabilities get a sense of what they deserve and support them to get it. Parents of children with disabilities also need group and organizational support.

Access to other people with disabilities who have an effective sense of outrage and who can be models of how to live well with disability have been very important to many people.

Ways to get people who otherwise wouldn't know people with disabilities, like Citizen Advocacy, help, especially when a person's disability makes it hard for the person to speak for him or herself or when a person is very isolated.

Sometimes people need a good lawyer.

Inadequate settings and equipment

Some people are in places that are physically unsafe.

Lots of ramps and curb cuts aren't well made.

Some people either lack equipment they need or have equipment that isn't safe. This can be easy to see — as when a person's wheelchair looks rickety. Or it can be harder to spot — as when a person isn't positioned right in a wheelchair that looks OK.

No recourse

People are more vulnerable when there are no effective means of recourse.

Some people with disabilities never see anyone but the people who perpetrate abuse. The supervisors and professionals and monitors who are supposed to check rely on reports and papers and walk through inspections instead of really coming to see, sharing the food, spending the night.

No one to share the person's life and ask why things aren't better

Things get worse if there is no one to notice when something isn't working, no one to ask "Why?", no one to figure out what are the right questions to ask, no one to see things from the person's point of view and try to know how it feels. But it's hard to know how things feel when you only have forms and check lists.

* Speaking for Ourselves is an advocacy group whose members are or have been clients of the mental retardation service system in Pennsylvania.

No real alternatives	If there is no real alternative for a person, procedures for recourse can't work very well. If someone needs another place to live and that other place isn't available, an appeals process can just be hollow.
Problems with service staff	<p>In addition to outright dehumanization, abuse or neglect, many people with disabilities depend on staff people who just don't do their jobs very well.</p> <p>Many staff don't seem to understand people with disabilities as people. Maybe this is made worse by trying to improve service by reducing what it takes to care for a whole person into a list of rules and procedures and teams.</p>
Disrespect and lack of understanding	Many staff are not respectful of the people they look after. They act as if people with disabilities should be grateful and cooperative with anything that gets done. Maybe this reflects social values that assign people with disabilities to second-class status.
Ignoring capacities	Many staff don't pay attention to people's abilities; they just focus on deficiencies. Maybe this reflects social values on verbal intellectual skills and physical ability that overshadow the contributions of people who are not obviously smart or typically skilled.
Lack of cooperation among helpers	Many times the staff people who need to cooperate in order to do a good job can't get it together. They may have meetings between the day and residential staff or between parents and school, but the meetings don't always result in collaborative work on what's best for the person. Maybe this reflects a social myth of self-sufficiency and individualism that makes people who obviously need others to cooperate seem threatening.
Disconnection from community	Many times staff people talk about integration without seeming to know much about where the mainstream really is or how, in a practical way, to help people with disabilities be more part of things. Maybe this mirrors the lack of social consensus on the inclusion of people with disabilities. Maybe it also reflects social confusion about what it means for anyone to be an active citizen in our complex, conflict-ridden world.
Problems finding a balance between neglect and overprotection	It is very hard to get the right balance of protection for people. On one side lies denial of the person's disability and a lack of necessary support and supervision. On the other side lies a level of excess protection that overshadows opportunities to grow more responsible for self and participate in life. The more individualized the support for a person, the more likely it is that a balance can be found. Group situations make a good balance between too many choices and too few choices almost impossible to find.

Avoidance and denial of problems	<p>Finding out about the hurtful things that are harder to see can be difficult. Many times the person with a disability knows something is needed and missing, but no one who can do anything about it will listen. Sometimes the person with a disability doesn't even know something that would help exists and couldn't ask for it even if someone would listen. Environments that encourage people in power to listen to people with disabilities and give people with disabilities information and effective control will be safer places than those that keep people with disabilities in the dark and decide everything for them.</p>
Failure to look and listen	
Personal characteristics	<p>Some people with disabilities are especially vulnerable. A person's situation needs careful attention if...</p> <ul style="list-style-type: none"> ...the person causes trouble and acts uncooperative ...the person has difficulty communicating ...the person seems especially fragile ...the person acts dependent and childlike ...the person does not seem to grow and change much over time ...the person has no real contact with family or friends ...the person does not seem capable of reciprocity in being involved with and contributing to a relationship <p>Sadly, these are the people that are most likely to be grouped together and isolated in the name of "appropriate treatment".</p>
Poverty and social marginality	<p>The line of vulnerability lies at the perimeter of our society. The more people are seen to be different, the harder they will seem to be to understand, the more likely they are to being grouped together, and the more difficult it will be for them to gain control of the resources they need. In stable times, fewer people are pushed over the edge and defined as "them". But the line can shift quickly in times of basic social change. And conditions can grow worse for people pushed outside the edges as uncertainty and a sense of scarcity increase. Under these conditions, efforts by people on the other side of the line to change things will seem especially threatening to people inside the social perimeter.</p>
Medicalization of basic needs	<p>In the United States, a great deal of what people with developmental disabilities need is paid for as a medical expense. Some of this makes sense (e.g. basic health care and some appliances); much of it makes little or no sense (e.g. personal assistants or homes paid for by Medicaid). Much of the rest is for special education expenditures and for rehabilitation. Our investments in people with disabilities don't flow from a concern for the welfare of all citizens; rather they flow from a concern to provide for the special needs of well defined, deserving groups.</p>

Belief that people with disabilities are of less worth

Our society spends a great deal on medical care. And we have not found ways to limit the application of high technology, high cost procedures. Within limited resources we spend most on heroic treatments in people's last days. But it's easier for policy makers to identify with high tech treatments for "all of us" (who can afford them) than it is to attend to the kinds of basic help people with disabilities need. In this context, some people see competition between the ongoing needs of a relatively few of "them" ("the disabled"), and the acute needs of "all of us". And in this competition, it's easy for policy makers to choose in favor of what they call "the greater good for the greater number."

Belief that meeting the needs of people with disabilities takes away from "us" in favor of "them"

A similar competition can dominate thinking about education and even rehabilitation services. Many people still think in terms of "educability" and "feasibility for rehabilitation" — categories that keep alive the sense of opposition between people who are more worthy of assistance and less worthy.

Getting left out of decisions about scarce resources

We have to discover how to decide things our ancestors never had to face. There is more and more discussion about the ethics of such decisions. But people with disabilities are poorly represented in such discussions and ethics experts are often as isolated from people with disabilities and as prejudiced against "them" as anyone else. People with disabilities need to watch and participate in these discussions about ethics, because conclusions about ethics can justify institutionalized neglect and abuse. The discussions are necessary; the issues won't go away. But we have to be active. Some policy discussions to get involved with include:

- Rationing access to medical care.
- Justifying euthanasia as a medical treatment.
- Focus on "wellness" and "prevention", especially when images of wellness do not explicitly include the possibility of disabled as a valued way to be a whole person.
- Merging the distinction between human and non-human species in a concern for animal rights.
- Distinctions that divide humanity into persons and non-persons.

We have to organize with other (potentially) vulnerable groups, including people with physical disabilities and people who are growing older to understand and confront these basic shifts.

Simplistic thinking and going for quick fixes

It's hard to face the facts about abuse and neglect. It's easier to think about things in black and white terms. A simple idea that "institution = bad and community = good" is misleading. There are hard things to get down to the deep part of. For example...

...we are rightly concerned to offer more and better support to families.

But we have to remember that some families are abusive and neglectful.

...we are rightly concerned to move people to smaller living environments. But we have to remember that some such places become abusive and neglectful.

...there is a growing awareness of — if not an increased incidence of sexual abuse of people with disabilities in all sorts of settings..

...many thoughtful people see current social conditions leading directly to the destruction of people with disabilities. We have to face the hard possibility that the trend toward infanticide and euthanasia may well be rising rapidly and not avoid this harsh reality with efforts to fine tune service systems.

In such situations we need to face the problems that do occur and look carefully at the different variables that create them: Why this family? Why this person? Why this setting? And we need to keep trying to identify ways to detect abuse that don't destroy what's good and finding ways to create healthy environments. We can't assume that the usual solutions — more money, more staff, more rules — are necessarily based on the right understanding of the problem.

Ignoring potential allies

There is another form of oversimplification that makes it hard to manage the issues arising from recognition of the vulnerability of people with disabilities. It's easy to define social values as simply negative and in need of change before any progress can be made. But it's not that simple.

Many people recognize the injustices done people with disabilities and sometimes will join to fight them.

Many people are willing to welcome individual people with disabilities.

Many people believe that, as one participant said, "god put us all here to take care of each other."

Ignoring contradictions in good intentions

But there are contradictions even within positive values. Religious concern can grow out of a sense of "dignity for full human beings/charity for the weak." This can set up a distinction between "providers" and "needers" that undermines community.

Lack of awareness of the history
of people with disabilities

People are vulnerable when they have no history. The dark realities of the history of people with disabilities aren't yet completely written. It's too easy to forget that people with disabilities get locked up, they get kicked around, they get put into ice packs, they get ECT and painful shocks as punishments, they get put in cages. And what is written isn't widely known. Children are beginning to learn something of the history of race and gender oppression, but they don't yet learn about the history of people with disability. Better understanding this history would increase a sense of rights for all, build recognition of the problems inherent in institutionalization as a response to people's needs, show us some models of living well despite discrimination, and make everyone more sober about the long term effects of efforts to reform complex situations.

What Keeps Joanie Safe?

David B. Schwartz

Joanie was living under the protection of one of the most sophisticated systems of safeguards of any person with the label of mental retardation in America.

It now seemed that Joanie Davis was not destined to end her life in an institution after all. Joanie had been taken to the Willowbrook State School for the Mentally Retarded as an infant, and there she had spent all of her young life. Willowbrook: after the expose, a name synonymous with horror and neglect. Where Geraldo Rivera had taken his television cameras and shown all, except for the stench, on the evening news. Where Governor Hugh Carey, living up to a campaign promise, could be seen in a television scene I still remember brushing the flies from the face of a child in a crib. Where no one ever left. Yet here Joanie was with me with her suitcase and ever-present smile, moving into a nice house on an ordinary street in a small upstate New York city. She, who never had control of her own life, who had been moved from ward to ward and finally to a “family care” home was moving in with us.

Joanie got to move because of a large and complex lawsuit against the state. Spurred by the Willowbrook expose and other changes, a shift in social policy was phasing down the institutions and making the creation of group homes possible. We had started a group home, and we were welcoming Joanie into it. We said to her, as I did to all new people in those early days, that this was her home and would be as long as she wanted it to be. The board of directors sent her a plant for her room. They were the first flowers that she had ever received. She was, as far as we were concerned, finally home. Another in a series of battered institutional veterans had been taken into our shelter and attention.

Some people adapt their basic natures to extremely adverse conditions by becoming withdrawn, or aggressive. Some, like Joanie, become especially friendly and likable, cultivating the affection of those in charge. It was easy to try to help her by taking her to one of the physicians in town that we trusted and getting a complete look at her physical condition. For it was clear that Joanie needed serious attention. Tiny; about four feet ten, Joanie walked with a stiff jerky shuffle that made her seem like her leg joints were fused. She had chronic high blood pressure and was on a lot of medication to control it. Most apparent of all, Joanie had a terribly unsightly skin condition that caused her skin to be constantly flaking off in a kind of fish-scale pattern. We got her the best of attention, and it helped a little. People tended to be put off by her skin condition, but Joanie was so lovable and outgoing that she soon overcame most people’s reluctance.

Joanie did so well over the years that she progressed more and more. I heard, long after I had left the agency that I had founded, that she was now living in an apartment with a roommate as she no longer needed the supervision and assistance of the group home. She and her roommate cooked their own meals with periodic help. She went to work every day at the sheltered workshop, and went to activities all over town. She grew to know her neighbors, and became accepted in the neighborhood. It was a long way from Willowbrook.

Almost ten years after I had met Joanie, I was back in town teaching a workshop in group home management at the university. Some of the present-day staff of my old agency took the course. During a break, one of them told me an upsetting story. She had been the person who had the most recent responsibility for supporting Joanie in her apartment, taking her shopping, helping her with her money, and being on call for emergencies. And Joanie had had an emergency. She started to have kidney failure.

After testing, it turned out that all of those years of having untreated high blood pressure at Willowbrook had done ineradicable damage. She was losing kidney function, and would die if she did not get dialysis treatments regularly. There was yet no dialysis unit in town. (This I knew, for people in that city had to drive an hour and a quarter to the nearest medical center for it.) But instead of arranging transportation to this medical center, or arranging for her to be temporarily hospitalized or cared for in that city and then come home, the state office charged with the welfare of former inhabitants of Willowbrook made a significant decision. They ordered Joanie's transfer to the nearest large state institution for the mentally retarded. There, Joanie, once a regular neighbor in a normal neighborhood, was put into a bed on a ward for people with the most severe disabilities. After so many years out, she was back as an institutional resident, and very ill. My promise of a permanent home was an empty one. It was the promise of a person who was no longer there.

Yet when Joanie was "disappeared" from her new home community, when this woman without family or real friends was taken back into the institution the only person who raised her voice in protest was the person who had the closest personal relationship with her.

The young staff member who told me this story was upset. She had thought that it was terribly wrong to put Joanie back in an institution, to give up her apartment forever. She thought it was wrong of the state office that was supposed to look out for her to send her away instead just because she was so ill and needed medical treatment. State institutions were not where you or I would go for medical treatment. This had to be heartbreaking for Joanie, she worried. She tried to get the agency that ran group homes and apartments where she worked to tell the state no. But she had found no support. Instead she had been told by the director of residential services that her advocacy was "threatening to get in the way" of

her work, and, if it continued, that it would be reflected in her next performance appraisal.

Her story prompted me to break my rule about meddling in my old agency's affairs, on Joanie's behalf, with only very limited success and at the necessary cost of good will. But it made me think deeply about the question of what was supposed to keep people safe in our mental retardation service systems, and in our world. For I had heard very many stories like Joanie's. This one was particularly compelling, however, for Joanie was living under the protection of one of the most sophisticated systems of safeguards of any person with the label of mental retardation in America. She lived in a residential service with internal monitoring. The residential agency was monitored by the quality assurance division of the state office of mental retardation with such particularistic rigor that if their reviewers found on a site visit that a resident's bedroom did not have a chair, a signed waiver that he or she did not want a chair had to be maintained on file in the residence office.

Joanie, too, had a case manager with the local office of the state office of mental retardation. Because she was a past inhabitant of Willowbrook this office was required to keep her under specific scrutiny and report her progress to a central office charged with overseeing members of her legal "class". She lived in the state with the most powerful independent oversight agency in the United States, the Quality of Care Commission for the Mentally Retarded. She was served by four separate service organizations. Yet when Joanie was "disappeared" from her new home community, when this woman without family or real friends was taken back into the institution, the only person who raised her voice in protest was the person who had the closest personal relationship with her. Under the most complex monitoring system available, the greatest wrong had been perpetrated upon Joanie Davis. The system for keeping Joanie Davis safe had not kept her safe at all. How could the system have failed?

The multiple effects of our answers to people's vulnerability show most clearly when traced through one person's biography.

How Regulatory Control Expands

David B. Schwartz

There is not more eloquent description of the process by which regulatory control expands in a democracy than that made by Alexis de Tocqueville in 1835 in *Democracy in America*.

It frequently happens that the members of the community promote the influence of the central power without intending to. Democratic eras are periods of experiment, innovation, and adventure. There is always a multitude of men [sic] engaged in difficult or novel undertakings, which they follow by themselves without shackling themselves to their fellows. Such persons will admit, as a general principle, that the public authority ought not to interfere in private concerns; but, by an exception to that rule, each of them craves its assistance in the particular concern on which he is engaged and seeks to draw upon the influence of the government for his own benefit, although he would restrict it on all other occasions. If a large number of men [sic] applies this particular exemption to a great variety of different purposes, the sphere of the central power extends itself imperceptibly in all directions, although everyone wishes it to be circumscribed.

Lessons

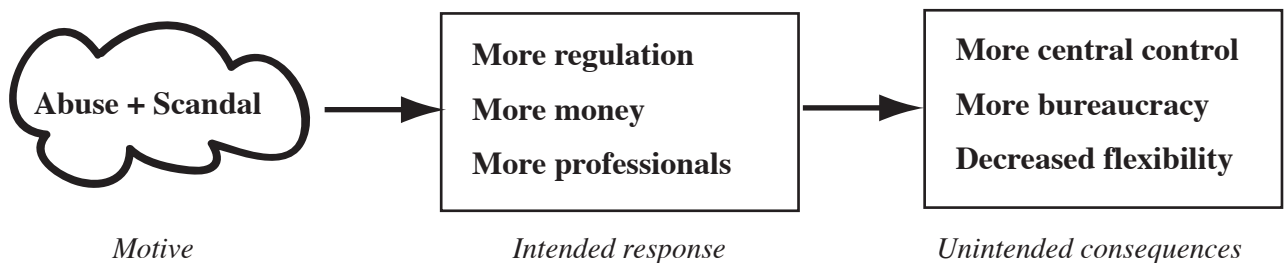
Regulation, and hence government control, over settings in which people with disabilities are found will always expand over time, even if individual government officials at particular times desire to limit it.

Each incident or scandal, or pattern of incidents, is likely to precipitate an expansion of regulatory control as a method of trying to keep whatever bad thing has happened from happening again.

The “passions of individuals,” most potently expressed through voluntary advocacy organizations, will unwittingly prompt the expansion of governmental regulatory control through attempts to protect those whom they represent.

The expansion of control will, by formalizing and increasing paperwork and related practices, increase the weight under which formalized caregivers must operate, at the cost of individual and organizational vitality.

The professionalization of relationships with people with disabilities will increase. The authority of bureaucracies will increase, and the power of citizens will conversely diminish.



There is more than a small touch of irony that today so many people perceive the regulation of the system as the problem. A few short years ago, advocates decried the absence of adequate regulation –a condition the permitted, and still permits, serious abuses of humans to occur under the guise of treatment. the widely publiized nursing home scandals of the early 70's brought about a strong regulatory response. as medicaid became a more important funding source in the mental retardation system, those regulatiory responses were lifted and transferred to this system without adequate consideration of their appropriateness or the system's ability to enforce those expectations. Like Topsy, they "just growed". Soon these regulations became the model for other, non-medicaid programs in the system.

–Clarence Sundram

Contrasting Approaches

Selecting reasonable action to increase people's security implies more than a choice of tactics. Two different approaches require consideration. The following pages contrast their contribution and limitations in making and keeping people safe and identify their different costs and the factors which contribute to increasing their effectiveness.

One approach, which we called **Administrative Regulation and Related Legal Advocacy**, formalizes the relationship between people with disabilities and those who provide assistance to them. This approach codifies expectations in statute, regulation, and policy, or — if these fail — in judicial decree. The system values compliance and rationally planned improvement in standard and practice. Judgments about the adequacy of response belong to professionals, with a variety of due process mechanisms to resolve conflicts.

The second approach, which we call **Lifesharing and Other Personal Commitments**, calls for and relies on personal commitment. People choose to build intentional community or protective relationships with one another. People value the struggle to live creatively in fidelity to the spirit of their commitments. Judgments about quality of shared life depend on mutual trust and listening among those who share a commitment.

Each approach offers something different; but the two mix poorly. Compliance undermines the spirit of commitment. Fidelity depends on trust and breaks down without personal identification and shared values.

Administrative Regulation & Related Legal Advocacy

Contributions

- * Allows rapid change. Some things can be done “with the stroke of a pen”.
- * Permits broad, uniform movements in policy.
- * Can send strong signals about system direction.
- * Can shape the common sense of what is unacceptable.
- * Can shape the common sense of what is possible and desirable.
- * Can clarify what is in people’s best interest.
- * Does not require waiting for public attitudes to change.
- * Offers public debate of difficult questions; can improve understanding by insuring that different points of view are heard and assumptions and conclusions are challenged.
- * Offers leverage to increase vulnerable people’s power to seek fair treatment in specific situations.
- * Can be used as a way to push new issues or start new initiatives.
- * Offers a way to bring people to the table to negotiate with one another.
- * Encourages people that something can be done; that progress is being made.

Limits

- Adversarial relationships, necessary for proper procedure, may harden, pushing apart people who need to work together to achieve results.
- Regulations are infrequently written by those most effected. The people closest to the situation typically have to rely on others who are experts in procedures to speak for them.
- Regulations limit flexibility — and provide an excuse for inflexibility. There is limited allowance for difference in individual situations.
- Regulations can be used on people with disabilities to maintain and extend the power others hold over them. They can be used to justify practices that are against the best interests of a person with a disability.
- Regulations are often very hard for people with disabilities to understand.
- Regulations can say different things about how people with disabilities should be treated depending on how the place they live is paid for. This can be confusing.
- Procedures for insuring fairness can get complicated and take a very long time.
- Because regulations have to take account of the interests of several different groups, they can represent a compromise on what would be best for people with disabilities. They can represent what the regulators think they can get people to do rather than what they think is best. This mixes up signals in the system.
- Regulations can be hard to change, even when people agree they don’t work well.
- Money isn’t necessarily attached to regulations. Providers can be asked to do things without enough money to do them. And providers that don’t live up to regulations can still go on getting money and keeping people.
- There are things that are important for people with disabilities that others can’t be required to do.
- Changes in words in regulations can make some people think that things are really different for people with disabilities. This isn’t always true.

Costs

- ☒ Regulations can drive up money expenditures without necessarily making people with disabilities very much better off.
- ☒ Regulations and plans developed to respond to unjust treatment of one class of people may lead the system to ignore the needs of people not protected by such designations. This fragments the system more.
- ☒ Regulations can build up animosity and separateness.
- ☒ It is hard for system managers and advocates to openly acknowledge the limits of regulation when it defines so much of their work and when it is one of the main tools available to manage a complex system.

What contributes to effectiveness?

- Ensure periodic review that accounts the positive and negative effects on people. Look for negative longer term effects that build up over time. Look for unintended consequences.
- Increase control of regulations by consumers. At least support the active involvement of consumer groups in negotiating regulations. This support may include helping people learn the skills they need to influence the regulatory process.
- Time limit regulations to ensure that they are renegotiated regularly.
- Involve consumers and people close to them in reviewing draft regulations to ask exactly what they should expect from regulations and to identify possible problems. This purchases more thoughtfulness and improved foresight at the cost of making regulatory changes take longer.
- Look for ways to regulate that support individualization and innovation.
- Make tests of parallel systems such as peer review instead of regulatory compliance.

Lifesharing & Other Personal Commitments

Contributions

- * Answers the fundamental human need for committed, freely given relationships and for community of support and effort.
- * Complements each individual's gifts.
- * Raises basic question — “Why are we here?” — for every member and provides the place for people to look for the answer with others who share the search.
- * Not necessarily dependent on human service funds.
- * Offers natural ways for people to meet and support one another without professional/client roles intervening.

Limits

- Can't be done for masses of people.
- Grows slowly in terms of the number of people included.
- Relationships develop over time. There are lots of ups and downs. There are disappointments and sorrows as well as achievements and joys. Lifesharing is not a “fix” for suffering, but a way to acknowledge and share suffering.
- There are limits to what people can do for each other within relationships of equality and friendship.
- Doing away with professional/client distinctions doesn't resolve issues of authority.
- There are very powerful social forces against lifesharing. It contradicts many common beliefs and practices.
- People do break personal commitments.
- There are some people lifesharing doesn't suit.
- Some people may face developmental challenges that they can only work out outside close community.
- Abuse is possible in lifesharing situations.
- Lifesharing arrangements look fragile.
- Lifesharing could become a fad.

Costs

- ☒ The intimacy of living together communally is threatening to many people.
- ☒ Some people need substantial help, come of which costs extra money.
- ☒ People sacrifice some privacy.
- ☒ Commitments limit people's autonomy and options.
- ☒ People face uncertainty and fear about "not fixing" difficult situations.

What contributes to effectiveness?

- More people to live voluntarily in intentional community, including people with positions in managing the service system.
- Maintain the space lifesharing needs to grow by respecting its limits and not expecting it to take over for large numbers of people.
- Avoid the temptation to present lifesharing as a fix.

Competing Social Tools

John McKnight

The associations of community represent unique social tools that are unlike the social tool represented by a managed institution. For example, the structure of institutions is a design established to create control of people. On the other hand, the structure of associations is the result of people acting through consent. It is critical that we distinguish between these two motive forces because there are many goals that can only be fulfilled through consent, and these are often goals that will be impossible to achieve through a production system designed to control.

The community environment is constructed around the recognition of fallibility rather than the idea. Most institutions, on the other hand, are designed with a vision imagining a structure where things can be done right, a kind of orderly perfection achieved and the ablest dominate...

The surest indication of the experience of community is the explicit common knowledge of tragedy, death, and suffering. The managed, ordered, technical vision embodied in professional and institutional systems leaves no space for tragedy. Indeed, they are designed to deny the central dilemmas of life.

In the proliferation of community associations, there is room for many leaders and the development of leadership capacity among many. This democratic opportunity structure assumes that the best idea is the sum of the knowings of the collected fallible people who are citizens. Indeed, it is the marvel of the democratic ideal that people of every fallibility are citizens. Effective associational life incorporates all of those fallibilities and reveals the unique intelligence of community.

Institutions, on the other hand, have great difficulty developing programs or activities that recognize the unique characteristics of each individual. Therefore, associations represent unusual tools for creating “hand-tailored” responses to those who may be in special need or have unique fallibilities. Our institutions are constantly reforming and reorganizing themselves in an effort to create or allow relationships that can be characterized as “care.” Nonetheless, their ministrations consistently commodify themselves and become a service.

Why is it, then, that social policy so often ignores community? One reason is that there are many institutional leaders who simply do not believe in the capacities of communities. They often see communities as collections of parochial, inexperienced, uninformed and biased people. Indeed, there are many leaders of service systems who believe that they are in direct competition with communities for the power to correctly define problems, provide scientific solutions and professional services.

In this competitive understanding, the institutional leaders are correct. Whenever hierarchical systems become more powerful than the community, we see the flow of authority, resources, skills, dollars, legitimacy, and

capacities away from communities to service systems. In fact, institutionalized systems grow at the expense of communities. As institutions gain power, communities lost their potency and the consent of community is replaced by the service of systems; the citizens of community are replaced by the clients and consumers of institutional products.

As one observes this struggle, there appear to be three visions of society that dominate the discourse.

The first is the **therapeutic vision**. This prospect sees the well-being of individuals as growing from an environment composed of professionals and their services. It envisions a world where there is a professional to meet every need, and the fee to secure each professional service is a right. This vision is epigrammatically expressed by those who see the ultimate liberty as the “right to treatment.”

The second prospect is the **advocacy vision**. This approach foresees a world in which labeled people will be in an environment protected by advocates and advocacy groups. It conceives an individual whose world is guarded by legal advocates, support people, self-help groups, job developers and housing locaters. Unlike the therapeutic vision, the advocacy approach conceives a defensive wall of helpers to protect an individual against an alien community. It seeks to ensure a person’s right to be a functioning individual.

The third approach is the **community vision**. It sees the goal as “recommunalization” of exiled and labeled individuals. It understands the community as the basic context for enabling people to contribute their gifts. It sees community associations as contexts to create and locate jobs, provide opportunities for recreation and multiple friendships and to become the political defender of the right of labeled people to be free from exile.

Those who seek to institute the community vision believe that beyond therapy and advocacy is the constellation of community associations — the church, the bowling league, the garden club, the town paper, the American Legion, the hardware store and the township board. They see a society where those who were once labeled, exiled, treated, counseled, advised and protected are, instead, incorporated in community where their contributions, capacities, gifts and fallibilities will allow a network of relationships involving work, recreation, friendship, support and the political power of being a citizen.

The informality of community is expressed through relationships that are not managed. Communities viewed by those who only understand managed experiences and relationships appear to be disordered, messy, and

inefficient. What these people fail to understand is that there is a hidden order to community groups that is determined by the need to incorporate capacity and fallibility.

While institutions and professionals war against human fallibility by trying to replace it, cure it, or disregard it, communities are proliferations of associations that multiply until they incorporate both the capacities and the fallibilities of citizens. It is for this reason that labeled people are not out of place in community because they all have capacities and only their fallibilities are unusual...

Professionals and institutions often threaten the stories of community by urging community people to count up things rather than communicate. Successful community associations resist efforts to impose the foreign language of studies and reports because it is a tongue that ignores their own capacities and insights. Whenever communities come to believe that their common knowledge is illegitimate, they lose their power and professionals and systems rapidly invade their social place.

The surest indication of the experience of community is the explicit common knowledge of tragedy, death, and suffering. The managed, ordered, technical vision embodied in professional and institutional systems leaves no space for tragedy. Indeed, they are designed to deny the central dilemmas of life. Therefore, our managed systems gladly give communities the real dilemmas of the human condition. There is no competition here. Therefore, to be in community is to be an active part of the consolation of associations and self-help groups. To be in community is to be a part of ritual, lamentation, and celebration of our fallibility.

The Loss of Spirit

David B. Schwartz

Believing that constantly increasing levels of regulation will keep the social environment of vulnerable people safe and healthy is like believing that constantly increasing doses of antibiotics will keep a malnourished child healthy. In its potential for misdirecting attention from deeper issues, it can unwittingly do long term harm to the fabric of human relationships through which human life really works.

Anecdotal evidence that our “caring systems” are suffering under the weight of regulatory paperwork is widespread. One has only to talk to any worker to hear stories of how caring is being displaced by compliance activities which were paradoxically originally installed by system advocates to improve care.

The deterioration of spirit signaled by these anecdotes is the main toxic effect of increased regulatory control. Once we wipe out spirit, we have killed off the heart of the entire enterprise. Caring and idealistic people are drawn to moral enterprises and to people in need. They tend to be driven away from bureaucratic machinery.

One of my friends remains at work despite the rising tide of regulation. A couple of years ago, he helped to set a person up in a little apartment. Life for this man flourished. He became known and accepted in the neighborhood, and became a fixture at the corner market. His life, after many years of bloodless warehousing and programming, began to mean something in a social context.

Eventually the inspector the state office of mental retardation came for a routine certification visit. He inspected the man’s apartment and found it substantially in compliance, except for one problem. The back stairway door, the required “second egress” in the code, was too short. People could bang their head running out if there were a fire. This was serious; the apartment would have to be decertified. The man would have to move.

Move/ My friend didn’t know what to think. But he had worked for the state office himself. He knew a few of the tricks. He tried a weak, ironic joke. He pointed out that in fact this person would never bump his head — he was only 5’5”. “Why don’t you just give me a waiver of regulations,” he asked, “a waiver for short people?”

The waiver was denied, but a creative bureaucrat found a solution. The agency’s operating certificate was limited “to only [allow] occupancy by clients who are 5’5” tall or shorter.” The man is still there. How long will my friend stay? My guess is not forever. Because every such event probably erodes his ability to maintain commitment to his work.

Strategies for Increasing People's Safety

Work for social change...

- People with disabilities and their families are on the short end of social power. Remedying this means more than just increasing participation in service planning or service delivery. To get to the root of the problem we have to increase the political power and cultural standing of people with disabilities. Any response that simply focuses inside the service system will be incomplete, no matter how desirable it may otherwise be.
- The key theme is keeping people together. Disabled and able together in all life experiences from preschool on up. In work, in recreation, and in all of community life. Making this happen takes caring coaches for both able and disabled people.
- We need to make it clear that powerlessness equals abuse. That information, plus support from someone who cares, plus access to effective methods of recourse are the minimums necessary to safety for people with little power and control.
- Personal relationships are an essential part of any system to discover and act on abuse and neglect. People need others to confide in, others to see what's happening for them.
- We need to encourage everyone — starting with ourselves — to inventory our own abilities and disabilities so that we know what we all have to give and so we can start working on the ways that each of us are weak in living well with other people.
- We are talking about increasing symbiosis among people. We need to talk more about humankind and less about people with disabilities as a “special” kind of human.
- We need to find more ways to link the interests of people with disabilities to other community members; for example through the development of cooperative housing associations.
- We lack a technology for changing attitudes. And some of us think a formula can't ever be found for the kind of change that's needed. But we can set the stage for attitudes to change. We can be sure that people have role models of people with disabilities whose lives are successful.

Any response that simply focuses within the service system will be incomplete

Support the contribution of families and friends...

- Many people would be sunk without the support and advocacy of their family and friends.
- We have to think carefully and face some hard facts about family life and committed relationships.
 - Lifestyles are changing. Many people have single parents. Many people have both parents working. Living well together takes time and having to advocate continually for necessities takes more time.
 - There can be big differences within families in the extent to which a family member with a disability is valued and accepted as an equally valuable person by other family members.
 - Many families and friends act apathetic —or numb— because even the services that are supposed to help are confusing and very hard to get what a person needs from them. Information is hard to find.
 - Not even getting listened to by people whose job is to help can burn you out on trying to ask for things from community members.
 - Families and friends can be abusive and neglectful, especially when they lack support. We have a lot to learn about improving the ability of family and friends to cope.
 - Some families and friends have very limited ideas about the possibilities for a person with a disability (so do many service workers).
 - There is a great deal of talk about families disintegrating. We have to figure out what all this talk means. We can't afford to just pass around a lot of clichés about how bad everything is without checking them out.
- Vouchers for family support and (early) education services could increase access to integrated settings.
- Many families need opportunities to plan seriously about, “What happens when we no longer can provide what our disabled son or daughter needs?”
- We need to develop better ways to get information to families in ways that make sense.
- Families need to know from their child's earliest years how important it is for disabled and non-disabled children to learn with and from each other.

Work on service system issues...

- Lots of people need at least some help from services. But as people with disabilities represent increasing cash value to service providers and service system operators, the incentives grow to find things wrong with people and to keep people dependent. Under these conditions services necessarily must push people with disabilities away from community association. We need to find counterforces to this threat.
- Some people have nobody to count on except a busy case manager, who has too many people and too much paperwork.
 - These people need a buddy to advocate for them instead of having to wait for a case manager to get around to them.
 - Self-advocacy organizations like Speaking for Ourselves can help if there are ways to meet and organize people who are alone and powerless.
 - Case manager's jobs should be restructured. They should spend enough time to get to know people and check how things really are. Not just short visits, or meetings, or looking at papers, but sharing experiences with people.
 - If this restructuring of case management isn't possible, make it clear to everybody that the case manager is there for the system's paperwork and can't do much to keep people safe or improve things. Otherwise, people will think things are better than they are. And that's dangerous.
- High turnover among direct service staff makes it very hard for staff to know a person well enough to make good judgments about acceptable risks.
- The contradictions between how services are funded and regulated and people's sense of what is right creates a problem. The stronger staff commitment to positive roles and experiences for people, the more likely a conflict with rules and funding patterns. This increases staff frustration that could lead them to quit or withdraw from their work. We need to experiment with alternative ways to monitor and regulate services.
- It's important for writers and enforcers of regulations to see the real effects of their work on what we value in people's lives.
- We need to create windows of opportunity to maintain contact and respectful discussion between people concerned with administration, people concerned with advocacy, and people who are lifesharing. Our discussion shows that each way needs the others; each can contribute to mutual education. All must learn to focus on social and cultural change. It's easy to divide ourselves; we have to work at coming together.

Support the contribution of service workers...

- Service workers (and regulators) need methods for “role release”: ways to give up some control in favor of people with disabilities and their families.
- Service workers can gain in ability to “walk in people’s shoes”; to look at decisions from the point of view of people with disabilities and to appreciate the life experiences that have influenced many people with disabilities.
- Service workers need to practice hearing what people with disabilities have to say.
- Building personal relationships between service workers, family members, and people with disabilities is important.
- It takes a lot of common sense to deal with people in a way that keeps them safe. Education and credentials don’t necessarily mean empathy for people.
- Service workers need opportunities to reflect on their work and their commitment to people with disabilities in small, soul-searching events.
- Service workers need to reflect on the kinds of educational experiences and back-ups that will help people with disabilities make good decisions in risky situations.

Accounting and Reducing the Costs of Regulation

Clarence Sundram

When we regulate not wisely, but too much, we stifle initiative without replacing it with something of higher value. We aim at a common level of undistinguished performance that eliminates both risks of failure and challenges to soar to excellence. We breed an attitude of compliance with regulation rather than reinforcing the sense of mission that draws so many people into this field. And too often, satisfying auditors and regulators becomes the mission rather than caring for the human beings the system was created to serve.

These results are understandable given the multiple and conflicting forces pulling and tugging at the employees who are caught in the middle. They have one set of duties that require them to meet almost every dimension of human need of residents of their facilities — a challenge that can well consume every ounce of their energy, skill, and commitment. They have another set of duties to comply with conditions that allow their programs to exist, to remain certified and funded. The regulatory system deals little or not at all with the first set of responsibilities but regularly scrutinizes the latter. Administrators and managers who worry about the external demands on their programs are forced to make sure they comply with regulatory requirements. When only one set of duties is regularly and systematically reviewed and reacted to both internally and externally, it is easy to create a value system that exalts paperwork over care. And, the truth is that often these paper duties may be more seductive because, in many cases, meeting the needs of people can be both physically and emotionally draining. But, over time, the priority for paperwork can have a by-product of eroding initiative and breeding apathy, with mindless tasks that try to measure the immeasurable or the irrelevant, while tasks which nourish and enrich the spirit go neglected...

1. Regulators need to become more conscious of the enormous power they wield and of its great potential to destroy initiative — the very life blood of the system. They need to be careful about the behaviors they reinforce and don't reinforce in regulated programs, and to think more critically about what they want to achieve beyond compliance. In particular, we need to consider whether there are better ways than endless documentation to ensure quality care. Our own experience in monitoring conditions in psychiatric and developmental centers suggests that direct observations by outsiders of a significant part of residents' waking hours provides a reliable barometer of actual performance of many

important duties, without reinforcing paperwork duties.

2. Program directors, professionals, direct care staff, parents, advocates —all of us— need to think anew what we want and don't want from a regulatory system and examine more carefully the cost of the choices we make. We cannot guard against all risks all the time without turning both our staff and their charges into automatons.
3. All of us need to consciously reaffirm the paramount value that undergirds the service system —providing care and all that word entails — for people who cannot care for themselves. We need to be strong advocates for these values and resist any activity that encroaches upon this fundamental obligation.

We often say, “We must produce programs of excellence.” Does this not display our fundamental error? For if caring can be produced, if it indeed is a product, then the quality of this product can be regulated. If caring is a resource to be purchased, then the process of helping care arise into the world is a process of production, in which economic and material laws are primary. From such beliefs, the eventual development of regulatory control is inevitable, for it proceeds logically from the same conception of the activity. That is why quality assurance programs in human service are so evocative of industrial quality control programs; the former were patterned directly upon the latter. We believed that we were dealing in both cases with “products.”

We must realize that we are confusing two very different approaches to human endeavor. We might think of these approaches as tools. The one, professionalistic and hierarchal, may work well to produce automobiles. The other — informal, relationships based, and oriented to community — is good at caring. Somehow along the way we have gotten the two muddled. We have found ourselves with the wrong tool in our hands. Thinking all problems to be nails, we strenuously hammer away at caring as things get steadily worse.

—David B. Schwartz

From: Regulation – Have we
all gone mad? *Quality of Care*,
September-October, 1987, p. 7.

Options for Action

To Make Children Safer

More powerful families

- We need to keep focus on strengthening and informing families with children with developmental disabilities. A child's parent or parents are the key to safety. Grandparents, aunts and uncles matter, too. So do brothers and sisters.
- When children live away from their families, it is important to make sure that families are welcomed, involved and listened to. If a child lives away from a family and has no family involvement, it's vital that the child have substitute family members.

Reduced isolation

- We need to work on ways to reduce family isolation and children's isolation. Non-disabled schoolmates and university students have made such a big difference for some of our families. We need more ways to increase the chances that each child with a developmental disability will get a chance to meet "the other people" who can give the gifts of acceptance and participation.
- We need to strengthen the sense of expectation that all children will be involved with their age peers in school and in recreation. Non-disabled children need to come to expect the presence of children with disabilities. This begins to overcome isolation and reduce the chances of abuse.
- We need clearer, more detailed ideas about how to get the resources we all rely on to be involved with children with developmental disabilities without smothering them. We need good schooling without all containing special education; we need recreation without isolated special Olympics.

More effective services

- How do we encourage the development and employment of more teachers who have the desire, the ability, and the assignment to facilitate the development of relationships between disabled and non-disabled students?
- We need to increase the range of alternatives available. People with disabilities are more vulnerable when they are uncooperative. They are more uncooperative when they are trapped in a situation that doesn't work for them. Most of the time there is only one situation possible. This increases the chances of a person getting trapped.

To Make Adults Safer

- There need to be clearer avenues of recourse for people in every program, no matter what its type. We need to ensure that someone who is in a dangerous situation has a way to let someone outside the setting know if there is a problem.
- We have to work systematically on the essential issue; changing attitudes and expectations about the place of people with developmental disabilities in their lives, in our communities, and in society. This essential work begins with our own personal relationships with people with developmental disabilities and our own active involvement with our fellow citizens in the life of our own communities.
- This kind of social change moves slowly, from person to person in social networks. This means keeping a long-term perspective on our policies and investments. People with developmental disabilities will be safer as more other citizens become personally involved with them.
- We need to continue learning about what it takes to build and strengthen personal relationships and social involvements for those people with developmental disabilities who would otherwise be isolated.
 - The best way to learn about this is through investments in local people's efforts.
 - We should support a variety of efforts to be sure that communities have people who will be there to ask for and support personal involvements.
 - As this body of experience grows from projects focused on assisting people to become part of community life, we need to invest in communicating their lessons and sharing their tools.
- We need to help systems explore more ways to put power, money, rulemaking, and monitoring in the hands of people with developmental disabilities and those people closest to them.
 - The system we have now generates increasingly detailed rules within a system that institutionalizes major inequalities and disempowers people. We need to experiment with major changes in these systematic ways of keeping people unequal and without the resources to stand up for themselves.
 - Just offering more of what we have now can't work to give people the power they need to be safer. But demand on the system — from people who have little or no help now or from advocates for people who are especially and obviously hurt by the worst of current services means big pressure for more. We need to focus influence and money on efforts to create windows for action to make the system different.

- There is much to learn about alternative ways to help people with developmental disabilities and the people closest to them to see, understand, and respond to the real risks in people’s lives.
- We need to face and explore the possibility that our social systems, including our service systems are collapsing. Many people have not considered this possibility and some people who have think it unlikely. But a number of thoughtful people associated with the council believe this is already happening, though they may not see the same causes or predict the same consequences. We need to find ways to assess this possibility (some would say, certainty) and help people explore the role of citizens in a collapsing situation.

Minimizing the Costs of Regulation

- Understanding and achieving a balance of risk and safety is complex.
 - Risk can come from strangers or outsiders, but it can also come from people you know and rely on such as service staff or family members. It would be easier to deal with this issue if all risk came from “outsiders” or if we could be confident that family and friends or professionals very seldom posed a significant risk.
 - There is a theory that people are safer in community settings, which are more open, than in institutional settings, which are more closed. But what does “openness” mean? Does “openness” mean having lots of government inspectors visiting? How can a place be “open” and still be private? Does “openness” mean that a person has lots of friends visiting? If so, just locating people in small houses doesn’t automatically mean they are in an open environment.
 - Regulation can contribute to people’s safety by ensuring that sufficient authority is available to deal with bad situations. But regulation can make balance hard to achieve. It’s very hard to develop regulations that are both powerful enough to rescue people from abuse and subtle enough to support people striving for balance.
 - The idea of “the dignity of risk” is a valuable corrective to the tendency to overprotect and over regulate. But it doesn’t provide much guidance for knowing when to choose for safety.
- We need to do some hard thinking to place this issue in the context of larger social trends. Over the long term, demand on human service systems will continue to rise rapidly as other large scale social changes make strong demands for new ways to organize and manage. Formal systems will get more fragile and more erratic.
- We need to ask what we can do now to shape an environment that promotes the development of alternatives to widening the existing regulatory stream.

SAFEGUARDS¹

Policy Bulletin, No. 3
Winter 1993

NOTE: The bulletin posted here was developed in 1993. Although it has not been updated, it contains information that continues to be extremely useful to people who are concerned about supports and services for people with disabilities. Please contact the Center on Human Policy if you would like updated information on this topic.

TABLE OF CONTENTS

- [About This Bulletin](#)
- [The Question](#)
- [The Paradox of Regulations](#)
- [Some Facts About Regulations and Quality](#)
- [Contrasting Approaches](#)
- [Options for Action](#)
- [Strategies for Increasing People's Safety](#)
- [Twelve Steps Policymakers Can Take to Reduce Regulatory Excess and Encourage Quality](#)
- [Additional Resources](#)

ABOUT THIS BULLETIN

This is the third in a series of Policy Bulletins presenting information based on and summarizing research findings relevant to federal and state policy on community integration for people with developmental disabilities. These Policy Bulletins are sent, free of charge, to people involved in policy issues at the national and state levels. They are available, for a fee that covers the cost of copying and handling, to others who write for copies.

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THE QUESTION

The question--What can we count on to make and keep people safe?-- frames an important perspective on the continuing work of building communities that offer people with developmental disabilities full and dignified lives. It arises from a realization of the vulnerability to neglect, abuse, and mistreatment risked by people who require substantial, long-term assistance to take and keep their rightful place as citizens. It is shaped by a sober recognition of the shortcomings of unregulated relationships between people with disabilities and their caretakers and the limitations and ironic effects of systematic efforts to keep people safe through professional, bureaucratic methods. Left to their own devices, a frightening number of care providers act inhumanly. But increasing investments in formal means to regulate these relationships don't proportionally increase confidence in people's safety. Indeed formal systems seem to weaken the spirit of commitment necessary for caring relationships to thrive. Discussion is animated by acknowledgment of the desirability and necessity of action to increase people's safety of both strengthening the ties of community and making necessary assistance more relevant and effective.

Efforts to ensure the safety of people who rely on services have an instructive history. Many of today's approaches to improving quality through policy, training, hands-on management, and external monitoring would be familiar to nineteenth century asylum keepers. Then, as now, their insufficiency raises a troubling issue. Can it be that the very design of well-managed settings that meet every need frustrates our attempts to embody our good intentions? Could it be that the community services we have carefully developed share too many characteristics with earlier, now discredited approaches? And if so, must people with developmental disabilities accept the built-in limits of total environments as the best available compromise in a dangerous world? What strategies offer ways to constructively engage these questions?

THE PARADOX OF REGULATIONS

by Steven J. Taylor

There once was a time when there were few rules and regulations governing the field of mental retardation. The institutions were essentially out of sight and out of mind, and their terrible conditions and abuses represented the field's dirty little secret. Then came the 1960s and the 1970s and the seemingly endless exposes of institutional conditions, law suits, and legislation designed to protect people with mental retardation from the abuses they were suffering. Now it seem, almost everything in the field of mental retardation and developmental disabilities is subject to rules and regulations.

The regulatory environment surrounding services for people with disabilities stifles innovation and creativity, places undue emphasis on paperwork at the expense of quality of services, and undermines normalization and community integration. The Medicaid program is one of the primary culprits in contributing to regulatory excess in the field of developmental disabilities. The Intermediate Care Facilities for People with Mental Retardation and Related Conditions (ICF/MR) program, other Medicaid programs (day treatment), and even the Medicaid Homes and Community-Based Services Waiver program are highly regulated and threaten to remove the heart and soul from community services. Medicaid, however, is only an extreme example of overregulation of services. Many states have developed regulations that exceed federal requirements and impose rigid rules on non-Medicaid-funded services, such as family supports. The major class action law suits of the 1970s and 1980s undoubtedly played a major role in transforming service systems from an institutional to a community-based model, but left a legacy of strict monitoring for compliance with impersonal standards based on a presumption of abuse and neglect in institutions and community programs alike.

The impact of regulations in the field of developmental disabilities is so pervasive that it extends beyond the boundaries of the service system itself into the domain of the community. In some instances, state agencies have attempted to impose regulations on nonfunded "life-sharing" arrangements and threatened to professionalize unpaid roommates and friends of people with developmental disabilities.

So, the question to be asking is not "Are services overregulated?" --because this seems like a foregone conclusion--but rather, "What should we do about overregulation given the historical pattern of abuse and neglect?" In the remainder of this article, I argue that regulations are paradoxical by nature and counterproductive to the achievements of their intended goals.

Regulations in the field of developmental disabilities represent the bureaucratization of values. The problem with rules and regulations lies not in evil intentions and narrow vision of those who promulgate them or in the insensitivity and ignorance of those who monitor their compliance, but in the bureaucratic nature of the regulations themselves. No matter how noble or humanistic the values underlying rules and regulations, the process of bureaucratization distorts those values and makes it less likely that they will be fulfilled. As Blatt (1981) wrote, "Surely there can be no doubt that if 'Love thy neighbor' were a federal regulation, it would become meaningless and useless" (p.346).

Regulations reflect the abuses of the past, and sometimes the present, but circumstances the potential of the future. The rules and regulations governing the field today are an outgrowth of institutional abuse and are designed with institutions in mind. For every form of evil and abuse that has been found at institutions, someone has come up with a rule or regulation to address it. Regulations are not without their rationales. When taken out of the institutional context, regulations lose their rationality. Regulations presume the impersonal, hierarchical, and bureaucratic structure of institutions. The further removed from this structure, the more irrational and counterproductive they come. Herein lies the paradox: In order to meet the regulations, as setting or a home must become impersonal, hierarchical, and bureaucratic, and these are some of the features that made institutions dehumanizing and abusive in the first place. As the field tried to move toward more person-centered and less institutional approaches to supporting people with developmental disabilities and their families in the community, regulations threaten to drag it back to the institutional model. It is a bit like subjecting home-cooked meals to the same rules that govern fast-food restaurants. This is the surest way to destroy the home-cooked quality of the meals.

Regulations are best suited to unnatural environments but encourage investment in those environments. The more unnatural the setting--the more it departs from typical home and family life--the more highly regulated it should be, at least at face value. Because institutions represent the most extreme form of unnatural settings, it follows that they should be subject to the most stringent regulatory requirements. Regulations and institutions seem to deserve each other. The closer any setting approximates an institution, the more highly regulated it should be. This leads to yet another paradox of regulations in the field of developmental disabilities: the more highly regulated a setting, the more resources it requires, and the fewer resources that are available to alternative settings.

Regulations foster ritualistic compliance and not fulfillment of their spirit. The more rigid the rules and regulations, the more compliance with them becomes an end in itself. Institutions and ICFs/MR become consumed with demonstrating compliance with the active treatment provisions of federal regulations, and the goals of active treatment take second place. Paperwork becomes synonymous with programming and looking good replaced doing good.

Regulations place control and power in the hands of regulators, and not people with developmental disabilities and their families. People with developmental disabilities and their families are often called "consumers" of services, but they are actually third parties in transactions between funders, with their funds and regulations, and public and private agencies, with their programs and services. Rules and regulations, whether imposed by federal programs, state agencies, or courts, place regulators and monitors as the guardians and protectors of people with developmental disabilities and their families and, in so doing, deprive them of control over their own lives.

Regulations direct attention to concrete and tangible things and trivialize the most important things in life. A final paradox of regulations is that the most important things in life are the most difficult to measure objectively. As a consequence, tangible things, such as the number of square feet per bed, and trivialize the most important aspect of services. Active treatment comes to be equated with paperwork, rather than the quality of programming. This is

why dismal programs with good policies and plan can attain certification and good programs with insufficient paperwork can be cited for deficiencies.

Regulations are often criticized for their narrow focus on the medical and treatment aspects of services to the exclusion of community integration and normalization, or social role valorization. Some states are actually moving to incorporate integration and normalization into their regulatory schemes and to require agencies to implement "outcomes"--oriented data-collection systems. Because regulations emphasize tangible things and trivialize important things, such schemes are doomed to suffer from the same problems characterizing other regulations.

If regulations represent a paradox, what are the lessons for regulatory reform in the field of developmental disabilities? First of all, **we need to be modest in our expectations of regulations.** In view of the historical pattern of abuse and neglect of people with developmental disabilities in institutions and other settings, regulations are a necessary evil to content with evils in the world. Because of their inherent limitation and counterproductive effects, however, we cannot expect impersonal rules and regulations to produce quality services or decent lives for people with developmental disabilities, and, in fact attempts to do so may actually have the opposite effect. Regulations should be kept to a minimum and confined to concrete health, safety, and related issues.

Second, **regulatory reform will depend on reform of the current developmental disability service system.** The current regulatory framework is an outgrowth of a service system dominated by institutions and agency-owned and operated facilities. As long as people with developmental disabilities remain in institutions, community ICFs/MR, group homes, and similar settings, these facilities should be subject to regulations. If, however, the service system and funding mechanisms shift to subsidies and voucher approaches for people with developmental disabilities and their families that place control directly in the hands of those who receive services, the need for regulations will be greatly reduced.

Third, **as an alternative to the current regulatory framework, people with developmental disabilities and their families should be provided with clear-cut rights and due process mechanisms through which to exercise those rights.** Despite its shortcomings, P.L. 94-142 contains vastly superior protections to the highly regulated ICF/MR program. If people with families can act on their own behalf as opposed to depending upon regulators and monitors, then disputes within the service system can focus on important things rather than the superficial aspects of services.

Finally, **informal mechanisms to promote the quality and responsiveness of services--agency self-evaluations, consumer surveys, self-advocacy, citizen advocacy--need to be supported and encouraged.** These are not a substitute for formal mechanisms in all cases, but in the long run stand a better chance of achieving quality of services or life.

Many states are experimenting with more flexible and responsive approaches to support children and adults with developmental disabilities in the community, and even some recent federal court orders have incorporated them. These approaches hold great promise, but it remains to be seen whether they will fall prey to the regulatory excesses dominating the field today.

Reference

Blatt B. (1981). *In and out of mental retardation*. Baltimore: University Park Press.

This is a revised version of an article that appeared in *Mental Retardation*, 30(3), 180-195.

SOME FACTS ABOUT REGULATIONS AND QUALITY

- **Quality cannot be mandated.**
 - **There are no guarantees of quality in any service system.**
 - **Multiple approaches, including informal approaches, offer the best promise in striving for quality.**
 - **Regulations and quality assurance procedures developed for traditional services are inappropriate for individualized, person-centered or family-centered services.**
 - **Regulations limit flexibility and can interfere with the attainment of quality.**
-

CONTRASTING APPROACHES

by John O'Brien and Connie Lyle O'Brien

Selecting reasonable action to increase people's security implies more than a choice of tactics. Two different approaches require consideration.

One approach, which we call "Administrative Regulation and Related Legal Advocacy," formalizes the relationship between people with disabilities and those who provide assistance to them. This approach codifies expectations in statute, regulation, and policy, or--if these fail--in judicial decree. The system values compliance and rationally planned improvement in standard and practice. Judgments about the adequacy of response belong to professionals, with a variety of due process mechanisms to resolve conflicts.

The second approach, which we call "Lifesharing and Other Personal Commitments," calls for and relies on personal commitment. People choose to build intentional community or protective relationships with one another. People value the struggle to live creatively in fidelity to the spirit

of their commitments. Judgments about quality of shared life depend on mutual trust and listening among those who share a commitment.

Each approach offers something different, but the two mix poorly. Compliance undermines the spirit of commitment. Fidelity depends on trust and breaks down without personal identification and shared values. See pages 6 and 7 for depiction of these approaches.

ADMINISTRATIVE REGULATION & RELATED LEGAL ADVOCACY

CONTRIBUTIONS

Allows rapid change. Some things can be done "with the stroke of a pen."

Permits broad, uniform movements in policy.

Can send strong signals about system direction.

Can shape the common sense of what is unacceptable.

Can shape the common sense of what is possible and desirable.

Can clarify what is in people's best interest.

Does not require waiting for public attitudes to change.

Offers public debate of difficult questions; can improve understanding by insuring that different points of view are heard and assumptions and conclusions are challenged.

Offers leverage to increase vulnerable people's power to seek fair treatment in specific situations.

Can be used as a way to push new issues

LIMITS

Adversarial relationships, necessary for proper procedure, may harden, pushing apart people who need to work together to achieve results.

Regulations are infrequently written by those most affected. The people closest to the situation typically have to rely on others who are experts in procedures to speak for them.

Regulations limit flexibility--and provide an excuse for inflexibility. There is a limited allowance for difference in individual situations.

Regulations can be used on people with disabilities to maintain and extend the power others hold over them. They can be used to justify practices that are against the best interests of a person with a disability.

Regulations are often very hard for people with disabilities to understand.

Procedures for insuring fairness can get complicated and take a very long time.

Because regulations have to take account of the interests of several different groups, they can represent a compromise on what would be best for people with disabilities. They can represent what the regulators think they can get people to do rather than what they think is best.

Regulations can be hard to change, even when

or start new initiatives.

people agree they don't work well.

Offers a way to bring people to the table to negotiate with one another.

Money isn't necessarily attached to regulations. Providers can be asked to do things without enough money to do them. And providers that don't live up to regulations can still go on getting money and keeping people.

Encourages people that something can be done; that progress is being made.

There are things that are important for people with disabilities that others can't be required to do.

Changes in words in regulations can make some people think that things are really different for people with disabilities. This isn't always true.

WHAT CONTRIBUTES TO EFFECTIVENESS?

Insure periodic review that accounts the positive and negative effects on people. Look for negative longer term effects that build up over time. Look for unintended consequences.

Increase control or regulations by consumers. At least support the active involvement of consumer groups in negotiating regulations. This support may include people learn the skills they need to influence the regulatory process.

Time limit regulations to insure that they are renegotiated regularly.

Involve consumers and people close to them in reviewing draft regulations to ask exactly what they should expect from regulations and to identify possible problems. This purchases more thoughtfulness and improved foresight at the cost of making regulatory changes take longer.

Look for ways to regulate that support individualization and innovation.

Make tests of parallel systems such as peer review instead of regulatory compliance.

LIFESHARING AND OTHER PERSONAL COMMITMENTS

CONTRIBUTIONS

Answers the fundamental human need for committed, freely given relationships and for community of support and effort.

LIMITS

Can't be done for masses of people.

Grows slowly in terms of the number of people included.

Complements each individual's gifts.

Raises basic questions-- "Why are we here?"--for every member and provides the place for people to look for the answer with others who share the search.

Not necessarily dependent on human service funds.

Offers natural ways for people to meet and support one another without professional/client roles intervening.

Relationships develop over time. There are lots of ups and downs. There are disappointments and sorrows as well as achievements and joys. Lifesharing is not a "fix" for suffering, but a way to acknowledge and share suffering.

There are limits to what people can do for each other within relationships of equality and friendship.

Doing away with professional/client distinctions doesn't resolve issues of authority.

There are very powerful social forces against lifesharing. It contradicts many common beliefs and practices.

People do break personal commitments.

There are some people lifesharing doesn't suit

Abuse is possible in lifesharing situations.

WHAT CONTRIBUTES TO EFFECTIVENESS?

More people to live voluntarily in intentional community, including people with positions in managing the service system.

Maintain the space lifesharing needs to grow by respecting its limits and not expecting it to take over for large numbers of people.

Avoid the temptation to present lifesharing as a fix.

OPTIONS FOR ACTION

by John O'Brien and Connie Lyle O'Brien

To Make Children Safer

More Powerful Families

➤ We need to keep focus on strengthening and informing families with children with developmental disabilities. A child's parent or parents are the key to safety. Grandparents, aunts and uncles matter too. So do brothers and sisters.

➤ When children live away from their families, it is important to make sure that families are welcomed, involved and listened to. If a child lives away from a family and has no family involvement, it's vital that that child have substitute family members.

Reduced Isolation

➤ We need to work on ways to reduce family isolation and children's isolation. Nondisabled school mates and university students have made a big difference for some of our families. We need more ways to increase the chances that each child with a developmental disability will get a chance to meet "the other people" who can give the gifts of acceptance and participation.

➤ We need to strengthen the sense of expectation that all children will be involved with their age peers in school and in recreation. Nondisabled children need to come to expect the presence of children with disabilities. This begins to overcome isolation and reduce the chances of abuse.

➤ We need clearer, more detailed ideas about how to get the resources we all rely on to be involved with children with developmental disabilities without smothering them. We need good schooling without all containing special education; we need recreation without isolated special olympics.

More Effective Services

➤ How do we encourage the development and employment of more teachers who have the desire, the ability, and the assignment to facilitate the development of relationships between disabled and nondisabled students?

➤ We need to increase the range of alternatives available. People with disabilities are more vulnerable when they are uncooperative. They are more uncooperative when they are trapped in a situation that doesn't work for them. Most of the time there is only one situation possible. This increases the chances of a person getting trapped.

To Make Adults Safer

➤ There needs to be clear avenues of recourse for people in every program, no matter what its type. We need to insure that someone who is in a dangerous situation has a way to let someone outside the setting know if there is a problem.

➤ We have to work systematically on the essential issue: changing attitudes and expectations about the place of people with developmental disabilities in their lives, in our communities, and in society. The essential work begins with our own personal relationships with people with developmental disabilities and our own active involvement with our fellow citizens in the life of our own communities.

➤ This kind of social change moves slowly, from person to persons in social networks. This means keeping a long-term perspective on our policies and investments. People with developmental disabilities will be safer as more other citizens become personally involved with them.

➤ We need to continue learning about what it takes to build and strengthen personal relationships and social involvements for those people with developmental disabilities who would otherwise be isolated.

- The best way to learn about this is through investments in local people's efforts.
- We should support a variety of efforts to be sure that communities have people who will be there to ask for and support personal involvements.
- At this body of evidence grows from projects focused on assisting people to become part of community life, we need to invest in communicating their lessons and sharing their tools.

➤ We need to help systems explore more ways to put power, money, rule making, and monitoring in the hands of people with developmental disabilities and those people closest to them.

- The system we have now generates increasingly detailed rules within a system that institutionalizes major inequalities and disempowers people. We need to experiment with major changes in these systematic ways of keeping people unequal and without the resources to stand up for themselves.
- Just offering more of what we have now can't work to give the people the power they need to be safer. But demand on the system-- from people who have little or no help now or from advocates for people who are especially and obviously hurt by the worst of current services--means big pressure for more. We need to focus influence and money on efforts to create windows for action to make the system different.
- There is much to learn about alternative ways to help people with developmental disabilities and the people closest to them to see, understand, and respond to the real risks in people's lives.

➤ We need to face and explore the possibility that our social systems, including our service systems, are collapsing. Many people have not considered this possibility and some people who have think it unlikely. But a number of thoughtful people believe this is already happening, though they may not see the same causes or predict the same consequences. We need to find ways to assess this possibility (some would say, certainty) and help people explore the role of citizens in a collapsing situations.

Minimizing the Costs of Regulation

➤ Understanding and achieving a balance of risk and safety is complex.

- Risk can come from strangers or outsiders, but it can also come from people you know and rely on such as service staff or family members. It would be easier to deal with this issue if all risk came from "outsider" or if we could be confident that family and friends or professionals very seldom pose a significant risk.
- There is a theory that people are safer in community settings, which are more open, than in institutional settings, which are more closed. But what does "openness" mean? Does "openness" mean having lots of government inspectors visiting? How can a place be "open" and still be private? Does "openness" mean that a person has lots of friends visiting? If so, just locating people in small houses doesn't automatically mean they are in an open environment.
- Regulation can contribute to people's safety by insuring that sufficient authority is available to deal with bad situations. But regulation can make balance hard to achieve. It's very hard to develop regulations that are both powerful enough to rescue people from abuse and subtle enough to support people striving for balance.
- The idea of "the dignity of risk" is a valuable corrective to the tendency to overprotect and overregulate. But it doesn't provide much guidance for knowing when to choose for safety.

➤ We need to do some thinking to place this issue in the context of larger social trends. Over the long term, demand on human service systems will make strong demands for new ways to organize and manage. Formal systems will get more fragile and more erratic.

➤ We need to ask what we can do to shape an environment that promotes the development of alternatives to widening the existing regulatory system.

STRATEGIES FOR INCREASING PEOPLE'S SAFETY

Work for social change...

➤ People with disabilities and their families are on the short end of social power. Remedying this means more than just increasing participation in service planning or service delivery. To get to the root of the problem we have to increase the political power and cultural standing of people

with disabilities. Any responses that simply focuses inside the service system will be incomplete, no matter how desirable it may otherwise be.

➤ The key theme is keeping people together. Disabled and able together in all life experiences from preschool on up, in work, in recreation, and in all of community life. Making this happen takes caring coaches for both able and disabled people.

➤ We need to make it clear that powerlessness equals abuse. That information, plus support from someone who cares, plus access to effective methods of recourse are the minimums necessary to safety for people with little power and control.

➤ Personal relationships are an essential part of any system to discover and act on abuse and neglect. People need others to confide in, others to see what's happening for them.

➤ We need to encourage everyone--starting with ourselves--to inventory our own abilities and disabilities so that we know what we all have to give and so we can start working on ways that each of us are weak in living well with other people.

➤ We are talking about increasing symbiosis among people. We need to talk more about humankind and less about people with disabilities as a "special" kind of human.

➤ We need to find more ways to link the interests of people with disabilities to other community members; for example, through the development of cooperative housing associations.

➤ We lack a technology for changing attitudes. And some of us think a formula can't ever be found for the kind of change that's needed. But we can set the stage for attitudes to change. We can be sure that people have role models of people with disabilities whose lives are successful.

Support the contribution of families & friends...

➤ Many people would be sunk without the support and advocacy of their family and friends.

➤ We have to think carefully and face some hard facts about family life and committed relationships.

- Lifestyles are changing. Many people have single parents. Many people have both parents working. Living well together takes time and having to advocate continually for necessities take more time.
- There can be big differences within families in the extent to which a family member with a disability is valued and accepted as an equally valuable person by other family members.
- Many families and friends act apathetic--or numb--because even the services that are supposed to help are confusing and very hard to get what a person needs from. Information is hard to find.
- Not even getting listened to by people whose job is to help can burn you out on trying to ask for things from community members.

- Families and friends can be abusive and neglectful, especially when they lack support. We have a lot to learn about improving the ability of family and friends to cope.
- Some families and friends have very limited ideas about the possibilities for a person with a disability (so do many service workers).
- There is a great deal of talk about families disintegrating. We have to figure out what all this talk means. We can't afford to hope for something that can't happen; but we also can't afford to just pass around a lot of clichés about how bad everything is without checking them out.

➤ Vouchers for family support and (early) education services could increase access to integrated settings.

➤ Many families need opportunities to plan seriously about, "What happens when we no longer can provide what our disabled son or daughter needs?"

➤ We need to develop better ways to get information to families in ways that make sense.

➤ Families need to know from their child's earliest years how important it is for disabled and nondisabled children to learn with and from each other.

Support the contributions of service workers...

➤ Service workers (and regulators) need methods for "role release": ways to give up some control in favor of people with disabilities and their families.

➤ Service workers can gain in ability to "walk in people's shoes"; to look at decisions from the point of view of people with disabilities and to appreciate the life experiences that have influenced many people with disabilities.

➤ Service workers need to clarify and change their own possible contributions to disempowering people through everyday practices and routines.

➤ Service workers need to practice hearing what people with disabilities have to say.

➤ Building personal relationships between service workers, family members, and people with disabilities is important.

➤ It takes a lot of common sense to deal with people in a way that keeps them safe. Education and credentials don't necessarily mean empathy for people.

➤ Service workers need opportunities to reflect their work and their commitments to people with disabilities in small, soul-searching events.

➤ Service workers need to reflect on the kinds of educational experiences and back-ups that will help people with disabilities make good decisions in risky situations.

Work on services system issues...

➤ Lots of people need at least some help from services. But as people with disabilities represent increasing cash value to service providers and service system operators, the incentives grow to find things wrong with people and to keep people dependent. Under these conditions services necessarily must push people with disabilities away from community association. We need to find counterforces to this threat.

➤ Some people have nobody to count on except a busy case manager, who has too many people and too much paperwork.

- These people need a buddy to advocate for them instead of having to wait for a case manager to get around to them.
- Self-advocacy organizations can help if there are ways to meet and organize people who are alone and powerless.
- Case managers' jobs should be restructured. They should spend enough time to get to know people and check how things really are, not just short visits, or meetings, or looking at papers, but sharing experiences with people.
- if this restructuring of case management isn't possible, make it clear to everybody that the case manager is there for the system's paperwork and can't do much to keep people safe or improve things. Otherwise, people will think things are better than they are, and that's dangerous.

➤ High turnover among direct service staff makes it very hard for staff to know a person well enough to make good judgments about acceptable risks.

➤ The contradictions between how services are funded and regulated and people's sense of what is right creates a problem. The stronger staff commitment to positive rules and experiences for people, the more likely a conflict with rules and funding patterns. This increases staff frustration which could lead them to quit or withdraw from their work. We need to experiment with alternative ways to monitor and regulate services.

➤ It's important for writers and enforcers of regulations to see the real effects of their work on what we value in people's lives.

➤ We need to create windows of opportunity to maintain contact and respectful discussion between people concerned with administration, people concerned with advocacy, and people who are lifesharing. Our discussion shows that each way needs the other; each can contribute to mutual education. All must learn to focus on social and cultural change. It's easy to divide ourselves; we have to work at coming together.

TWELVE STEPS POLICYMAKERS CAN TAKE TO REDUCE REGULATORY EXCESS AND ENCOURAGE QUALITY

1. Treat different kinds of services differently; regulate agency- operated facilities, but permit flexibility for family-centered and person-centered supports.
2. Encourage phase-out plans for institutions and community-based facilities as an alternative to costly compliance plans.
3. Organize and support consumer, parent, and citizen monitoring communities AND act on their findings.
4. Specify rights and establish procedural safeguards for individuals with disabilities and families to challenge agency decisions.
5. Recognize quality services; highlight innovative agency practices.
6. Fund citizen advocacy programs.
7. Create funding mechanisms to enable adults with disabilities to rent or own their own homes.
8. Promote agency self-evaluations and external evaluations.
9. Provide funding to enable families or adults with disabilities to purchase services directly.
10. Disseminate information on innovative and promising practices.
11. Require agencies supporting people in their own homes to develop quality of life guidelines and plans as an alternative to certification.
12. Establish parent and consumer advisory committees and involve them in all aspects of decision making.

ADDITIONAL RESOURCES

Apolloni, T., Meucci, S., & Triest, G. (1981). *Monitoring the quality of life experienced in living arrangement: A guide to citizen participation*. Sacramento: California State Council on Developmental Disabilities, 1507 21st Street, Suite 320, Sacramento, CA 95816.

This paper provides a rationale as well as concrete suggestions for implementing a citizen monitoring system as a supplement to professional reviews.

Biklen, S. K., & Moseley, C. R. (1988). "Are you retarded?" "No, I'm Catholic.": Qualitative methods in the study of people with severe handicaps. *Journal of the Association for Persons with Severe Handicaps*, 13(3), 155-162.

The article offers valuable guidelines for interviewing individuals with limited use of language.

Bradley, V. J., Ashbaugh, J. W., Harder, W. P., Stoddard, S., Shea, A., Allard, M. A., Mulkern, V., Spence, R. A., & Absalom, D. (1984). *Assessing and enhancing the quality of services: A guide for the human service field*. Cambridge, MA: Human Services Research Institute, 2336 Massachusetts Avenue, Cambridge, MA 02140.

This report provides a valuable analysis of the philosophical and practical issues related to quality assurance followed by a framework for developing cost effective review systems that encourage innovative services.

Bradley, V. J., & Bersani, H. A. (Eds.). (1990). *Quality assurance for individuals with developmental disabilities: It's everybody's business*. Baltimore: Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624.

In presenting the varying perspectives on quality assurance, including those of consumers and family developing a more responsive system.

Mason, C. Y. (1990). *Consumer choice and satisfaction*. Washington, DC: National Association of Rehabilitation Facilities, P.O. Box 17675, Washington, DC 20041.

This is a report of a consumer survey conducted to measure the degrees of choice and satisfaction in the lives of individuals receiving supported employment services. Included are examples of questions and techniques found to be effective.

McKnight, J. L. (1989). *First do no harm: A policy maker's guide to evaluating human services and their alternatives*. Evanston, IL: Center for Urban Affairs, Northwestern University, 2040 Sheridan Road, Evanston, IL 60208

From a unique perspective, this paper shows the need and offers suggestions for evaluating the negative effects inherent in the structure of human service intervention.

O'Brien, J., O'Brien, C. L., & Schwartz, D. (Eds.). (1990). *What can we count on to make and keep people safe? Perspectives on creating effective safeguards for people with developmental disabilities*. Decatur, GA: Responsive Systems Associates. (Available from: Center on Human Policy, Syracuse University, 805 S. Crouse Avenue, Syracuse, NY 13244- 2280)

Members of the Pennsylvania Developmental Disabilities Planning Council discuss the issue of how to strengthen community ties and improve services to increase the safety of individuals who require long term assistance.

Options in Community Living. (1987). *Options policy on quality of life*. Madison, WI: Options in Community Living, 22 North Second Street, Madison, WI 53704.

Options in Community Living, a support service agency for adults living in the community, prepared this policy statement to identify conditions that must exist to ensure a valued lifestyle in the community.

Patterson, J., & Associates. (1992). *Quality of life review & Quality enhancement process*. Tucson, AZ: Quality Associates, 3211 West Westwood Place, Tucson, AZ 85745.

This is a workbook designed to guide team reviews of an individual's quality of life. Also included are strategies for enhancing the planning process.

Schalock, R. L. (Ed.). (1990). *Quality of life: Perspectives and issues*. Washington, DC: American Association on Mental Retardation, 1719 Kalorama Road, NW, Washington, DC 20009.

Quality of life is examined here from a variety of critical perspectives, including conceptualization for the purpose of measurement.

Schwartz, D. B. (1992). *Creating a conceptual revolution in community and disability*. Boston: Brookline Books, P.O. Box 1046, Cambridge, MA 02238.

David Schwartz, Director of the Pennsylvania Developmental Disabilities Planning Council, reflects on the Pennsylvania experience. He discusses the dilemmas surrounding funding decisions and quality assurance issues that result.

Taylor, S. J. (1992). The paradox of regulations: A commentary. *Mental Retardation*, 30(3), 185-190.

This article reframes the relationships between regulations and quality of life. Though they sometimes act as a safeguard against institutional abuse, regulations are shown to undermine the potential for quality of life.

Wieck, C., Nelson, J., Reedstrom, C., Starr, J., & Stone, N. (1989). *Quality assurance resources: Instruments, organizations, and publications*. Arlington, TX: The Arc- US, P.O. Box 6109, Arlington, TX 76005.

This book describes and provides ordering information for quality assurance instruments, organizations, and publications for monitoring services.

FAMILY ISSUES

Family members of people with disabilities are as varied as are other Americans, and cannot be categorized as having one view about topics such as whether their son or daughter should live in an institution. Much depends on their own life experiences. Depending on where they live, or where their son, daughter, brother or sister lives, they will have had very different experiences. No organization can claim to speak for "all" parents. However, family members' membership in the major national parent/family organizations (as well as professional and consumer organizations) that have taken positions in favor of community development and institution closure is much, much higher than membership in any family organization that advocates for maintaining institutions. Most family members, by far, want their sons and daughters to live in the community, with adequate supports. Even without adequate supports, most parents would rather wait for community services (by having their sons or daughters placed on waiting lists) than to have their child placed in an institution. There are significant waiting lists for community supports and essentially none for institutionalization. There is not new demand for institutional care.

That said, family members have many, many questions and concerns that must be addressed with respect and deep listening. This toolkit attempts to answer some of the many concerns families may have. This section looks more narrowly at concerns and feelings which families have about deinstitutionalization.

Common Concerns

Some common comments, and responses that can be given, follow:

<i>Show me where my son or daughter will live when they leave the institution.</i>	As programs are usually developed one at a time, frequently there is no place to show until the time a person is about to leave the institution. This is a strength, not a weakness, a sign of individualization instead of routinization.
<i>My son or daughter needs a level of care not possible in the community.</i>	Level of care is not a place. The ICF/MR model was made up out of whole cloth, the best guess in the early 1970s about how to care for people. The intensity, duration and frequency of supports a person needs can be delivered anywhere. It is not about real estate, it is about providing each person what he or she chooses based on his or her preference and desires.
<i>My son or daughter was in the community for a while and he failed and was brought back to the institution.</i>	Systems sometimes fail people, but the person has not failed. There is no excuse for a poor quality community program. But it is possible to have a rich and full life in the community, and it is not possible to do so in an institution.

Attached are three resources for advocates facing questions and concerns about family matters:

- The most recent research synthesis (and a summary of that synthesis) of parent attitudes about residential placement before and after deinstitutionalization. This synthesis shows that parents who initially opposed community placement for their son or daughter were, for the most part, much more positive about it after their family member had moved, and it offers their suggestions for ways of making the transition more acceptable and comfortable for parents. Even though this synthesis was published in 1991, there has been little research on this topic since then.
- A paper, written by Sue Swenson of The Arc of the US, that addresses family concerns in a "question and answer" format.

RESOURCES:

Anderson, L., & Larson, S. A. (1995/96, Winter). Parental attitudes toward deinstitutionalization. In M. F. Hayden, K. C. Lakin, & S. Taylor (Eds.), *IMPACT: Feature Issue on Institution Closures*, 9(1). Minneapolis: Institute on Community Integration, University of Minnesota.

Larson, S. A., & Lakin, K. C. (1991). Parent attitudes about residential placement before and after deinstitutionalization: A research synthesis. *JASH*, 16(1), 25-38.

Swenson, S. (2004). *My son or daughter is not the same as yours: How to answer that question*. Silver Spring, MD: The Arc of The United States.

INCLUDED WITH THIS SECTION AS BACKUP DOCUMENTS:

Anderson, L., & Larson, S. A., (1995/96, Winter). Parental attitudes toward deinstitutionalization. In M. F. Hayden, K. C. Lakin, & S. Taylor (Eds.), *IMPACT: Feature Issue on Institution Closures*, 9(1). Minneapolis: Institute on Community Integration, University of Minnesota.

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Parent Attitudes About Residential Placement Before and After Deinstitutionalization: A Research Synthesis¹

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This paper reviews 27 studies of parental attitudes on the deinstitutionalization of a family member. In 12 of the studies, the family member was institutionalized. Those studies showed overwhelming satisfaction with the institutional placement and general opposition to deinstitutionalization. In seven studies, the family member had already moved from an institution to the community. Those parents retrospectively reported lower levels of satisfaction with the earlier institutional placement, lower levels of opposition to deinstitutionalization, and high levels of satisfaction with community settings. The three studies in which parental attitudes were sampled both before and after deinstitutionalization mirrored the other studies, showing high levels of general satisfaction with institutional placements before deinstitutionalization and high levels of satisfaction with community placements after deinstitutionalization. Also summarized are parental concerns about deinstitutionalization, their continuing concerns about their children's community placement, their perceptions of the positive outcomes of community living, and ways to facilitate parental satisfaction with deinstitutionalization.

Descriptors: community integration, community services, deinstitutionalization, developmental disabilities, families, group home, institutionalization, mental retardation, parents, residential

Deinstitutionalization as a public policy led to a reduction of over 60,000 residents of state mental retardation institutions between 1977 and 1988 (White, Lakin, & Bruininks, 1989). About 15% of these indi-

viduals returned to live with a parent or relative and about 12% were transferred to another state facility (Scheerenberger, 1988), whereas more than 44,000 individuals and their families faced the changes and uncertainties of moving from large, state-operated facilities to a wide range of alternative, predominantly small, community-based residential settings. The trends in the last 10 years show continued depopulation of state institutions at an average rate of about 4% per year (White, Lakin, Hill, Wright, & Bruininks, 1988). At that rate, tens of thousands of families in coming years will be affected by continuing deinstitutionalization.

Parents have been intensely involved in the deinstitutionalization process, both individually and collectively, in many different ways. Parents, often with the assistance and support of professionals, provided a large part of the early momentum for deinstitutionalization, and had a primary influence on federal and state legislative and administrative initiatives fueling this major social change (Frohboese & Sales, 1980). However, parents have also played other roles, including passive observer and adamant foe.

Finding and maintaining a safe, caring, respectful, and permanent place to live for family members who have mental retardation and who are living away from home is one of the major concerns and challenges that parents face. Not surprisingly, then, parental responses to the prospect of deinstitutionalization vary considerably, depending on the extent to which parents perceive these qualities in long-term housing for their family members in institutional versus alternative community-based settings. Many parents publicly and privately resist deinstitutionalization on the basis of negative perceptions, causing considerable polarization of sentiment among groups of parents and other concerned people (Frohboese & Sales, 1980; Landesman-Dwyer et al., 1980; Payne, 1976). On one side of the broad issue of deinstitutionalization are the largest national professional and parent organizations, such as the Association for Retarded Citizens, the Association for Persons with Severe Handicaps, and the United Cerebral Palsy As-

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sociations, which support continued deinstitutionalization of all people with mental retardation and related conditions. On the other side, are much smaller, but often extremely active, groups of parents and professionals committed to keeping institutions open, including the Congress of Advocates for the Retarded and the Voice of the Retarded.

Whatever an individual's or group's position with respect to the general issue of depopulating large public institutions, it is clear that many families whose members face movement from institutions to community-based settings can experience strong feelings of uncertainty, fear, betrayal, and/or guilt (Conroy, 1985; Mitchell, 1988). Attention to parental attitudes and perspectives should be an important feature in planning and providing services and supports for deinstitutionalization programs.

During the last 10 years, two comprehensive reviews have been published on parental responses to deinstitutionalization. The first, by Frohboese and Sales (1980), reviewed the historical context of parental opposition to deinstitutionalization. This study examined archival, public testimony, and interview data to delineate in great detail concerns expressed by Nebraska parents regarding the impeding deinstitutionalization of their sons or daughters. In addition, the authors analyzed possible reasons for those concerns, and potential strategies to address them. The second, by Conroy (1985), reviewed theoretical and applied research published between 1957 and 1983 on parent responses to deinstitutionalization, and possible psychological reasons for those responses. Conroy identified four major gaps in the literature on parental responses to deinstitutionalization, including (a) the lack of a representative national sample of families of persons who are institutionalized, (b) limited understanding of the reasons for parental opposition, (c) the lack of pre-test/post-test studies of changes in parental attitudes, and (d) potential unexamined differences between parents of adults versus parents of children who are to be deinstitutionalized.

This review extends these earlier summaries of research on parental attitudes by summarizing all identifiable studies on the attitudes and perspectives of parents of currently or formerly institutionalized family members regarding movement from institutional to community placements. Particular attention is paid to changes in attitudes associated with the experience of deinstitutionalization and to addressing the gaps noted by Conroy (1985). It also examines the specific concerns underlying parental opposition to deinstitutionalization, examines parental evaluations of the positive outcomes of deinstitutionalization and continuing concerns about community settings, and identifies strategies to address parental concerns and to facilitate parental satisfaction with deinstitutionalization.

Method

Three general types of research were examined for this review. One type surveyed parents of persons who were currently living in public institutions. In those studies, parents were simply asked about their satisfaction with the current institutional living arrangement, and in most instances how they would feel about having their son or daughter moved to a community-based residential setting. A second type of study surveyed parents whose formerly institutionalized sons or daughters were currently living in community settings. Those parents were asked about their satisfaction with the current community-based residence, how satisfied they had been with the institution when their son or daughter was living in it, and how they had felt about their child moving into the community. A third type surveyed parents twice: first, while their son or daughter was still institutionalized, and later after he/she had moved to a home in the community. Those parents were questioned about their satisfaction with each type of placement while their children were actually there and about their opinion on the deinstitutionalization of their child.

The three types of research described above were identified by five basic means. First, a computer search was conducted of the *Psychological Abstracts* and *ERIC* databases from 1974 to 1988 using appropriate descriptors. Second, requests for studies on these topics were made of all State Planning Councils on Developmental Disabilities which, at the time, were preparing their Congressionally mandated studies of "consumer satisfaction" (as required in the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987). Third, additional studies were located in the reference lists of previously identified studies. Fourth, a manual review was conducted of articles published between 1978 and 1989 in 27 journals, including the *American Journal of Mental Retardation*, *Education and Training of the Mentally Retarded*, *Journal of the Association for Persons with Severe Handicaps*, and *Mental Retardation*. Finally, persons known to be involved in or knowledgeable about investigations of this type were contacted to obtain unpublished or informally published research, including dissertations, theses, and unpublished manuscripts. More than 35 studies were identified and reviewed for this report. Of the 23 studies reporting quantitative information, four were published in professional journals, one was indexed in *Dissertations Abstract International* and was obtained from University Microfilms, and 18 were unpublished or had limited publication by a state mental retardation/developmental disabilities unit or other governmental organization.

Twenty-three of the studies were summarized by creating a simple scale that grouped parental attitudes into three categories: positive, neutral, or negative. For each study, the percentage of all parents reporting pos-

itive, neutral, or negative satisfaction was recorded. If a particular study included nonresponse or missing data, percentages were recalculated using only positive, neutral, or negative answers. Simple mean percentages were computed and weighted by the total number of parents surveyed in each study.

Several rules were developed for summarizing the findings. First, when a question about deinstitutionalization was asked directly (e.g., "How do you feel about deinstitutionalizing your son or daughter?") the response was coded directly. However, when parents were asked about deinstitutionalization indirectly (e.g., "Where would your son/daughter best be served?"), a negative opinion about deinstitutionalization was inferred if parents considered their family member better served in an institution. Conversely, if the parents responded that a community setting would be the best, their attitude about deinstitutionalization was coded as positive. In the few instances in which parents were asked their opinion about the best residential option for their son/daughter both now and in the future, responses reflecting attitudes at the present time (i.e., "now") were coded. Second, when parental attitudes after movement to a community setting were measured on more than one occasion, the responses with the longest interval after deinstitutionalization were recorded. Third, when it was possible to separate the attitudes of parents whose son or daughter had moved to a nursing home or large private institution from those whose son or daughter had moved to a community-based facility, only the parents whose sons or daughters moved to community-based facilities were included. Finally, the vast majority of persons whose responses were studied were parents. However, small numbers of other relatives (e.g., siblings, grandparents) were sometimes included and could not be separated in the data summaries.

Review of the identified studies also revealed many observations by parents regarding factors affecting their attitudes, both before and after deinstitutionalization. There were three basic types of observations: direct open-ended comments of parents, open-ended comments that were categorized and/or summarized by researchers, and parent opinions solicited through closed-ended questions. Qualitative observations from all 27 studies are listed without quantitative ordering. No effort was made to quantify the number or proportion of parents expressing each view, or to suggest that these are universally or even widely held views. Rather, all views expressed by two or more parents were included in the summaries to reflect, in a broad qualitative way, parental experiences and perceptions. The number of parents holding these views, therefore, may vary considerably from item to item.

The process for identifying and categorizing parental comments involved several steps. First, each study was

reviewed and parental observations were listed. Lengthy and complex comments were edited into one or more one-sentence comments. Each successive comment was compared with those already listed. Comments that were identical or essentially the same were not added to the list but existing comments were sometimes modified to include the subtle expansion of an idea. For example, Feinstein, Lemanowicz, Spreat, & Conroy (1986) quoted one parent as saying "I am happy for him. He is doing great at Fernwood. He is more alert and happy." They quoted another parent as saying "I think it was the best move ever made for our son. He is happier and more content." In this case, one of the resulting combined statements was "The person became happier, more communicative, more aware, more content, and more relaxed." After the complete list of comments had been generated, each study was reviewed again to confirm that all comments were included.

The second step involved classification. Broad categories were defined by separating comments made before the move from those made afterward. The latter were further divided into positive and negative comments. Comments made by parents and researchers about how the deinstitutionalization process could or should be improved were also isolated. Next, individual parent statements were categorized based on the headings developed by Frohboese and Sales (1980), summary statements made by other researchers or parents, and subcategories developed by the authors. One author then classified all the comments by heading and the other author reviewed the classification decisions. Joint decisions were made about comments that were in question. Each study was then reviewed a third time to ensure that all specific comments had been included and that those made by only one parent in one study were specifically identified.

The final step in creating the qualitative tables involved making minor editorial changes to express all comments in each table in a consistent format, such as making noun usage uniform (e.g., son/daughter, him/her, he/she became "the person"), and generalizing references to specific sites, such as to "the institution" or "the setting", etc., depending on the context. Once all of these editorial changes were completed, the studies were reviewed a final time to check whether the core content of all comments were included on the tables. Comments made by only one parent were eliminated.

In addition to this qualitative listing, 10 studies provided quantifiable parental observations on specific positive or negative aspects of the move. A summary table was constructed of the quantifiable observations reported in two or more independent studies. A mean of the study means was computed for studies reporting the percentage of parents who noted positive, neutral, or negative responses to each item. Another mean of

the study was computed for studies that reported mean scores for all parents on a 5-point Likert-type scale.

Findings

Table 1 summarizes the responses of parents of currently institutionalized individuals. These studies asked parents about their satisfaction with the public institution in which their son or daughter resided, and about their feelings regarding moving their son or daughter from the institution to a community setting. Table 1 shows high levels of satisfaction with institutional settings/services, with a weighted average of 91.1% of the parents indicating that they were satisfied (from somewhat to very satisfied) with the institutional setting, whereas a mean of 4.9% of the parents were dissatisfied. When asked their opinion about deinstitutionalization of their son or daughter, 74.2% of these parents had negative reactions (from somewhat to very opposed). Only 20.6% of the parents were positive about such a move.

Table 2 summarizes the findings of studies in which parents were surveyed after their son or daughter moved to the community. These studies asked parents about their satisfaction with the community living setting/services where their son or daughter currently resided and retrospectively about their initial opinion of the move. The length of time between deinstitutionalization and the measurement of parental satisfaction with the community setting ranged from 2 months to 2 years (three studies) to 5 to 7 years (three studies). An average of 88.0% of parents were satisfied (from somewhat to

very satisfied) with the community setting/services. Interestingly, the only study that found a satisfaction rate lower than 84% (68% satisfied) was the earliest of the post-release studies in which the "community placements" averaged 22 residents, a typical pattern of the mid-to-late 1970s. When the parents in these studies were questioned retrospectively about their satisfaction with the institution in which their son or daughter had once lived, an average of 52.3% of the parents said they had been satisfied with the institution, whereas 31.5% said they had not been satisfied during the time their family member was living there. When these parents were asked retrospectively about their initial opinion regarding the proposed move, an average of 56.5% of the parents reported initial positive opinions, whereas only 26.6% reported initial negative feelings.

Table 3 shows the results of studies that surveyed parents both before and after the move. In each of these studies, most of the parents were surveyed both before and after the move, but none of these studies reported pre- and post-move responses for exactly the same group. These studies measured parent satisfaction with the community a median of 1 year after the move, with a range of 6 months to 4 years. Each of these studies found high levels of parent satisfaction with both institutional (83.3%) and community (86.9%) settings. Two of the three studies reported higher proportions of parents satisfied with the community living arrangements than with the institutional setting. Among the three pre/post-move studies, an average of 15.1% of the parents reported positive opinions about a proposed

Table 1
Parent Attitudes About Residential Placement: Parents Surveyed During Institutional Placement

Authors (Date)	State	No.	Residence ^a		Satisfied w/Institution			Opinion re: Move		
			Institution	Community	Positive	Neutral	Negative	Positive	Neutral	Negative
Brockmeier (1974)	NE	754	X		94	3	3	9	6	85 ^b
Conroy & Feinstein (1985) ^c	CT	223	X ^d		77	10	14	32	22	46
Conroy & Feinstein (1987a)	GA	308	X ^d		72 ^e		1 ^e			
David et al. (1983)	MN	322	X		88	6	6	22	0	78 ^f
Heller et al. (1986) ^g	IL	184	X		93	—	7	25	—	75
Kjos (1981)	MN	223	X		92	7	1	18	2	80 ^f
Marsh (1984)	NC	464	X		95	0	5	28	0	72 ^f
Meyer (1980)	PA	273	X		79	15	5	14	0	86 ^f
Spartz (1986)	MN	349	X		98	0	2	30	0	70
Spreat et al. (1987)	USA	284	X		93	0	7	23	17	60
Vitello et al. (1985)	NJ	152	X		91	—	—	—	—	67
Weighted mean% ^h			X		91.1	4.2	4.9	20.6	5.1	74.2

^a This column indicates whether the person with mental retardation was living in a public institution or a community-based setting at the time the parents were surveyed.

^b This survey asked if the respondent prefers that the relative remain in the institution.

^c Parents of those in or moving to nursing homes were excluded.

^d These studies asked how satisfied the respondent was with the place his or her relative was living, while all of the other studies asked about satisfaction with the level of care/programming/services.

^e These numbers represent only those who were very satisfied or very dissatisfied and were not included in calculations.

^f These percentages were in response to a question that asked where should your son or daughter live.

^g The people in this study moved from a larger state institution to a smaller regional institution.

^h The Conroy et al. (1987a) and the Vitello et al. (1985) studies were not included in the calculation of the weighted means because the information was incomplete.

Table 2
Parent Attitudes About Residential Placement: Parents Surveyed During Community Placement

Authors (Date)	State	No.	Residence ^a			Satisfied w/Institution			Opinion re: Move			Satisfied w/Community		
			Institution	Community		Positive	Neutral	Negative	Positive	Neutral	Negative	Positive	Neutral	Negative
Bradley et al. (1986) Bureau of Evaluation (1986)	NH	102 ^b		X ^c	38	8	55	79	7	10	84	5	11	
	WI	63		X ^{c,d}						15	93	5	2	
Feinstein et al. (1988) Horner et al. (1988) Landesman-Dwyer et al. (1980)	MN	29		X ^{e,e}							96	0	4	
	MN	110		X	61	16	22	68	10	22	90	6	5	
	OR	31		X ^c	74	20	6	23	58	16	90	10	0	
	WA	50 ^f		X ^c				26	12	62	68	23	10 ^g	
Rudie & Reid (1984) State of Wisconsin (1989)	MN	74		X	53	21	26	55	21	24	91	8	1	
	WI	197		X ^c							89	2	9	
Weighted mean %			X		52.3	14.8	31.5	56.5	16.7	26.6 ^h	88.0	5.8	6.5	

^aThis column indicates whether the person with mental retardation was living in a public institution or a community-based setting at the time the parents were surveyed.

^bSixty-four of the subjects had been institutionalized; the others had not.

^cThese studies asked how satisfied the respondent was with the place his or her relative was living, while all of the other studies asked about satisfaction with the level of care/programming/services.

^dThis was the response after 2 months in the community and was used in the calculation of mean satisfaction with the community.

^eThis was the response after 12 months in the community and was not used in the calculation of mean satisfaction with the community.

^fThe community facilities in this study ranged in size from 1 to 88 residents with an average of 22.

^gOnly the 31 families who had actually visited the community homes were asked this question.

^hThe Bradley et al. (1986) "Opinion re: move" response was not included in the calculations of the weighted mean.

move to the community when asked prior to the move. However, when asked *after* the move about their initial opinion, 61.8% of the parents reported they had had positive opinions (similar to the 56.5% reporting retrospective positive opinions regarding the move in the post-move-only studies).

Qualitative comments of parents on their concerns, observations, and suggestions about deinstitutionalization, and specifically about parental involvement, were included in the 23 studies reviewed, and in four additional studies that examined parent attitudes and experiences with deinstitutionalization but that did not contain measures of satisfaction that could be expressed quantitatively. Tables 4 through 7 categorize these comments and provide examples of the observations and experiences of parents that underlie the parent attitudes reported in Tables 1, 2, and 3. The suggestions made by parents and/or researchers regarding efforts that were, or might have been, made to make the deinstitutionalization process less stressful and more positive for parents were also summarized.

Table 4 records 51 reasons expressed by two or more parents for their opposition or concern about deinstitutionalization. In general, the parents were concerned because of (a) their perception of the superiority of the institutional environment, (b) the potential or existing problems in community settings, (c) the perceived problems with the deinstitutionalization process, and (d) the potential negative implications for the family of deinstitutionalization. Table 5 notes 40 concerns, often continuing concerns, that parents had about community settings after their son or daughter moved to a community-based residence. Major categories of concern included (a) negative changes in the person who moved, (b) unsatisfactory conditions in some community settings, (c) inadequacies in the programs or services available in some communities, (d) staffing problems, such as high turnover in the community settings, (e) perceived problems with the administration of the community services, and (f) negative impacts of the deinstitutionalization process on some families. Table 6 records 45 positive outcomes noted by parents after a move from institutional to community settings. Categories of positive outcomes included (a) positive changes in the person, such as increased happiness, (b) positive environmental features, such as a more home-like setting, (c) improved services, including higher quality of services, (d) positive staff characteristics, such as being respectful and encouraging, and (e) positive family impacts, such as increased enjoyment in visiting. Finally, Table 7 records 41 recommendations made primarily by the researchers who conducted these studies, but also by some parents, concerning ways to facilitate parental satisfaction with the process and outcomes of deinstitutionalization, ways to make deinstitutionalization less stressful for individual families, and

Table 3
Parent Attitudes About Residential Placement: Parents Sampled During Institutional and Community Placement

Authors (Date)	State	No.	Residence ^a		Satisfied w/Institution			Opinion re: Move			Satisfied w/Community		
			Institution	Community	Positive	Neutral	Negative	Positive	Neutral	Negative	Positive	Neutral	Negative
Conroy & Bradley (1985)	PA	472	X		83	11	7	14	14	72			
Conroy et al. (1987)	PA	369		X							88	6	6
Eastwood (1985)	MA	32 ^b 38	X		92	3	5	32 88	18 6	50 6	84	6	9
Feinstein et al. (1986)	LA	11 53	X ^c	X ^c	70	30	0	43	28	29	81	19	0
Weighted mean % ^d			X		83.3	10.9	6.7	15.1	14.3	70.6			
Weighted mean % ^e				X				61.8	18.8	19.4	86.9	7.5	5.6

^a This column indicates whether the person with mental retardation was living in a public institution or a community-based setting at the time the parents were surveyed.

^b This study used an institutional contrast group that was not the same as the community group.

^c These studies asked how satisfied the respondent was the place where his or her relative was living, while all of the other studies asked about satisfaction with the level of care/programming/services.

^d These means reflect opinions of parents surveyed during institutionalization.

^e These means reflect opinions of parents surveyed during community placement.

ways that the service delivery system could be more responsive to family needs. Four of the five categories of suggestions related to ways of encouraging and involving parents in the deinstitutionalization process. The fifth category included changes in the service delivery system that would address parental concerns.

In addition to noting the broad range of comments summarized in Tables 4 through 7, several studies asked parents specific questions. A review of those reports revealed six items that appeared in at least two independent studies. These items noted parental responses to questions regarding changes resulting from deinstitutionalization. Some studies reported the mean response of parents on a scale of 1 to 5 (1 = very satisfied, or substantial positive change in their family member; 5 = very negative, or substantial negative changes). Other studies reported the percent of parents reporting positive, neutral (no change), or negative change in the area listed. As shown in Table 8, most parents in these studies reported positive changes in their son's or daughter's happiness and relationships with others after the move to the community. Most also reported satisfaction with the availability/adequacy of needed services, and the competence of staff in community settings. Parents reported that no change in their own relationships with their sons or daughters was associated with the move. However, only 43.7% of the parents reported positive feelings about the security of funding for community residences.

Discussion

As previously noted, Conroy (1985) identified four major gaps in the literature on parental responses to deinstitutionalization: (a) the lack of an adequately representative national sample of families of persons

who are institutionalized, (b) limited understanding of the reasons for parental opposition, (c) the lack of pre-test/post-test studies of changes in parental attitudes, and (d) potential unexamined differences between parents of adults versus parents of children who are to be deinstitutionalized. The studies reviewed here respond to at least three of these four gaps.

The first gap was partially addressed in the study by Spreat, Telles, Conroy, Feinstein, & Colombatto (1987), which included a representative national sample of 284 parents of institutionalized persons. More impressively, the state and local studies reviewed here surveyed over 4,000 parents from fourteen different states, including five from the Northeast Census region, four from the Midwest, three from the South, and two from the West. All reported similar findings.

The gap in understanding parents' reasons for opposing deinstitutionalization was addressed to some extent in the summaries of parent perceptions in Table 4. Although the comments noted were not ranked in terms of frequency or the strength of the perceptions, all came from more than one parent and most were mentioned in more than one study. Table 4 represents the diversity of reasons for parental opposition to deinstitutionalization. Further study is needed to determine which reasons are most frequent among parents of people in institutions.

The third gap, an absence of pre-release/post-release investigations, was not adequately addressed by any of these studies. Although three studies attempted to measure parent attitudes at two or more points in time, one used completely different groups, and the other two used overlapping but not identical groups. This area remains a major limitation of the data base on changes in parent attitudes related to deinstitutionalization. On

Table 4
Reasons for Parental Opposition to Deinstitutionalization

I. Some parents believe that institutions are better environments for some people. (4, 7, 10, 11, 14, 16, 19, 21, 22, 24, 25, 27)

- Parents feel that mental retardation experts, special resources and services are more readily accessible in a centralized institution.
- Parents believe that staff in the institution are caring and loving.
- Parents think that institutional residents have more freedom to walk on grounds.
- Parents feel that the family member would be happier and more satisfied with "their own kind" in the institution.
- Parents believe the family member needs an institutional level of care, protection, security, and 24-hr supervision because of their level of mental retardation, medical needs, or behavioral needs.
- Parents view the institution as a permanent home for their family member.
- Parents felt the person would die if he/she had to leave the institution.
- Parents consider the person too vulnerable or otherwise "not qualified" to move to the community.
- Parents believe that the family member will never achieve the level of independence needed for community living.
- Parents feel that the family member has no potential for further educational or psychological development.
- Parents believe that the family member has mental retardation and is not and can never be made normal. Therefore, they should not be treated as such.
- Parents are concerned because the family member previously failed in a community setting.
- Parents felt that normalization, the developmental model, least restrictive environments, and dignity of risk were inappropriate concepts for persons with mental retardation.

II. Some parents prefer the institution because they perceive currently available community-based settings as undesirable or inappropriate. (1, 4, 7, 11, 12, 14, 18, 20, 21, 22, 24, 25, 27)

Environmental safety

- Parents are concerned about coed settings. They fear that sexual activity would be permitted indiscriminately.
- Parents are concerned about the compatibility of people within the house and the appropriateness of groupings.
- Parents fear exploitation or inadequate supervision to protect the safety and health of their family member in community settings.
- Parents are concerned about the safety of the physical structure, cleanliness, physical layout, maintenance, fire safety, and age.

Quality of services

- Parents are concerned that needed experts or services (especially medical and behavioral services) are not as available or are insufficient in community settings (particularly in rural areas).
- Parents fear there is an absence of supportive services in the community, particularly for those with severe medical or behavioral problems.
- Parents fear that smaller may mean less: facilities, equipment, activities, and care.
- Parents are concerned that program quality, and comprehensiveness will be less than in the institution.
- Parents perceive that community residences don't provide proper care.

Effect on the person

- Parents fear that moving would cause physical and mental stress, or that the person could not adjust to community living.
- Parents fear that the relative would be harmed by changes in relationships with staff, and other residents.
- Parents fear the move will have a negative effect on the person's relationship with family members.

Community reactions

- Parents are concerned about negative neighbor and public reactions or rejection by the community.
- Parents sense that society would not tolerate integration of persons with mental retardation.

Administrative structure

- Parents perceive administrative and systemic shortcomings in community systems and policy implementation practices.
- Parents have more faith in state supervision than in local supervision and monitoring of services.

Staffing problems

- Parents believe that the quality, number, comprehensiveness, expertise, and type of staff are not as good in the community.
- Parents feel that community staff provide inadequate supervision.
- Parents believe that community facilities cannot attract and keep a sufficient number of qualified personnel.
- Parents are concerned about turnover in community settings.

Stability/permanence/financing

- Parents are concerned that funding for specialized services and staff will not be available in community settings.
- Parents are concerned about the financial instability of community programs in general.
- Parents are concerned about the stability of specific community providers (i.e., opening and closing facilities) because their future viability and reliability is unknown.
- Parents fear the unknown (i.e., they worry about moving their family member from a stable to an unknown environment).
- Parents worry about the stability of the placement especially over the very long term. Older parents especially want a permanent place for their son/daughter to live.
- Parents worry that the client will be pushed into yet another more independent setting.

III. Some parents are opposed to deinstitutionalization because the process itself is seen as injudicious. (11, 14)

- Parents feel that decisions about who and how many people should move are not made based on individual needs.
- Parents fear that the person will be "dumped" into an inappropriate placement.
- Parents fear the loss of parental control and decision making authority over residency and service decisions.

IV. Some parents are opposed to deinstitutionalization because they feel that it will have an adverse impact on the parents or family members other than the person with mental retardation. (4, 7, 11, 14, 16, 21)

- Parents thought that the original decision to institutionalize was final and permanent but it is now being renounced.
- Parents fear they may have an increased burden of care.
- Parents are concerned about their ability to meet the physical and emotional demands of those who are deinstitutionalized.
- Parents fear the potential financial impact on the family.
- Parents fear an increased burden in terms of their social life, job, recreation/vacation opportunities, or time spent alone or with their spouse.
- Parents fear possible strains on family harmony and functioning.
- Parents feel that deinstitutionalizing some will have negative funding ramifications for the institution.
- Parents feel that emotional stresses including guilt related to institutionalization, anger, confusion, fear of the unknown, and embarrassment resurfaced during the consideration of deinstitutionalization.
- Parents were concerned that the person would move farther away.

Note. The sources for the comments in each major section are indicated by the numbers in parentheses. The numbers refer to entries in the reference list.

Table 5
Continuing Concerns about Community Settings

- I. The person who moved was considered to have changed for the worse.** (8, 12, 15, 20)
- The person gained a significant amount of weight.
 - The person appeared more belligerent, rude, or hostile.
 - The person's appearance, hygiene, or attire was perceived as worse.
- II. The environment of the community setting was not satisfactory.** (8, 18, 20)
- The physical conditions or upkeep of the home was poor.
 - The parents were concerned that we are developing a lot of mini-institutions.
 - The person's clothing disappeared.
 - Other resident's behavior problems negatively affected the family member's life in the community home.
 - The home was crowded/too small.
- III. The programs or services available in the community were considered inappropriate or inadequate.** (1, 3, 8, 11, 12, 15, 20, 26)
- Needed services in areas such as recreation, transportation, dental, communication, day program, job training, education, psychology, health services, medicine, and behavior were not available on the premises, were inadequate, or were inappropriate.
 - There was a need for additional training and better supervision for residents.
 - The parents were concerned about the safety of, and the level of supervision for the person in the residence and in the community.
 - The day program was not integrated into the community.
 - The person moved before the facilities were ready.
 - The person had to move again because of another person's behavior problems.
 - The person doesn't like his/her job.
 - Parents were uncertain about the permanence of community programs.
 - The family member needed more to do, a greater chance to get out, and more integrated experiences.
 - There was perceived to be an absence of meaningful training activities in the day programs.
 - Parents were concerned about services for persons who were aging.
- IV. There were staff-related problems in the community setting.** (1, 3, 4, 8, 11, 15, 20, 26)
- The setting had high staff turnover rates.
 - There was inconsistency related to turnover.
 - The staff members were poorly paid, too young, or inadequately trained.
 - The resident was not getting enough attention.
 - Staff members had to do too much paperwork.
 - No funds were available for increased staff for a person who had behavioral or medical emergencies.
 - Communication between staff and parents was not good.
 - More staff members were needed for community activities.
- V. There were perceived problems with the administration or structure of the community service system.** (1, 4, 5, 8, 11, 12, 15, 18, 20)
- The funding for community programs was considered inadequate.
 - The parents had a lack of faith in the continuation of funding for community services.
 - Parents were concerned about burial funds and handling of individual finances.
 - There was considered to be inadequate monitoring and outside supervision.
 - The parents noticed problems with case management.
 - Parents were apprehensive about future relocation and transfers and prefer the status quo.
 - The person was moved or reinstitutionalized due to behavioral or other problems.
 - Parents worried that the person will be reinstitutionalized if the community setting fails.
 - There was a lack of acceptance of the family member by the community.
- VI. The deinstitutionalization process was seen as having a negative impact on the family.** (1, 4, 5, 8, 12, 15, 20, 26)
- There was inadequate communication between care providers and guardians.
 - Parents were not able to have a say in what happened to their family member.
 - There was a limit on the number of days the person could be away from the residence to be with family.
 - The resident now lived farther away from the family.

Note. The sources for the comments in each major section are indicated by the numbers in parentheses. The numbers refer to entries in the reference list.

a more positive note, the findings of the three studies that did sample groups of parents at more than one point in time had results that were very similar to those of both the pre- and post-release studies.

The final gap perceived by Conroy (1985), understanding the differences that may exist between parents of children and youth and parents of adults, was addressed only indirectly in three studies. Marsh (1984) reported a small, but statistically significant, difference in the mean age of residents whose parents opposed and those whose parents supported community placement ($M = 33.38$ and $M = 29.41$, respectively, $t = 3.61$, $df = 332.7$, $p < .001$). Spartz (1986) also reported that

the age of the son or daughter was related to parental opposition to community placement ($\chi^2 = 6.562$, $df = 2$, $p = .038$, $N = 319$), but again the magnitude of differences was small. Finally, Meyer (1980) reported that younger respondents were more likely to prefer community placement both in the present and in the future. Although differences in attitudes as related to the age (and other characteristics) of the parents of institution residents remains an important issue, practically speaking, the number of children and youth in institutions is decreasing rapidly. Children and youth (0 to 21 years) comprised only 10.6% of all residents of public facilities in 1989, with children aged 0 to 14

Table 6
Positive Outcomes Related to Community Placements

-
- I. The person who moved to the community was considered to have changed for the better.** (1, 4, 8, 9, 11, 12, 13, 15, 18, 20)
- The person became happier, more communicative, more aware, more content, and more relaxed.
 - The person showed increased warmth, affection, and self-esteem.
 - The person showed improved emotional development.
 - The person developed more social relationships with other people.
 - The family member had a positive attitude about returning to the community residence after a home visit.
 - The person became more confident, independent, and responsible.
 - The person's quality of life improved.
 - The family member was clean and well cared for and showed better hygiene and appearance.
 - The family member was acquiring skills through daily activities.
 - The family member was considered to be showing positive behavioral changes and skill development in areas such as daily living, communication, and behavior problems.
 - The family member is living well now whereas at the institution he merely existed.
- II. The qualities of the environment in the community setting were judged to be better than those of the institution.** (1, 4, 8, 11, 12, 15, 20)
- The location was considered better (closer to family members, resources, etc.).
 - The environment was considered more stable and relaxed than the institution.
 - There was an every day appearance of family life.
 - The setting allowed a more normal lifestyle.
 - The setting was warmer, smaller, and more homelike.
 - The setting was seen as more comfortable.
 - The smaller size allowed for increased individual attention.
 - The community setting was considered the best place this family member has ever lived.
 - The home is clean and well cared for.
- III. The services available in the community setting were seen as better than what was available in the institution.** (1, 3, 4, 5, 8, 11, 12, 18)
- The services were considered higher quality in the community.
 - All needed services were currently available, including behavioral, medical, vision, OT/PT, speech, self-care, independent living, etc.
 - More one-to-one personal attention was available.
 - The house was judged to be well managed, efficient, and intelligently run.
 - Enjoyable activities, and recreation opportunities were available.
 - The day program was felt to be enjoyable and doing a good job.
 - There were more opportunities to learn, experience new environments and activities, and make friends in the community.
- IV. The staff were considered as having a positive impact on the person.** (1, 3, 4, 5, 8, 11, 18, 20)
- Staff provided personalized attention and interest.
 - The residence had good quality staff who were sincere, knowledgeable, capable, and skillful.
 - The staff of the community facility showed respect for residents.
 - The staff do a good job.
 - The staff encouraged residents to learn new things, to talk more, and to be more social.
 - The residence was perceived to have good staff/client ratios.
- V. The move was reported to have a positive impact on the parents and family.** (1, 3, 4, 8, 11, 12, 15)
- The move was reported to have improved the relationship between the person, the staff, and the parents.
 - The relative now lived closer to parents and family.
 - The parent enjoyed visits to the community setting.
 - Siblings now felt more comfortable visiting their brother or sister.
 - The lives of the individual and of the family had changed for the better.
 - The parent was more aware of daily life events of the family member.
 - The move allowed an increase in the frequency of visits.
 - Parents were more able to give suggestions about care.
 - Parents want the person to continue living in the home.
 - The move resulted in positive attitudes about the benefits of deinstitutionalization.
 - The parent and the family members now felt better, happier, and were more at peace about the living situation.
 - Parents now have increased expectations for the development potential of their family member.
-

Note. The sources for the comments in each major section are indicated by the numbers in parentheses. The numbers refer to entries in the reference list.

years old constituting 2.7% of all residents and 4.7% of all releases, and youth 15 to 21 years old constituting 11% of all discharges (Scheerenberger, 1990).

Although these studies produced a wealth of information, certain methodological limitations were evident. First, there are questions about the reliability and validity of the survey instruments. The majority of these studies used unpublished instruments with untested

reliability, although the use of satisfaction scales is commonplace. The results may also have been influenced by a response bias. Heal & Fujiura (1984) noted that attitudinal variables, such as parental satisfaction, are susceptible to differences in the way the survey was administered, to the characteristics of the investigator administering the surveys, and to the characteristics and roles of the respondents. The David, Morris, and Suom-

Table 7
Ways to Facilitate Parental Satisfaction with the Deinstitutionalization Process

-
- I. Attend and respond to the perceptions, needs, and concerns of family members. (1, 4, 10, 14, 15, 20, 21, 22, 24, 25, 27)**
- Professionals should recognize that families have information and experiences that create legitimate concerns about community settings.
 - Professionals should acknowledge the extent to which unresolved concerns and philosophical disagreements between parents and professionals can be detrimental to successful community reintegration and habilitation.
 - Professionals and policy makers should create support services for families going through the process to respond to the needs and concerns of parents.
 - Professionals should make referrals to support groups of parents who have gone or who are now going through the process of deinstitutionalization.
 - Professionals should minimize conflict with parents.
 - Professionals and planners should provide a formal forum through which parents can express their feelings and fears.
 - Professionals should provide specific counseling, training, and education to help families develop realistic expectations, fears, and motivations.
 - Service providers and other professionals should establish ongoing means to listen actively, address, and resolve additional parent concerns.
 - Service providers and other professionals should provide accurate written and visual information about alternatives to institutional care, and about the ability of persons with disabilities to learn and grow.
 - Professionals should counsel, train, and inform families about the capacity of community group homes to provide services.
- II. Facilitate participation of the person and his or her family in the decision making process related to deinstitutionalization. (2, 4, 14, 15, 18, 20, 22, 24, 25, 27)**
- Professionals should individually inform the family about impending moves in ways intended to reduce anxiety and build support necessary for a smooth transition.
 - Professionals should encourage increased involvement by the family in the transition process to help them arrive at realistic expectations, fears, and motivation, as well as to provide a sense of control over their child's well being.
 - Professionals should provide formal and structured hearings designed to treat family concerns with dignity.
 - Service providers and other professionals should consider and utilize families as a valuable resource in planning for the successful placement of their relatives into the community.
 - Professionals should consult with parents throughout the decision-making and placement process.
 - Service providers and other professionals should invite parents to team-meetings where possible moves will be discussed and follow-up with families after the meetings.
 - Professionals should provide an opportunity to choose knowledgeable between community and institutional settings if both are available.
 - Professionals should inform parents about the details of community facilities in which their relative may be placed as soon as they are available.
 - Professionals and policy makers should provide for parental control and consent in the placement decision.
 - Professionals should take enough time to make sure the transition process is done right in the minds of the families.
- III. Arrange opportunities for family members to learn about and visit potential community sites. (1, 4, 5, 15, 20, 27)**
- Professionals should arrange for parents who have been through deinstitutionalization to provide input to professionals during preliminary planning and implementation phases.
 - Professionals should arrange that parents who have been through deinstitutionalization can meet with the institution parent association, small groups, or individual parents.
 - Professionals should share the positive feelings of parents who have been through the process in written or audiovisual forms.
 - Professionals should provide parents opportunities to contact parents of previously deinstitutionalized persons, including matching families whose members have similar experiences or needs.
 - Professionals should provide opportunities for parents to visit good community settings.
 - Before the move, service providers and other professionals should arrange informational sessions and schedule open houses at the new residence.
- IV. Establish and maintain effective communication links between community providers and family members. (1, 4, 5, 15, 20, 27)**
- Professionals should provide information about the type of community residence to which a particular person will be moving.
 - Service providers and other professionals should maintain contact with, and involvement of, parents by sharing information regularly about their resident's adjustment to the placement, the habilitation plan, and the availability of community services.
 - Service providers and other professionals should inform parents when there are placement problems.
 - Planners should use placements as close as possible to the family.
 - Service providers and other professionals should involve parents when there is a breakdown that jeopardizes a placement or that necessitates movement to a new setting.
 - Professionals and policy makers should conduct ongoing periodic family surveys to evaluate satisfaction and obtain other feedback.
 - Professionals and policy makers should continually address ongoing problems in community services and communicate to families about those efforts.
- V. Provide federal, state, and local support to ensure that quality community-based options are available and have long-term viability. (1, 5, 6, 8, 14, 15, 21, 22, 24, 25, 27)**
- Policy makers and professionals should develop needed service structures to ensure an adequate level of services in community settings and communicate to families about those efforts.
 - Policy makers and professionals should develop community resources that demonstrate the ability to provide quality programming consistently over time.
-

Table 7—Continued

- Policy makers and professionals should continue to work to increase state and federal commitment to the development of support for additional and more specialized community alternatives.
- Policy makers and professionals should establish permanent systems to monitor and evaluate quality of community services effectively and educate parents about these efforts.
- Policy makers and professionals should promote and publicize efforts that enhance the image of permanence for community settings.
- Policy makers and professionals should include the family in the formal structure of the quality assurance system for each individual.
- Policy makers and professionals should involve families in local and state policy planning related to deinstitutionalization and the development of community service.
- Researchers, policy makers, and professionals should research, demonstrate, and communicate about deinstitutionalization from the perspective of the consumer, the citizen moving to the community.

Note. The sources for the comments in each major section are indicated by the numbers in parentheses. The numbers refer to entries in the reference list.

Table 8
Quantitative Summary of Parental Comments Regarding Changes Resulting from Deinstitutionalization

Parental Opinions After Deinstitutionalization	No. of Studies	No. of Parents	Mean Score ^a	Mean Percent Reporting ^b		
				Positive	Neutral	Negative
Change in son's or daughter's happiness after the move	3	161		74.7	18.6	6.7
Parental feeling that needed services are available/adequate in the community setting	1	27	1.74	74	15	11
Change in relationships between son or daughter and other people after the move	2	166	1.86			
Parental satisfaction with the competence of the community staff	1	25	1.86	68	24	8
Change in relationship between parents and son or daughter after the move	3	198	1.86			
Parental feeling that the funding for community residences is secure	5	713		77.1	(12.9) ^c	(10.5) ^c
	3	198	2.39			
Change in relationship between parents and son or daughter after the move	1	102		25	75	0
Parental feeling that the funding for community residences is secure	3	198	2.48			
	3	499		43.7	(27.5) ^c	(31) ^c
	3	198	2.57			

^a These studies reported results as a mean score on a scale of 1 to 5. All of the means have been converted so that a score of 1 means very satisfied or much change for the better, whereas a score of 5 means very dissatisfied or much change for the worse.

^b These studies reported the simple mean percentage of parents who reported each level of satisfaction.

^c The percentages listed in parentheses were based on a smaller number of studies than the positive rating. This happened when one or more study reported only the percent of parents who reported positive answers.

ala study (1983) addressed the possibility that different investigating agencies may induce differential responding by sending half of the surveys on the letterhead of an institution, and the other half on the letterhead of the Governor's Planning Council on Developmental Disabilities. However, they found no statistically significant differences in the responses of the two groups.

Second, questions can be raised about the representativeness of the findings. The state and regional studies reviewed here had response rates ranging from 50% to 84.4%, with a median of 63%. The lone national study (Spreat et al., 1987) reported a considerably lower response rate of 35.5%. The question of whether the responders varied systematically from nonresponders was addressed by Conroy & Bradley (1985), who noted no significant differences between these groups on a subset of the most critical items. The issue of representativeness also applies to whether the characteristics of persons moving to community settings whose families reported satisfaction were comparable to the characteristics of those who remained in the institutions, whose families' eventual satisfaction after deinstitutionalization we may wish to infer. As deinstitutionalization

has progressed, the people remaining in institutions typically have more severe impairments than those moving to community settings (White, Lakin & Bruininks, 1989). However, in the five studies (c.f. Tables 2 and 3) reporting the level of retardation, a mean of 56% of those who were deinstitutionalized had severe or profound mental retardation.

Finally, the majority of the studies of post-deinstitutionalization attitudes used retrospective data rather than pre/post data. While this practice afforded the opportunity to examine the differences between retrospective and prospective attitudes, it also demonstrated that this approach is not adequate for determining what would have actually been said in a pre/post survey. Clearly, future research that seeks to examine accurately changes in attitudes must measure these attitudes both before and after the intervention.

This review revealed several patterns in the results of parent attitude studies. Across the different types of studies, parents whose offspring were living in institutions at the time of the survey were overwhelmingly satisfied with the institutions (90.0%). Despite the considerable criticism of institutional settings in contem-

porary scholarly writing and court opinions (Haney, 1988; Heal, 1988; Scheerenberger, 1983), parents of institutionalized adults and children still feel that institutions serve their son or daughter well. In most studies (10 of 12), 60% or more of the parents of currently institutionalized people were opposed to moving their offspring from an institution to a community setting. This pattern has remained quite constant across time and is still evident in the studies conducted in the late 1980s.

The studies that asked parents to look retrospectively at their satisfaction with institutions were particularly interesting. There was a substantial discrepancy between parents' reported satisfaction with institutional settings when they were asked prospectively (i.e., before movement from the institution) versus parents' reported satisfaction about institutional settings when asked retrospectively (i.e., after movement to the community). The mean level of satisfaction with the institution for retrospective studies was 52.3%. However, when questions were asked during institutional placement, the mean level of satisfaction across all types of studies was 90.0%. In addition, across all types of studies an average of 19.9% of parents surveyed during their child's institutionalization reported positive opinions about a move to the community, but retrospectively, an average of 57.7% of parents reported initial positive opinions.

These findings raise an important question about why parental responses change so dramatically. It may be that parents who have had the opportunity to see their family member in a small community living arrangement have a different frame of reference and a new perspective on institutional living. Once having seen the nature of the community residences, the institution may not look as good as it once did. This in turn may have affected their recollection of past satisfaction. An alternate possibility was suggested by Conroy (1985). He explored the possibility that changes observed in parental responses after deinstitutionalization can be explained by dissonance theory. Basically, his explanation was that the decision to place a child in an institution, despite the negative consequences of such a decision for the child, could create a state of high post-decisional dissonance. This dissonance is reduced over time as parents come to adopt a position that the institution is what the relative needs. Placement into a community setting provides strong evidence that the institution was less appropriate than the parents once believed. This then results in a change in attitudes about both the institution, and about the appropriateness of the community setting.

The summary of quantitative data on parental attitudes about residential placement shows clearly that prior satisfaction with institutional care and reservations about community care in time turns into satisfac-

tion with community settings for the majority of families. Nine of the 10 studies that surveyed parents about community settings found that over 80% of the parents were satisfied. The summary of family comments about the process of deinstitutionalization, however, clearly shows there are many ways this process can be improved to respond better to the concerns and needs of families. Parents are concerned about deinstitutionalization and community placement for a variety of reasons. Some of the reasons for resistance to deinstitutionalization turn out to be contradicted by the realities of community living. For example, there is strong evidence that moving from an institution to a small community setting is associated with positive outcomes for persons with all levels of mental retardation. Some of these positive outcomes are improved adaptive behavior (Larson & Lakin, 1989) and increased social participation (Conroy & Bradley, 1985; Hill & Bruininks, 1981; Horner, Stoner & Ferguson, 1988; Molony & Taplin, 1988). Furthermore, more parents in the studies summarized in Table 8 reported increased happiness and improved social relationships among persons who moved, and a wide variety of other positive outcomes were noted by parents in the studies summarized in Table 6. Finally, concerns expressed before the move about the availability and adequacy of services, and the competency of staff turned out not to be concerns for most parents after the move. When such evidence is available to counter concerns noted by parents, professionals have an obligation to provide in a respectful manner information to facilitate the reduction of parental anxiety. This will require establishing and maintaining effective communication links between providers and family members. Responding to parental uncertainty about their son or daughter's future lifestyle by arranging opportunities to learn about and visit community sites and talk with parents of persons who previously moved to the community also appear to be helpful.

On the other hand, some of the concerns raised by parents before deinstitutionalization turn out to be continuing concerns after deinstitutionalization. These continuing concerns underline the importance of attending and responding to the perceptions and concerns of family members before, during, and after their child moves from an institution to a community setting. The importance of responding to parental concerns and encouraging their participation in the deinstitutionalization process was also confirmed by Stoneman and Crapps (1990), who found that the amount of parental involvement in the deinstitutionalization process appears to be a strong predictor of future involvement by parents. Acknowledging parental concerns before the move, facilitating parental participation in the deinstitutionalization process, and involving parents in ongoing quality assurance efforts to address concerns such

as those noted in Table 5 requires only the commitment to do so. Responding to parents' concern about the stability of funding for community settings and other systemic matters requires broader attention to federal, state, and local policies as they affect and assure long range support for community services.

However, the clearest message in these studies is that the overwhelming majority of parents become satisfied with community settings once their son or daughter has moved from the institution, despite general predispositions to the contrary. The primary implication that may be drawn is that professionals, policy makers, and advocacy groups still have much to do in implementing programs that will assist parents in developing as early as possible the positive, less stressful attitudes about deinstitutionalization and community living that eventually almost all parents come to feel.

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Parental Attitudes Toward Deinstitutionalization

by Lynda Anderson and Sheryl A. Larson

With the growing number of state institution closures, many parents are concerned about finding and maintaining a safe, caring, respectful, and permanent home in the community for their sons and daughters who have mental retardation. The possibilities and uncertainty of the move away from institutions have stimulated parental responses ranging from ardent support for deinstitutionalization to adamant opposition. Many studies have examined parental attitudes and expectations related to deinstitutionalization. Twenty-one such studies reviewed by Larson and Lakin (1991) reported on observations by parents regarding the move from institutions to the community, and offered suggestions for families and individuals in making the transition. From these studies, the following conclusions emerged about parent attitudes toward their son's and daughter's lives in institutions and in the community:

- **The vast majority of parents were satisfied (secure, content, and comfortable) with their family member's public institution placement.** Eleven of the studies surveyed parents while their family members lived at the institution on their opinion about moving to a community setting. Ninety-one per cent of the parents were somewhat or very satisfied with the institution. Only 21% of the parents supported the idea of having their son or daughter move to a community setting.
- **The vast majority of parents changed their attitudes about community placement after their family member had moved to the community.** Four studies surveyed parents before and after their family member moved to a community setting from the institution. Only 15% of these parents had a positive reaction to their family member moving before the move occurred; after the move, 62% of the parents expressed a positive opinion about the move to the community. Before the move, 83% of the parents reported satisfaction with the institution; after the move 87% were satisfied with the community setting.
- **After experiencing community services, parents viewed the institution less positively than they did when their family member lived there.** Seven studies interviewed parents whose sons or daughters had moved from an institution to a community home about their satisfaction with the institution, the community setting, and their opinion of the move. Only 52% of these parents expressed satisfaction with the institution, and 56% of the parents reported they had a positive reaction about their family member moving to a community home before it happened. This compares with an 83% pre-discharge rate of satisfaction with the institution and a 15% rate of support for the

move. The same parents reported an 88% rate of satisfaction with their children's community living experiences.

- **Parents observed improved quality of life and relationships for their family member after the move.** In five studies, more than 65% of the parents reported after the move that their family member was happier, that relationships between their son or daughter and other people improved, that needed services were available, and that staff members in the homes were competent. Fewer than 12% reported negative changes in these areas. The only area in which parents reported considerable uncertainty was the 31% who felt that community funding was less secure than institutional funding.

Those parents initially opposed to their child's move to the community offered a number of reasons for their attitude. In open-ended responses in 16 studies, parents said they were initially opposed to the move because they felt that the institutions were better than community homes at responding to the specific characteristics or needs of their children; available homes were inadequate in terms of safety, service quality or staffing; the process involved in the decision to move people was unfair, improper or disrespectful; or they felt movement to the community would increase the caregiving responsibilities of the family members. While most parents were ultimately satisfied with the community placement, many offered recommendations for lessening the fear about the move. They suggested those planning for people's moving must acknowledge as legitimate the fears and wishes of the family and respond to them as well as they can. They must include the person who is going to move and the family members in decisions related to the move. Visits should be arranged for family members to potential community sites, and parents who have been involved in previous moves should act as guides in these visits and/or be available in other ways to parents. Government agencies should assist in establishing communication between families and community providers. Finally, they emphasized the importance of public articulation of government commitments to funding and other policies to ensure the viability, continuity, and quality of community settings.

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MY SON OR DAUGHTER IS NOT THE SAME AS YOURS: HOW TO ANSWER THAT QUESTION

By Sue Swenson

The Arc of the United States

2004

We often hear that people in institutions are “the most disabled,” and that community living only works for people with “mild” disabilities. The facts don’t back this up: people who live a decent life in the community have a full range of disabilities including very fragile medical conditions and complicated neurological conditions. People might believe the myth just because it is repeated a lot—or maybe it seems true because:

- In the past, we used to think of institutions as “hospitals” and of residents as “patients.” That attitude led to thinking of institutional residents as “sicker.” Now we know that disability is not the same as illness. So nobody is “sicker.”
- When you put disabled people all together in one place, they each seem more disabled. So people in institutions seem more disabled than people who are participating in the community. People in the community can work and have friends, so they automatically seem less disabled.
- Sometimes people who have lived in a segregated setting for a long time do in fact develop serious secondary disabilities. Loneliness and boredom can be terribly disabling, not to mention the effects of not being moved or cared for properly. And some people are abused, which can add to a person’s disability. If people become more disabled inside these institutions, then we should not make them live there.
- The bottom line is this: Everybody is human. Even the most severely disabled people are human, each and every one—because all human parents have human children. And all human beings have human rights. We do not accept the idea that there are some people who are so disabled that they lose their human rights—to have a name, to have an identity, to grow up in a family, to have relationships, to be free of abuse, to have property, to participate in the community. To be who you are. These rights are threatened by institutional placement—so no matter how disabled someone is, they should not be institutionalized.

Questions & Answers

<p>Q. But these places look so nice!</p>	<p>A. Yes, and some prisons look like country clubs. But they are still prisons. You can make it clean, you can make it big, you can even make it beautiful, but you can't change the fundamental fact that the purpose of an institution is to lock people with disabilities away. When one governor closed the institutions in his state, he said it was unbelievably easy to convert them to prisons. Doesn't that tell us a lot?</p>
<p>Q. Don't more people have more freedom on the institutional grounds?</p>	<p>A. Webster's says freedom is: "1: the quality or state of being free: as (a): the absence of necessity, coercion, or constraint in choice or action; (b): liberation from slavery or restraint or from the power of another." Typically in an institution, someone will be told when to get up, when to bathe, with whom to talk, when, what and how to eat, when to go to the bathroom, what to look at, what to say or not say, and when to sleep. They may be able to take a short walk in the open air, but people who have lived "inside" tell us they are only free in their dreams. Their day is a nightmare. By the very nature of institutions, the people who live there have days that consist of constraints, necessity and coercion. In the best places, it may be a gentle program of habit and control. In the worst places, force is used to achieve compliance, and drugs are often used to achieve compliance in any case. No, there is not more freedom on the institutional grounds. The best institution cannot be as free as somebody's own home.</p>
<p>Q. Aren't they more home-like than they used to be? Aren't people safer?</p>	<p>A. This is like arguing about the degree when the real issue is one of a fundamental principle. It is a waste of time and money to make an institution seem like a home if the institutional controls stay in place. It is like trying to make a silk purse out of a sow's ear. How much better it would be to make an actual house seem like a home: to take the funding that would have been used to create the illusion of a home in an institution and use it instead to create the trustworthy supports that someone really needs to be comfortable and safe at home.</p>
<p>Q. How can we close institutions and put all those people in the community on waiting lists?</p>	<p>A. Systems can only do so much at once. The hard part is not figuring out how to serve everyone in the community—it is figuring out whether to do so. Once the decision is made, the organization can stop wasting energy pursuing multiple strategies and focus instead on achieving fair and equitable supports for everybody. We have waiting lists because we waste so much agency time and expertise trying to 'manage' the inevitable closure of the institutions. We need to turn the agencies' attention entirely to community supports. Plans</p>

	<p>are important, and goals, and decent funding: with these, we can get people the support they need. And somebody needs to figure out who gets served when: people coming out of institutions or people who have always lived in the community and need more help than they used to. Or both. It is probably a mistake to put all of the new resources behind people who are coming out of institutions, because people on the waiting lists need help, too. But, yes, it is possible to help everybody be safe and live a decent, ordinary life.</p>
<p>Q. Do we have the capacity to serve greater numbers of people?</p>	<p>A. Each state and local community has different capacity. When we bring large numbers of people out of very large institutions, we must think through issues that affect where the person will live and where the capacity will need to be created: Near their retired parents? Near a sibling? Which sibling? In a house with other people? In the community, people should not be dropped into “slots” or assigned to “beds.” Since community capacity is best created based on a person-centered plan, it is true that the “capacity” can’t really exist in advance. Community providers and families work together to create capacity one person at a time. If the funding is there, the supports can be built. Almost anywhere, almost any time. What is needed is the will to do it.</p>
<p>Q. What do quality community supports look like? What would you see if you were seeing quality?</p>	<p>According to the Council on Quality and Leadership (see their mission statement at http://www.thecouncil.org/), quality community supports use person-centered processes to keep people safe; offer people choice; and direct dollars wisely. So if you are seeing quality, you would see a lot of variation from person to person based on the person’s wants, needs, dreams, challenges and dangers. You would see systematic, ongoing measurement, monitoring and reporting, and you would see system improvements over time. You would see open reporting and lots of communication. You would see that community and family life provide lots of informal “monitoring” as family members and neighbors just naturally “keep an eye on things.” You would see a system that asks the person with the disability and their family: “How are we doing?” “What would you change?” People would have the ability to determine for themselves, with support, how to live and what to do. They would be engaged.</p>
<p>Q. Aren’t there problems in the community?</p>	<p>A. There are problems everywhere in human life. People with disabilities can’t be expected to live a perfect life any more than anybody else can. What we need and want is the right to live an ordinary, decent American life, just like</p>

	<p>everybody else. We know there will be frustrations, problems, and even some risks. But there will also be respect, challenge, achievement, friendship and even love. These are what make risk worthwhile. We hope, like everyone else, to minimize the risks and maximize the rewards. We don't want to live in the community with everyone else because we think it will be perfect: we want to live there because it is right. Vaclav Havel said, "Hope does not consist in being assured that the outcome will be perfect: it exists in knowing that the process is right."</p>
<p>Q. Why are centers of excellence in state institutions a bad idea?</p>	<p>A. Access to decent health care—medical and dental—is a huge problem for Americans with disabilities. People with developmental disabilities have the same range of other health concerns as all other people—plus they have to deal with the disability. For many decades, substandard or unlicensed care was provided to residents of institutions. This new model would suggest that “developmental specialists” could be trained in institutions. There are several problems. First, people with developmental disabilities need access to a full range of generalists and specialists—surely this model would not suggest that we could train specialists who are expert in the needs of people with developmental disabilities, too? We also would not want to train doctors who can practice “well enough to treat developmentally disabled people.” And even if he or she is by chance a wizard, it is too easy for the one “developmental” specialist to prescribe a way of life along with a nutrition plan and anti-seizure meds. It is too easy to slip into “life as treatment,” which negates the personhood and abrogates human rights. People with disabilities remind us that a disability is not a disease. Many are acutely aware of the attitudes of physicians being otherwise. The choice of a personal physician is a personal choice. People should not be “assigned” to someone by the state. Once you segregate health care, even for training purposes, you run the risk of developing attitudes that are not supportive of a person's rights. An institutional setting teaches acceptance of a "hospital" model as a way of life. And that way of life negates freedom and basic rights. When doctors back up that attitude that a hospital existence is OK for some people, or that is OK to imprison people who have not committed crimes, then it gains credence with legislators, who may or may not have enough expertise in the civil and human rights of disabled people. If developmental specialists of any stripe think that institutionalization or a medical model is OK, or if they overtly support it, then they are incompetent to</p>

	<p>practice medicine or dentistry in this century, whether or not their support is based on strong personal empathy for individuals they treat, and whether or not they were trained in a time when the only way to support people was in a hospital environment. Few, if any, persons require that kind of support in this century, and if they do, then the technology and medical support should be engineered to meet their individual needs. More physicians with this hospitalization/institutionalization mindset must not be trained in 2004. A person with a disability is more than a medical patient, even if they have a specific and debilitating “syndrome.” People should not be in a position where a medical professional dictates their life.</p>
<p>Q. Will my son or daughter be rejected by the community? Isn't there a place for segregation where he or she can be with their kind?</p>	<p>A. It is hard to be the parent of a son or daughter with disabilities—not so much because of the child’s disabilities but because of your own expectations. First, you feel sad because you weren’t able to give your son or daughter the perfect life you were aiming at. Then, you have to struggle to teach them what you never had to learn yourself: how to live a decent life with a disability. It is normal to worry about whether your child will be “accepted” or not. But it is better to teach them to be strong and to realize that there are almost no young people in America who don’t get teased. Kids get teased and adults get rejected because they are too fat or thin, too short or tall, too white or too black, because they are disabled or even because they are too smart or “too perfect.” Should we have segregation to solve all of these problems? Segregation has been the answer for kids who have disabilities too often. We need to teach our sons and daughters to love themselves—which is possible no matter how disabled they are—and how to stand up for themselves and take care of themselves when someone hurts their feelings. The best way to learn how to teach this to our sons and daughters is to develop friendships with disabled people ourselves: even one such friendship can open our eyes to what is possible, and to our common humanity. Getting to know someone with disabilities can help us see that our sons and daughters are with their own kind whenever they are with other human beings.</p>

IV. Strategies

- a. State Strategies
- b. Strategies for Advocates
- c. Working With the Media
- d. Position Statements
- e. The Olmstead Decision

STATE STRATEGIES

Background

In the 1970s, states focused on “reforming” institutions. As people realized that institutional reform was not the right goal, beginning in the early 1980s, states put increased focus on institutional closure. On January 31, 1991, New Hampshire closed Laconia State School and became the first state in the country to provide all of its services to people with mental retardation in the community. There were 125 closures, or planned closures, by 2000, in 37 states (Braddock, 2002, p. 91). States that had closed all of their public institutions by 2001 included New Hampshire, D.C., Vermont, Rhode Island, Alaska, New Mexico, West Virginia, Hawaii, and Minnesota (Braddock, 2002, p. 92).

Issue

Many strategies and lessons can be learned from states that have closed institutions. These include states that have closed all public institutions, as well as states that have made substantial progress toward complete closure. Different strategies are used by different states. For example, some are more public about their intention to close institutions, while others do it without public announcement. In order to fully understand various state strategies, it is necessary to understand the particular circumstances and background that led to closure. For instance, it is important to understand the long, hard advocacy work that is involved (see information on advocacy and legal strategies).

This information sheet summarizes some of the key state strategies of institutional closure.

Key State Strategies

1. Building a shared vision of “community for all” among many different individuals and groups.
2. Planning that involves a wide variety of individuals who represent different organizations and interests.
3. Closing the front doors. This involves identification of the pathways that lead to institutionalization, and work to provide alternatives. In doing this, some states (e.g., New Hampshire, Michigan) have chosen to focus on children first, and then move on to adults. Many states have laws eliminating admissions for children or requiring a court to order the admission.
4. Working to increase community supports. This includes identifying and addressing gaps in the community service system and ensuring that there is adequate funding for community services including the availability of very intensive supports for people with significant medical needs or behavioral challenges.

5. Inclusion of people with the most severe disabilities, complex medical needs, and behavioral issues early in deinstitutionalization efforts. This will ensure that lessons are learned about what it takes to support all people in the community.
6. Recognition that there will be compromises associated with institutional closure. For example, during closure, everyone may not have the opportunity to move to the most individualized setting possible right away. However, it is most important that these compromises are recognized, so they can be addressed at a later time. At the same time, it is critical to avoid institutional closure through transfers to other public or private institutions or mini-institutions in the community. Otherwise, nothing will have been accomplished and people will remain at those places for a long time.
7. Recognition that some parents will have great fears about moving their son or daughter from the institution. It is important not to see these parents as “the enemy,” but to work to answer questions and dispel myths. Clear and constant communication is crucial.
8. It is crucial to address workforce issues as part of the institutional closure process. For example, during the closure of Brandon Training School in Vermont, the Vermont Division of Developmental Services made significant effort to assist staff in getting other jobs. At the same time, it is important to be clear that, ultimately, decisions about institutional closure must be based on what is best for people with disabilities (e.g., quality lives in the community) rather than the workforce issues.
9. It is also important to address local community issues related to institutional closure, such as the economic impact of closure as well as future land use. For instance, again, during the closure of Brandon Training School in Vermont, some of the citizens of the community of Brandon were concerned about the economic impact that closure would have upon the community (e.g., on small businesses) as well as what would become of the facility and land around it. The Vermont Division of Developmental Services formed a task force to work with the citizens of Brandon to discuss and address these issues. The facility is now used for multiple purposes including: real estate developer office, school supervisory union office, senior housing, day care, and a community meeting space. Examples from other states include former institutional facilities that have been converted to use as business/industrial parks and condominiums with golf courses. Again, as with workforce issues, it is important to be clear that decisions about institutional closure must be based on what is best for people with disabilities (e.g., quality lives in the community).

10. States often use public education campaigns as part of their efforts to address community opposition to deinstitutionalization. However, states cannot wait until opposition has been resolved to implement deinstitutionalization. And, experience has shown that community members often become more accepting as they have positive interactions with people with disabilities who are included in their communities.
11. Many states have passed legislation related to zoning so that group homes cannot be excluded from residential neighborhoods based solely on neighborhood opposition. At the same time, states, regions, and localities find that there is virtually no opposition when they develop more individualized alternatives to group homes. In addition, as has been addressed elsewhere in this tool kit, these individualized alternatives offer people with disabilities much greater choice and control in their lives.

INFORMATION IN THIS SECTION IS BASED ON THE FOLLOWING:

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CLOSING BRANDON TRAINING SCHOOL: A VERMONT STORY

The Brandon Training School (BTS), Vermont's only public institution for people with mental retardation and developmental disabilities, opened in 1915 and closed in 1993. During those years, a total of 2,324 people lived there. This article examines the closure process for Brandon; it is based on a larger report of a study conducted by the Center on Human Policy.

The Idea of Closure

The values of a community or group of people permeate and influence what they do, including how their service systems operate. People in Vermont felt that shared values such as "caring for one's neighbors" and "those who have the least deserve more" helped create a consensus in support of closure. Additionally, people felt that Vermont's small size facilitated the communication and collaboration involved in closure.

Closing Brandon took at least 20 years. Vermonters who have been connected to the developmental disability service system for 20 years or more trace the idea of closing BTS back at least to the mid-1970s. In those days, more people were leaving BTS than entering, and the census had gone down, dropping from nearly 700 in 1968 to around 450 in 1976. A few key people attended workshops conducted by Wolf Wolfensberger and his colleagues, adopted normalization as a philosophy that should be applied in Vermont, and talked about developing a broader range of community services. The idea that BTS should be closed was raised and became a part of their overall mission. Those leaders began to develop some of the pieces that were later

seen as crucial strategies that led to closure.

The Vermont Association for Retarded Citizens (now the Arc), the state, and the Developmental Disability Law Project worked to establish legislative bills and executive orders that helped to build the community service system. Another major event of those years was the filing of a lawsuit by the Vermont Developmental Disability Law Project (Protection and Advocacy agency) on behalf of Robert Brace and five other residents who wanted to move into the community. The settlement in 1980 of this lawsuit, called the "Brace Decree," included a 10-year plan for developing community resources and moving most of the approximately 300 residents out of Brandon. Although the settlement did not mention closure, according to one of the lawyers, "we knew that if in fact they carried out the terms of the settlement...they were going to end up with three people in the place," and it would have to close.

Nearly 250 people moved into the community in 1979 and the early 1980s, due in part to the state's successful application for and use of the Medicaid Home and Community Based Services Waiver. Later, community placement dropped, as resources and political support for movement dwindled. By 1988, when a new Director of the Division of Mental Retardation was appointed, the average daily number of residents in Brandon was nearly the same as in 1982. Division staff came to believe that many statewide problems could be traced to the continued existence of Brandon.

In Vermont, as elsewhere, a community of advocates--parents, attorneys, professionals, and caring citizens--had a dramatic effect on the shape of services and on the eventual closure. One said,

It's not like we sat down 20 years ago and said, "How are we going to do this?" We really built our philosophy and our mission. And built up the community, by success and by demonstrating it. That's the biggest teacher, I think, more than just words.

The philosophy and the mission were based on a simple ethic: that in Vermont, everyone should be in the community. That ethic was first carried out in the school systems across the state, which are among the most inclusive of any state.

The judicial review process was used for at least 15 years, and the finding almost always was that the person should leave the institution. One attorney reflected, "I think one of the things about Vermont that is different is that our project worked very much, a lot of the time hand in hand with the Division of Mental Retardation." People seemed to see them almost as allies rather than adversaries, because both had the interest of the residents, and the need to move them into the community, in mind.

Beginning the Closure Process

In 1988, following the appointment of a new Division director, closure planning actively began. The following year, the Director distributed a "Unification Plan," which outlined the problems and a solution: unifying the system by closing Brandon and converting to a fully community-based system. The Unification Plan had three major objectives: (1) to convert the system of services from a two-tiered structure supporting

both the institution and the community, to a unified community-based system; (2) to move all remaining residents of BTS to the community; and (3) to build the capacity of the community mental retardation system to respond to special education graduates, families in need of in-home support, young adults aging out of social services custody, persons with mental illness and mental retardation, persons with mental retardation who commit crimes, and persons in crisis.

Once the Governor's office, the legislature, the vendors, and the advocates had agreed that Brandon should be closed, many pieces had to be put in place. Until Brandon closed, bridge money had to be allocated so that both the institution and the community services could operate as effectively as possible, and so that new community programs and an infrastructure could be developed. The needs of the state workers who would lose their jobs had to be addressed, and the community providers had to develop the programs and infrastructure that would allow them to serve both the residents of Brandon and people waiting for services. Financial issues such as the fact that Medicaid reimbursement rates would be lower for community services than for Brandon, and the need to develop an individual budgeting mechanism, had to be dealt with.

While the Unification Plan had stated that it could be done, not everyone agreed at first on how to do it. The Division planned to move ahead, selecting those agencies that were willing to work with them to start with. If need be, they were prepared to develop additional agencies to assist in this process. However, the existing providers came together and developed an implementation plan showing how they could work to

make closure and expansion of community services occur in a concrete and timely way.

One theme that came up repeatedly was that what was good for the residents of Brandon Training School had to be the starting place for decision-making. This belief was shared by people from almost all of the stakeholder groups. The only people who opposed closure also used "the good of the residents" as their reason. These stakeholders included some members of the Brandon Training School Association, many of the employees at Brandon, and some of the Brandon townspeople (many of whom were also employees or families of employees). It was evident by 1990, however, that BTS could and would close, and that the major stakeholders would be able to work together to make it happen.

Division's Role in Closure

The Division developed and followed through with many structural changes that made closure possible. They developed an individualized budgeting approach to funding community services, using the Medicaid waiver. They created an infrastructure that would support closure, working actively with the providers and developing or funding what they felt they would need to carry out the plan. For example, the providers felt strongly that they needed a backup system to handle crises, especially those involving behavior that was dangerous to an individual or the people around him or her. The Vermont Crisis Network was developed to respond to this felt need.

The Division also developed criteria regarding where and how people could be placed in the community. One criterion was that, whenever possible, people should live close to their friends and families, and that family members and/or guardians would be

as involved as possible in the planning and placement decisions. The Division also empowered Brandon staff members to have input into placement decisions.

Division staff met monthly with all of the community agency directors. During these meetings they received commitments to serve each person who was supposed to move during that month. Because the money they had to spend was to come from money saved through the closure process, they transferred funds at different times, with the transfers tied to the layoffs that occurred as the dorms were emptied. The bridge money they were allocated, \$400,000 a year for 2 years, gave them the ability to support somebody in the community before the layoff of staff in the institution could be completed.

The central coordinating function carried out by Division staff members was critical to the success of the closure process. In addition to orchestrating the timing and the numbers of placement, they followed up on problems along the way and worked closely with the institution director and his staff.

Finally, the Division did a great deal to support the BTS staff in getting other jobs. The Department of Employment and Training opened an office on campus, with computer banks of jobs. They also had job fairs, and made resume books that people could look through. The Agency of Human Services, at the Division's request, granted a special priority for people coming from BTS for new state job openings.

Community Providers' Response: Service Planning and Development

Community services in Vermont are provided primarily through nine community

mental health centers, which provide both mental health and mental retardation/developmental disabilities services. Years ago, the directors of the services for people with mental retardation and developmental disabilities formed their own organization, the Vermont Mental Retardation Program Directors. This organization, and the individual directors, played a major role in the closure of BTS, the development of individualized services, and the creation of safeguards. As they worked on these issues, they benefited from the accessibility and collaboration of state and regional administrators.

Moving toward individualized services. As was to be expected in the deinstitutionalization process, certain pressures influenced the effort to develop individualized services. For example, the decision of where residents of BTS moved was somewhat determined by the capacity of the different agencies. Other pressures, such as the commitment to employ staff of BTS and to serve a large number of people in a short period of time, influenced the development of services, as well.

Though they realized that some group living situations would have to be developed in the interest of time, directors as well as state administrators agreed to develop only a very limited number of agency-operated facilities. Instead, they relied on a service model called the "developmental home" to serve the largest group of people. This typically consists of a person or family who agrees to share their home with an individual and support him or her. Funding levels are determined on an individual basis by the agency that is developing services. In many of these situations, it is a staff person from BTS who has invited an individual to live in his or her home.

Directors are aware that some of these situations may not be the most ideal or individualized possible. In any institution closure process, such trade-offs inevitably occur in the interest of timely closure. At the same time, the fact that they have acknowledged the trade-offs, and have not created create a lot of group living situations will facilitate the future development of individualized services. In addition, the directors' efforts to create and maintain responsive agencies by keeping agency size small and supporting staff enhances their capacity to develop further individualized supports.

Creating safeguards. During the closure process, Vermont's capacity to support people in crisis situations in the community grew through the establishment of a statewide crisis network, as well as the development of expertise at local levels. Though the Vermont Crisis Network offers emergency placement in some cases, it was developed primarily as a system to build the capacity of agencies around the state to support people in crisis. From the beginning, there was a strong belief that service providers must maintain primary responsibility and enable people to stay in their homes regardless of problems they may have. There are three levels of services provided through the network: (1) interested members of agencies throughout the state participate in monthly meetings to present challenges and problem solve together; (2) members of the network are available to visit an individual, his or her family, and the agency providing services to assist them in developing a plan for change; and (3) in situations where a person is considered at risk, the network provides emergency, temporary placement, while the agency is involved in developing the capacity to support the person.

Conclusion: Key Factors Related to Closure

1. Recognition of shared values and common vision. It was significant that shared values and a common vision were held and recognized across a variety of groups of people within the state, including many parents, people with disabilities, state administrators, agency administrators, and advocates. This, in turn, influenced other key groups, such as union representatives, legislators, and Brandon community members, many of whom adopted and added to the vision.

2. Long-term efforts of advocates in building a consensus. The shared values did not just naturally emerge. They were the result of years of work by advocates to build a common vision through education, training, litigation, judicial oversight, and personal networking.

3. Accessibility of state administrators. Many people reported that the accessibility of state administrators facilitated the work toward closure. They seemed

to be knowledgeable about what was going on at the local level, and people felt comfortable walking into their offices and talking with them.

4. Responsiveness of administrators. It seemed to people that administrators made every effort to be responsive. In the first place, they took time to listen to people's issues. Second, they made sincere efforts to respond in some way to these issues.

5. Good communication and trust between people. The fact that there was good, open communication between a wide variety of individuals and constituencies facilitated the closure process. People could disagree and debate issues without feeling that their relationships would be jeopardized.

6. Focus on building the capacity of the community. Rather than focus on the closure of Brandon, alone, emphasis was placed on expanding and strengthening the community service system. Resources were allocated to the community service system to support this effort.

7. Significant and careful planning. State administrators and community service providers devoted considerable time and effort to planning for the closure of Brandon and expansion of the community service system. The planning process attempted to anticipate needs and to put structures in place to deal with potential challenges. Planning also encompassed alternative employment options for BTS staff. While closure did cause some difficulties for employees, the large majority were offered reasonably comparable positions.

8. Collaboration among community service providers. Rather than competition between service providers, there was significant collaboration among them. Together,

they reached consensus about supporting closure, and planned and strategized ways to best serve people in the community by building on existing strengths of providers and working to fill in gaps in the service system.

9. Development of a positive working relationship with the local community around issues of closure. The closure of BTS presented some hardships on the Brandon community. It was positive that state administrators worked collaboratively with Brandon community members to deal with issues, particularly regarding alternative uses for the facility.

10. Maximizing the opportunities for development of individualized supports at the time of closure and in the near future. Finally, as people moved out of Brandon, efforts were made to assist as many people as possible to move to individualized settings of their choice. However, as in any process of institutional closure, it was not feasible to create individualized settings for a large number of people in a relatively short period of time. In light of this, however, the state made little use of group homes and other facilities, and relied more extensively on placement in developmental homes. This seemed to be a reasonable compromise, one that is preferable to group homes and one that will create less obstacles to future development of individualized supports.

The experience of closure of BTS has demonstrated both the possibilities for institutional closure, as well as the possibilities for operation of an entirely community-based service system. While the task of closure and conversion to a community-based system was on a much smaller scale in Vermont than in most other states, the experiences nevertheless provide valuable strategies and lessons for those elsewhere

interested in working toward closure.

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Thoughts and Impressions on Institutional Closure

by Steve Taylor

Having followed successful institutional closures from a distance, observed less successful efforts closer to home, and participated in numerous meetings on the planned closure of Syracuse Developmental Center, I have formed some thoughts and impressions on the closure process. Of course, no definitive conclusions about institutional closure can be reached yet. We need more examples of how to close institutions in all regions of the country and in states not noted for their forward-looking administration of developmental disability services before we write the step-by-step instructions, if ever we can. However, it is not too early to begin to draw some generalizations about institutional closure from experiences to date:

- **There are different ways to close an institution.** Institutions have been closed successfully in one of two major ways. The first is to announce the closure far in advance with broad political and public support. The second is to gradually and quietly depopulate an institution to the point at which the costs of continued operation are prohibitive and no responsible public official can justify the expense. Which strategy works best? The former seems to have worked in Vermont, while the latter seems to have been effective in New Hampshire. It is preferable to have political consensus in favor of closure and to close an institution through a planned, orderly, and public process. However, the political and economic climate will dictate the strategy that will work best in any particular state; in some states, circumstances may argue against a public announcement of closure far in advance. What is most important is not which strategy is used, but whether responsible officials do, in fact, have a strategy for closure.
- **Where the people go is more important than whether an institution is closed.** Institutional closure is a worthy goal, but it is merely the means to the end – community integration and inclusion. If an institution is closed through transfers to other public or private institutions, the creation of mini-institutions in the community, or the re-naming of units on institutional grounds, then little has been accomplished and, potentially, much harm has been done. Institutions must be closed in a manner that gives each person increased opportunities to participate in community life.
- **Compromises need to be made in the closure process.** No state has replaced an institution with a totally individualized system of community supports. The goals of institutional closure and the development of individualized services are inconsistent, and perhaps contradictory. This creates a difficult dilemma. Should people be forced to remain in institutions while states realign their policies and fiscal mechanisms and service providers develop the capacity to offer individualized services on a large scale? Or, should institutional closure proceed even though all people will not be able to be supported in individualized ways? Either path represents a compromise in values and desired outcomes. The only reasonable way to approach the dilemma is to ask which path will cause the least harm to the fewest people. From this vantage point, continued institutionalization cannot be justified. Even if ideal services cannot be developed, people should not be denied the opportunity to live a better life in the community. Institutional closure will require compromises. Compromises are most dangerous when they are not acknowledged as such.

The Community Imperative

A Refutation of All Arguments in Support of Institutionalizing Anybody Because of Mental Retardation

In the domain of Human Rights:

*All people have fundamental
moral and constitutional rights.*

*These rights must not be abrogated
merely because a person has a
mental or physical disability.*

*Among these fundamental rights is the
right to community living.*

In the domain of Educational Programming and Human Service:

*All people, as human beings, are
inherently valuable.*

*All people can grow and develop.
All people are entitled to conditions
which foster their development.*

*Such conditions are optimally provided in
community settings.*

Therefore:

*In fulfillment of fundamental human rights,
and*

*In securing optimum
developmental opportunities,*

*All people, regardless of the severity of their
disabilities, are entitled to community living.*

*The Community Imperative, was issued by the
Center on Human Policy, Syracuse University, in
1979 in response to backlash against
deinstitutionalization.*

- **People with the most significant needs should be moved into the community throughout the institutional closure process.** People with the most severe disabilities, including those with complex medical and behavioral needs, should have equal opportunity to live in the community. For this reason alone, they should be moved into the community during all stages of institutional closure. More than that, community providers need time to develop the capacity to support people with the most significant needs in the most responsive and individualized ways. When people with severe disabilities, as a group, are the last to leave an institution, it is likely that they will be placed in the most restrictive and least integrated settings, simply because planners and providers lack the skills and experience to support them in other ways.
 - **Institutional closure should proceed with concrete benchmarks and tangible indicators of progress.** The more carefully planned an institutional closure, the greater the probability that an institution will be closed in timely fashion and replaced with responsive services in the community. At the minimum, administrators and planners should establish targets for census reduction and the development of residential, vocational, medical, and other community supports and services as well as vehicles to monitor progress toward meeting those targets. In instances in which closure has been initiated by bodies or officials other than administrators responsible for closing an institution, closure plans should address implementation steps, specific descriptions of the kinds of community services to be developed, and strategies for safeguarding quality.
 - **When the goal of institutional closure is explicit, all relevant parties should be involved in the process and information should be readily available.** Institutional closure can be controversial, but this does not justify excluding relevant parties – advocates, parents, institutional staff, local elected representatives, community providers, and others – from planning or withholding information about the process. Once a policy of closure has been adopted, all interested persons should have the opportunity to participate in planning and to voice their concerns. Suspicion, distrust, low morale, and rumors serve no one's interests.
 - **Institutional parents should not be treated as the enemy.** In some states, institutional parent groups have been vocal opponents of closure. Many parents placed their sons and daughters in institutions years ago on the advice of professionals when few, if any options were available. Now, some parents are fearful of losing the sense of security provided by the bricks and mortar of the institution. These parents are mistaken in believing that their sons and daughters belong in institutions and that security cannot be provided in the community. But they did not create the institutions and are deserving of sympathy and respect. Quality community services and the long-term commitment of community providers will eventually allay parental fears and concerns.
 - **Advocates and administrators have complementary roles to play in institutional closure.** Advocates have served as important catalysts for change, including the closing of institutions, and have a critical role to play in monitoring the closure process and the quality of services in the community. Yet the success of closure efforts will depend upon competent and committed administrators. Advocates should not attempt to manage the closure process, but should direct their efforts to making sure that the right persons are in position to accomplish the goal. The most successful administrators know how to work with advocacy groups and are open to external scrutiny and review.
 - **Closure should be accomplished in a manner that minimizes disruptions in people's lives.** Under the best of circumstances, moving from a highly regimented and controlled life in an institution to less restrictive settings in the community can be a disorienting experience. Repeated movement of people from one institutional unit to another prior to closure should be avoided at all costs.
 - **Institutional closure should result in a decentralization of decision-making regarding services.** With the closure of public institutions, decision-making should shift from state capitals to local communities. People with developmental disabilities themselves and those who are close to them should have a major say over where and with whom they will live and how they will be supported. Decentralization of decision-making does not mean that appropriate governmental bodies should abandon their legitimate oversight role.
- Despite progress, the fact that nearly 150,000 people with developmental disabilities remain in public and private institutions and nursing homes is a sobering reality. Regional and state variations in deinstitutionalization efforts are striking. We need to be reminded that not everyone agrees that all people with mental retardation belong among us and have fundamental human rights. Many of the same arguments made previously to oppose deinstitutionalization are used today to oppose school inclusion, non-aversive interventions, and other humanistic efforts. We must continue to speak out clearly and forcefully on the issue of institution versus community living so that all people, regardless of the severity of their disabilities, are afforded the opportunity to live in the community and experience the associated rights and responsibilities of citizenship.
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Executive Summary¹

In June 1999, the U.S. Supreme Court addressed the debate about appropriate care options for people with disabilities. In *L.C. & E.W. vs. Olmstead*, the court ruled that states are required to provide community-based services for people with mental disabilities if treatment professionals determine that it is appropriate and the affected individuals do not object to such placement. The Court further concluded that states are responsible for community-based placement if they have the available resources to provide community-based services. States that maintain waiting lists must make a good faith effort to move those on the list to community programs at a reasonable pace.

This report provides profiles of states that have made innovative changes in their service delivery systems to increase the number of community-based placements and reduced institutional placements. Using information from interviews from state disability service agency directors, academics, advocates and state policymakers, this report answers the following questions:

- o How far along are states in deinstitutionalizing their disabled populations?
- o What percent of disabled people live in community settings and in state hospitals?
- o What kinds of medical and social services do these populations need, and what are the service gaps?
- o Are there any models of care that could be considered "best practices" for states?
- o What are the costs associated with care for this population, and how are services funded?

The report finds that states have great flexibility through traditional Medicaid and Medicaid Home- and Community-Based Waiver programs to redesign their disability service delivery systems to emphasize community-based placement for persons with mental retardation and other developmental disabilities (MR/DD) who are capable of living in the community. Increased communication and cooperation among those with MR/DD and their families, state agencies, providers, policymakers and advocates have been instrumental in transforming systems that have relied too heavily on institutions to serve disabled populations.

The report also finds great variation in state progress and approaches to de-institutionalization. Nine states and jurisdictions-Alaska, the District of Columbia, Hawaii, Maine, New Hampshire, New

¹Davis, D., Fox-Grage, W., & Gehshan, S. (2004). Executive summary. In *Deinstitutionalization of persons with developmental disabilities: A technical assistance report for legislators*. Denver & Washington, D.C: National Conference of State Legislatures. Available: <http://www.ncsl.org/programs/health/Forum/pub6683.htm>

Mexico, Rhode Island, Vermont and West Virginia-have closed all their public institutions. These states are considered the successful models of deinstitutionalization and the pioneering examples of states that have created community-based delivery systems for their developmentally disabled populations. In addition, states like Michigan, Minnesota, Colorado and West Virginia have taken progressive steps to decrease the number of persons with MR/DD who are housed in public institutions.

The report concludes that, although barriers exist in some states that keep them from moving completely to a community-based service delivery system, states can use a number of strategies and proposals to eliminate their reliance on institutional care. These strategies include:

Building community resource networks and community crisis/emergency response systems to address the reason people initially are institutionalized;

- Creating systems of long-term care for people with disabilities that are more consumer-driven and include more home-and community-based services;
- Developing guidelines that reflect the state's individual MR/DD populations and regional variations;
- Emphasizing the search for better ways to treat disabled individuals both medically and socially;
- Experimenting with various payment models for personal assistance services, such as direct payment for services and vouchers;
- Convening a task force of legislators, state agencies, providers, and people with developmental disabilities and their families to discuss and report on the service needs of people with developmental disabilities;
- Establishing a statewide data-collection system that identifies people with developmental disabilities, their demographic and personal characteristics, and their service needs; and
- Appropriating money to operate both the institutional and community services until a community-based infrastructure can be developed.

Introduction¹

During the past two decades, parents of the disabled, disability advocacy groups and state policymakers have worked to serve more people with developmental disabilities in the community rather than in large, state-operated facilities. As a result, the number of people with developmental disabilities in public institutions declined from 149,892 in 1977 to 51,485 in 1999. (1) However, many states have not been able to move quickly enough to accommodate the demand for community placements.

On June 22, 1999, the U.S. Supreme Court addressed this contentious issue. A recent Supreme Court case, *L.C. & E.W. vs. Olmstead*, highlighted that, although states generally support the idea of a community-based delivery system and provide community services, many of them continue to rely heavily on their public institutions to provide services to those with developmental disabilities who are capable of living independently. As result, many states, including Georgia, continue to maintain waiting lists of people with developmental disabilities who are hoping to receive care in less restrictive settings.

In the case, two mentally retarded women, L.C. and E.W. (also diagnosed with schizophrenia and personality disorder, respectively) were voluntarily admitted to a psychiatric unit of a Georgia state hospital. Their treatment professionals eventually determined that the women were qualified to receive care in an appropriate community-based program, but the women were placed on a waiting list for the services and remained institutionalized. The women filed suit against Georgia officials, alleging a violation of the Americans with Disabilities Act for the state's failure to place them in a community-based program.

The Court ruled that states are required to provide community-based services for people with mental disabilities if treatment professionals determine that it is appropriate and the affected individuals do not object to such placement. (2) However, the Court concluded that states are responsible for community-based placement if they have the available resources to provide community-based services. The Court also requires that states demonstrate that they have a comprehensive, effective working plan, including timetables and progress reports, for placing qualified people in less restrictive settings. States that maintain waiting lists must make a good faith effort to move people on the list to community programs at a reasonable pace.

¹ Davis, D., Fox-Grage, W., & Gehshan, S. (2004). Introduction. In *Deinstitutionalization of persons with developmental disabilities: A technical assistance report for legislators*. Denver & Washington, D.C: National Conference of State Legislatures. Available: <http://www.ncsl.org/programs/health/Forum/pub6683.htm>

In light of this ruling, an assessment of the trends and models of care for the developmentally disabled is warranted. More important, there is a need to disseminate as much accurate and useful information as possible about the needs of people with disabilities, as well as the delivery and financing of services targeted toward them. State policymakers will want to be aware of the approaches and options available to them as they respond to the needs of their constituents with developmental disabilities. The recent trends in closures of public institutions and the increasing cost of institutional care require that lawmakers develop innovative alternatives to expensive, often unnecessary institutional care. Because legislators control the funding for these programs, it is important for them to understand the service gaps in their state system of care for individuals with disabilities, the number of people who are in need of services and the sources of funding streams. Thus, this report attempts to answer the following questions:

- How far along are states in deinstitutionalizing their disabled populations?
- What percent of disabled people live in community settings and in public or private institutions?
- What kinds of medical and social services do these populations need, and what are the service gaps?
- Are there any models of care that could be considered "best practices" for states?
- What are the costs associated with care for this population, and how are services funded?

The purpose of this report is to educate legislators and legislative staff about a vulnerable population—persons with MR/DD—that often is overlooked. The report describes models of care and state approaches to serving their disabled populations. It also gives legislators options for providing appropriate and necessary community services to those with mental retardation and developmental disabilities who are capable of living independently, while ensuring their safety and continued access to needed services.

Background

In the early part of this century, people with mental retardation and other developmental disabilities received services in large public institutions or were cared for by their families with very little financial and social support from the government. In the 1960s, due largely to a series of class action lawsuits and the scrutiny of institutions by an increasingly vocal advocacy movement, the appalling conditions and the poor treatment of patients in these institutions were revealed. Thus, the debate about care options for the disabled shifted to the idea of deinstitutionalizing those with

developmental disabilities who are capable of living in the community and developing a more flexible service delivery system to serve them. However, the early wave of lawsuits resulted in decrees requiring states to improve conditions at public institutions without expanding the options of care provided.

In the 1970s, legal challenges sought not only to improve the conditions in public institutions, but also to eliminate the unnecessary institutionalization of people with developmental disabilities who are capable of living in their own communities. Many experts agree that most people in state hospitals could live in the community if they had the appropriate services, such as intense supervision, therapy and 24-hour medical care. Many communities, however, fall woefully short in providing these services.

More recently, states have responded to the desire of people with developmental disabilities and their families for a range of options for care and independent living by increasingly replacing institutional care with community-based services. However, there is wide variation in the rates of deinstitutionalization, funding for community-based services and social and political commitments to developing a community-based delivery system.

In 1991, New Hampshire and the District of Columbia became the first state and jurisdiction to close their only public institutions for people with developmental disabilities and develop a delivery system based entirely on community-based services. Since then, six states-Alaska, Maine, New Mexico, Rhode Island, Vermont and West Virginia-have followed suit, and other states are using waivers and other innovative ways to reduce their dependence on institutional care. [\(3\)](#) Once dominated by large state-run institutions, systems of care for people with developmental disabilities are undergoing continued change, with community services increasingly replacing institutional care.

What Are States Doing?¹

Since the 1950s, the trend among state developmental disabilities agencies has been toward deinstitutionalization and community care. However, state approaches and progress vary considerably. Some states were spurred into action by a wave of class action litigation, while others have had few legal or legislative inducements to transform their delivery systems.

There is no dispute that the cost of institutional care is higher than the cost of services provided in community-based settings. The average cost of institutional care is more than six times the average cost of community-based care--\$94,348 for institutional care versus \$14,902 for community-based care. (25) This cost gap caused some states to increase spending on services provided through community-based programs (figure 6 contains a description of community-based services). By 1998, 45 states and the District of

Figure 6.

What Are Community-Based Services?

Community-based services are long-term support services for people who need help with activities of daily living (ADL) outside of large state institutions or nursing homes and in their own homes and communities. Community-based care originated as an outgrowth of the idea of meeting the needs of people with disabilities by emphasizing quality of life issues: presence in the community; health and safety; personal growth and opportunity; and self-determination. Community-based services include the following types of services, provided in community settings:

- Residential services and supported living facilities, including community-based residential placements in supervised apartments or group homes with case manager visits.
- Personal assistance services (PAS), including a range of human and mechanical assistance for those people of any age who require help with routine ADL and health maintenance.
- Care planning and case management, including a comprehensive assessment by a case manager and people with disabilities of their individual needs and the network of aid agencies and programs appropriate for providing care.
- Day programs, including placement in activity centers, habilitation and adult skills programs.
- Vocational services, including supported employment programs, vocational evaluations, job training and placement, and work adjustment programs.
- Other quality of life services, such as recreation and leisure activities, transportation and early intervention programs.

¹ Davis, D., Fox-Grage, W., & Gehshan, S. (2004). What are states doing? In *Deinstitutionalization of persons with developmental disabilities: A technical assistance report for legislators*. Denver & Washington, DC: National Conference of State Legislatures. Available: <http://www.ncsl.org/programs/health/Forum/pub6683.htm>

Columbia were spending more for community services for the developmentally disabled than for coverage for congregate residential services. [\(26\)](#) However, four states-Arkansas, Delaware, Kentucky and Mississippi-spent just as much or more for institutional care than for services provided in community-based settings. [\(27\)](#)

Trends

As noted earlier, there has been considerable variation in state progress and approaches to deinstitutionalization. Nine states and jurisdictions-Alaska, the District of Columbia, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont and West Virginia-have closed all their public institutions. [\(28\)](#) These states are considered to be successful models of deinstitutionalization and the pioneering examples of states that have created community-based delivery systems for their developmentally disabled populations. In addition, states like Michigan, Minnesota, Colorado and West Virginia have taken progressive steps to decrease the number of those with MR/DD who are housed in public institutions. [\(29\)](#)

However, some states continue to rely heavily on services provided in public facilities and have been slower to place people with disabilities in the community. Arkansas, Connecticut, Delaware, Louisiana, Mississippi, New Jersey, North Carolina, South Carolina, South Dakota, Texas and Virginia continue to rely heavily on their public institutions to provide services to their developmentally disabled population (see [table 4](#)). Most of these states have a comparatively high number of institutionalized people relative to the disabled population. More importantly, in these states 50 percent or more of those with MR/DD typically are committed to institutions for 16 or more people. [\(30\)](#) On a positive note, although some states lag behind others in reducing their institutional census, all states have reduced the number of people who receive service in large public facilities.

The trend toward closing institutions gained renewed momentum during the recession of the early 1980s. Successful litigation and more stringent federal enforcement of the ICF/MR regulations required more facility staff, which resulted in higher costs for facilities that were not downsized. There was new pressure to close institutions as average daily costs of institutional care began to increase and the number of those residing in institutions began to decrease. Because of declining numbers of residents in institutions, the average daily cost for living in an institution increased by 19 percent between 1988 and 1992. [\(31\)](#) This increase occurred while the average daily institutionalized population decreased from 91,582 in 1988 to 75,477 in 1992, a difference of more than 15,000 residents. [\(32\)](#) Today, the average daily cost for a stay in a public institution is \$258, compared to \$84 in an HCBS setting. [\(33\)](#)

It is difficult for states to operate a completely community-based service delivery system when large public facilities are available as a "safety net." Moving large numbers of people from institutions to community

settings requires that states provide a wide range of supports, including mental and physical health care, a crisis response system, housing assistance and income support. Some states have met the challenge.

New Hampshire. [\(34\)](#)

New Hampshire was the first state to move to an exclusively community-based system. The state became an early innovator of a community-based system by enacting RSA-171-A in 1975, a law which mandated the development of individual service plans and created 12 area agencies designated to provide community-based services. Although New Hampshire had only one institution, a federal court decision in 1981 decreed that the state develop a community-based service system and eliminate unnecessary institutionalization. Thus, New Hampshire's Division of Developmental Services decided to pursue a plan that combined institutional reform and community placements. [\(35\)](#)

In 1984, New Hampshire received a HCFA waiver to expand its community-based service system. Its use of HCBS waivers was more extensive than that of many other states, including case management, personal care and residential support, supported employment and environmental modifications such as home adaptations. [\(36\)](#) This use of the waiver was the centerpiece of the Division of Developmental Services' plan to create "individualized housing and regular work opportunities." [\(37\)](#)

The state continued to pursue a more extensive community-based system of care when the New Hampshire legislature passed the Family Support Act of 1989. The act provided direct financial support for community services by providing public funds for the 12 area agencies, which previously were not appropriated any public funds. The area agencies consist of private, autonomous providers that contract with the state to provide services.

The 12 area agencies are responsible for submitting to the state detailed plans-as well as progress reports and proposed budgets-for placing the disabled in the community. The agencies usually emphasize enhanced family care and out-of-region placements.

- o Enhanced family care placement-Case managers attempt to locate people's most significant familial and community ties, regardless of the region, as the first setting for potential placement. If a patient's family no longer lives there, managers pursue placements in surrogate families in the region where MR/DD patients grew up.
- o Out-of-region placement-Case managers place the disabled in the regions in which they grew up as opposed to the regions where they may have received services in an institution. Because some regions may have a more extensive network of community-based services, managers are more likely to seek placements in those regions. However, attempts to place

those with MR/DD in regions that may not have the most extensive network of care-but in which the patient once lived-prevents the over-utilization of services in a particular region.

By 1991, all the developmentally disabled had been placed in community settings. The last state institution, Laconia, finally closed because the vast majority of residents had been placed in the community. The state legislature aided the further development of the community system by allowing institutional funds to be transferred directly into the community services system instead of into the state general fund. In 1998, total spending for developmental disabilities was \$123.5 million, with community spending accounting for 99 percent of the total (\$122 million). [\(38\)](#) The remaining spending included federal ICF/MR reimbursements and state matching funds.

Maine. [\(39\)](#)

The conditions in Maine's only institution, Pineland, resulted in a 1978 consent decree that required Pineland to provide better living conditions and treatment for its disabled residents. Between 1978 to 1994, local providers of community services began to expand and to improve the community-based service delivery system. As the disabled moved into the community, the money was available for those who needed services outside the institution, further expanding the community system. Community spending-as well as spending to finance institutional reform-increased steadily until 1992, when institutional spending began to decline and Pineland faced closure.

In 1994, another consent decree declared that the original 1978 decree could be vacated if Pineland were closed. The momentum already had moved away from providing institutional care. The executive and legislative branches allowed the courts and the bureaucracy to determine the movement to community-based care. The 1994 consent decree further expanded the use of community-based care by proscribing the use of a crisis response system in which emergency beds are made available for those who need them until a longer-term community setting is found.

Michigan.

Michigan provides an example of a state's persistently innovative role in transforming its MR/DD services delivery system. In 1979, 80 cents of every dollar spent on mental retardation residential and community services was allocated to state institutions. [\(40\)](#) Several developments helped transform Michigan's delivery system into a model for other states that want to decrease reliance on their institutions.

- The Macomb-Oakland Regional Center, opened in 1973, focused on family support services, family preservation and permanency planning. The center helped avert unnecessary institutional placement when support and services could be found in a community setting.

- A lawsuit, *Michigan Association for Retarded Citizens vs. Smith*, focused on the conditions found in the Plymouth Center, a large state institution.
- The Community Mental Health Act, enacted by the Michigan Legislature, provided financial incentives to county boards of mental health and retardation to provide community services. Funds that were saved from closures were reallocated to finance community residential services and family support. [\(41\)](#)
- The Michigan cash subsidy program provides \$250 per month for families earning up to \$60,000 to pay for clothing, education aids, out-of-pocket medical expenses and transportation. The program allows people with developmental disabilities to combine their cash subsidy with the \$5,500 from SSI. The subsidy eliminates the routine practice of reducing benefits from public programs when persons with MR/DD receive additional benefits from other programs.

As a result of Michigan's determined efforts, nine state institutions were closed between 1981 and 1996. In 1998, only 283 residents remained in state institutions, down from 12,615 in 1965. Furthermore, the cash subsidy program provided support to 4,645 individuals with MR/DD and their families in 1996. Nearly 7,000 families received respite care, counseling and in-home services. Michigan allocated 95 percent of its total mental retardation resources for family support and community care, compared to a national figure of 72 percent. [\(42\)](#)

Waiting Lists

As the trend of deinstitutionalization gained wider support throughout the disabilities services community, the demand for community-based services has outpaced the rate of state expansion of community services. As a result, waiting lists for community-based residential services have become a reality for state developmental disabilities services agencies. Researchers and advocates consider waiting lists to be a reflection of system failure because it indicates that a state has been unable to expand its supply of services fast enough to accommodate the increase in demand for community care. [\(43\)](#)

As shown in [table 5](#), 37 states report a total of 46,482 people on waiting lists for residential services or community-based residential placement. Four states-California, North Dakota, Rhode Island and Wyoming-and the District of Columbia report that they have no one on waiting lists for residential services. Some states-such as Vermont, South Dakota and Kansas-have small waiting lists that reflect short gaps in providing services to individuals; it does not indicate shortfalls in capacity. [\(44\)](#)

However, the more troubling data in [table 5](#) is the percent by which states must expand their residential service programs to accommodate those in need. For example, Alaska would have to expand its residential programs by 82 percent to accommodate the 337 people on its waiting list for services. Georgia, the state at the center of the *Olmstead* case, would have to expand its programs by about 40 percent to accommodate

the 1,900 MR/DD people on its waiting list. Nationwide, there is a need for an approximate 18 percent growth in residential services to accommodate those MR/DD people who are on waiting lists.

STRATEGIES FOR ADVOCATES

This tool kit is filled with “talking points” for advocates during discussions on institution closure. Each of the sections addresses a question or issue that could be raised by those wanting to keep institutions open, or by policymakers wanting to know more about the issue.

This section, however, presents a smorgasbord of strategies that can be adapted by advocates to fit the situation in their own states (also see the separate section on working with the media).

Inform and Organize

- Pull together a coalition of key stakeholders who are willing to learn about and inform others about what has been done elsewhere in regard to institutional closure. Then, inform them on what you know, and let them inform you. This group or coalition can form the basis for your organizing.
- Gather signatures or endorsements for position statements or a statement of principles, and disseminate these to decision-makers (see section on *Position Statements*).
- Consider litigation. **Note: a section on litigation will be developed at a later date. It will be available on the Tool Kit web site and by contacting the organization that provided you with a copy of the Tool Kit. Please let them know if you wish to have the litigation section when it has been completed.**

Work with the Governor and Executive Branch

One person wrote us this message as we were pulling together this tool kit: “Essentially you need a strong Governor who makes the decision and sticks to it. I have closed SODC(s) [State Operated Developmental Centers] in four different states and it is always a political decision and only works if the leadership is strong enough to insist that it shall be done.” While institutions have closed in states where the Governor opposed closure, having the Governor’s support is better, and will make it more likely that the transition is smooth and good for the people affected. How to gain that support?

- Make appointments with the Governor, his or her staff members, and/or heads of state offices, and take a group to these meetings; develop your position and present it succinctly, with backup resource documents that address the most important issues.
- Work as an individual, not as a representative of a nonprofit organization, on the Governor’s political campaign, and make sure his/her staff members know about your organization and its views.

- Write position papers that address major issues that are important in your state (“choice,” for example); offer well-thought-out solutions to state problems.
- Present information on how other states have achieved closure. Select states that are close to yours in population and other demographics, where possible. You may contact the organizations responsible for this tool kit for this kind of information.
- Make it clear that you represent a large number of people who are not going to go away until your goals have been achieved.
- Find people who are close to the Governor—acquaintances, donors, political supporters, etc.—and help them to convey your message about the importance of closure directly to the Governor.

Work with the Legislature

- Make sure your legislators know who you are and what you represent. Meet with them and their staff members as often as you can, even when there is not a crisis or a specific piece of legislation or political issue currently in front of the legislature.
- Testify when there are legislative hearings related to community services and institution closure.
- Propose legislation, if you have developed a relationship with a legislator who will introduce it.
- As an individual (not as a representative of a tax-exempt organization), work on legislative campaigns, or host a coffee meeting for a candidate in your home.
- Hold forums for candidates, where each answers questions about your issues.
- Send questionnaires to candidates and publish their answers as widely as possible.

Work with Key Departments in State Government

- Develop relationships with officials in departments that oversee and fund the services for people with developmental disabilities. Invite them to speak at events you sponsor, or to address your board meetings, for example. If you have disagreements, air them and explain your positions (backing them up with current information and research).
- Be a source of cutting-edge ideas for state departments. Get on Internet mailing lists that discuss and inform on national trends and great ideas.
- Develop position papers that detail directions policymakers could take. For example, a coalition in New York developed a “most integrated setting” position paper related to Olmstead implementation. The position paper listed changes that could be made in current practice and was distributed to policymakers in several state departments, the Governor, and legislators. It

was also endorsed by dozens of organizations and coalitions, and their endorsements were made known to policymakers. The information in this tool kit is tailor-made for this activity.

Hold a Public Forum on Institutional Closure or Other Issues

- Organize people in your community or in the state capitol to plan and put on a public forum in a governmental space (legislative chambers, city council chambers, etc.).
- Invite legislators from your community and other decision-makers to the forum; give them time to respond, but at the end of the evening, after they've heard the testimony.
- Plan the testimony so that powerful speakers representing various constituencies are "on" first, followed by audience members who wish to speak (for example, lead off with a parent whose child was once institutionalized and is no longer, followed by a person who once lived in an institution, followed by a university professor who has studied institutions, followed by someone now institutionalized, and so on).
- Make sure all the major issues are addressed by someone.
- Publicize the forum widely.
- Have petitions and/or position statements for people to sign or endorse, along with fact sheets and other materials (see section on position statements).
- Have good moderators who will introduce the evening and the legislators present as well as keep time (2-3 minutes per testifier is best) so the forum stays lively and impassioned.
- Consider videotaping and/or transcribing the forum, and editing these afterwards to present as testimony to state officials and legislators (especially if your forum is not in the capitol).

Study Good Web-Based Materials on Advocacy

- <http://www.thearc.org/ga/trainmat.html> is the training page of The Arc, and covers how a bill becomes law (national), how to be an effective legislative advocate, tips on writing or emailing a member of Congress, how to have a meeting with a legislator or their staff, general tips on working with the media, and how to write a letter to the editor of your local paper
- <http://www.tash.org/govaffairs/> has links to help you contact your Senator and/or Representative, along with links to Senate and House Committees that make decisions on policy affecting people with disabilities.
- <http://www.ndss.org/content.cfm> has a tab at the top labeled "Advocacy Center." Click on that for lots of great information for advocates, including tips for advocates, organizing coalitions, interacting with policymakers, and others.

- <http://www.disabilitypolicycenter.org/> is the web site of Bobby Silverstein, former principal advisor to Senator Tom Harkins and now Director of the Center for the Study and Advancement of Disability Policy (CSADP). CSADP provides public education, leadership development and training, technical assistance and information dissemination, and conducts action-research and analysis of public policy issues affecting individuals with disabilities and their families.

WORKING WITH THE MEDIA

Work with Reporters and Editorial Boards

- Develop events that will interest the media and help you to get the word out, such as a public forum, a candidates' night, a rally for institution closure, etc.
- Cultivate specific reporters who have an interest in (or are assigned to cover) your topic. Make sure they are informed every time something newsworthy is about to occur (your forum, rally, etc.), or has occurred (an allegation of abuse in an institution, for example). Make sure they receive a written statement detailing your position each time you contact them.
- With a group, make an appointment with the editorial board of a local media outlet (e.g., the most well-read newspaper in your area). Present a compelling case for your view of a critical situation (e.g., a proposed bill to re-open an institution).
- Get stories to the media about a real person who left an institution in your state and is now having a good life in the community, or about a parent or family member who once had misgivings and now is pleased with the results of their family member's move into the community.
- It is important that families, professionals, advocates and people who left institutions are seen as having one voice. Journalists, like the general public, get sidetracked or confused by infighting between groups.

Letters to the Editor & Op-Ed Pieces

Letters to the editors of newspapers and magazines, along with op-ed pieces (opinion essays that appear on the editorial pages of newspapers), can be very influential at the local or state level. For example, a leader of an organization fighting for closure of an institution in their area could write an op-ed piece for a local newspaper, and members could follow up by writing response letters, the more the better. The controversy could stimulate a newspaper to assign a reporter to write an article, especially if the op-ed piece and letters provide new or formerly unreported information (e.g., cost comparisons, personal experiences, parents' perspectives). It could also prompt the newspaper's editorial board to print an editorial in favor of closure.

One consequence of such efforts is that local legislators may be influenced to stand up for closure of an institution in your area, or for closure of an institution in another part of the state.

Advocates can also use the media to influence state-level policymakers, who are most likely to make the final decisions about closure of an institution. Letters to the editor or op-ed pieces can be submitted to the newspapers in the state capital, for example. Statewide advocacy organizations can ask

their members to write to their local newspapers, creating an impression of a statewide groundswell for closure.

This section includes sample op-ed pieces and letters to the editor. Your organization may wish to adapt them for its own purposes or to develop its own.

Ideas to Help You Get Your Letter to the Editor Published:

- Use your own words--ideas that come directly from you will be most powerful.
- Keep it very brief and to the point--if your newspaper has a word limit, stick to it or they may make it shorter. It will be better to do your own cutting so your most important points are kept.
- One key to getting your letter published is to respond right away to a specific article (or another letter or editorial) that has just been published. Don't wait too long or they may feel your letter is out of date.
- Be sure to include contact information including your name, address, phone number and e-mail address. Often newspaper editors need to call to make sure you are the person who wrote the article. They don't print your phone number or any contact information.
- Your newspaper's letters page should give you an email address or a fax number to use, or you can look on the newspaper's web site, call them, or try these web sites:
<http://congress.org/congressorg/dbq/media/> or <http://capwiz.com/thearc/dbq/media>.

Help the Media to Do a Great Job of Covering Disability Issues

- Go to the web site of the Center for an Accessible Society, <http://accessiblesociety.org/>, and click on "media" in the box on the left side of the page. There are many resources within this web site, which was created for journalists writing about disability issues.
- Go to <http://www.raggededgemagazine.com/mediacircus/styleguide.htm> for a style guide for journalists. The home page of *Ragged Edge Magazine*, <http://www.raggededgemagazine.com/>, leads to all sorts of good articles, such as <http://www.raggededgemagazine.com/0199/d199me.htm> for tips on working with reporters on your issues or <http://www.raggededgemagazine.com/mediacircus/opedtips.htm> for tips on writing op-ed pieces that get published.
- Go to the disability section of the Journalists' Toolbox web site, <http://www.journaliststoolbox.com/newswriting/disabled.html>, for an enormous number of links and resources, including disability statistics and guidelines for journalists.

- Go to the web site of the National Center on Disability and Journalism, <http://www.ncdj.org/>, to <http://www.ncdj.org/newsletter.php> for their newsletters or to <http://www.ncdj.org/styleguide.php> for a style guide for journalists.
- Go to the “Resources for Reporters” page of the web site of the Institute on Disability, <http://www.iod.unh.edu/reporters-room.html> for another style guide for journalists.

I am both the Executive Director of The Arc of Mississippi, and the father of a child with developmental disabilities. And after reading the article by Peggy Matthews (Residential community for retarded adults eyed) December 31, I feel compelled to respond.

I believe those working to create Son Valley have good intentions, but they should have learned years ago that segregation is not a viable option in America. Housing people with disabilities in segregated communities, no matter how new and spacious, is outdated and unacceptable. Segregation hurts not only our older neighbors and people with disabilities but also every single person who will be missing out on the opportunity to get to know them and learn from them. Almost every study done on segregation of people with disabilities shows they fare better when included in regular places, not segregated in special places.

If Son Valley becomes a reality, how often do you think that your children and grandchildren will have the opportunity to interact with the people who live there? Don't you think that you would have a much greater chance of meeting, interacting, and befriending a senior citizen with disabilities if he or she were residing in the same setting as your grandmother? Or do you even want to meet and learn from them? Is a diverse community important to you? Should longevity be punished by removing older people from society?

The Arc, as well as the rest of the disability advocacy field, has been tireless in its efforts to move our society forward, to eliminate the isolation of places like Son Valley and the stigmatization of individuals with disabilities. The Arc believes freedom and equality are unattainable in segregated environments. Son Valley would represent a giant leap backward for our society, back to a time when some members of our communities were worth less than others.

We MUST take advantage of the services and programs that organizations such as The Arc have worked so hard to supply in our state. We must keep all of our citizens with disabilities and our elderly citizens close to us. We must stand beside them, and learn from them, and appreciate them for being unique individuals. We cannot lock them away in segregated villages!

If you would like to discuss this further, please do not hesitate to call.

Matt Nalker

The Arc of Mississippi
7 Lakeland Circle Suite #600
Jackson Ms 39216
982-1180
matt@arcms.org



The Arc of the United States

*People First, Visionary Leadership,
Community Participation, Diversity, Integrity and Excellence*

Reply to:

1010 Wayne Ave., Suite 650
Silver Spring, MD 20910
(301) 565-3842 (301) 565-3843 Fax

Reply to:

1331 H St., NW, Suite 301
Washington, D.C. 20005
(202) 783-2229 (202) 783-8250 Fax

October 7, 2003

The Editor
State Journal Register

Re: Lincoln Developmental Center

To Whom It May Concern:

Your article on Lincoln Developmental Center Initiating a new era for LDC presents information out of step with today's realities for people with intellectual and developmental disabilities.

The article tells only part of the story of institutionalization and presents an impression for your readers that institutions may enjoy broad support. They do not!

It's likely that very few of your readers have ever actually been to an institution for people with developmental disabilities. Lincoln Developmental Center represents a concept whose time has past. In Illinois today, there are dozens of competent and caring service providers who are, daily, providing quality community services for people just like those at institutions like Lincoln. There are also thousands of people with developmental disabilities living in our communities with their families, many of them with aging parents, who need those and want same community services.

Deinstitutionalization has been taking place in the United States for the past three decades. In the 1990s alone there was a 44 percent decline in the number of persons in state-operated institutions. It's critical to note that primarily potential cost savings did not drive these reductions. Indeed, if cost were the only consideration, then we as Americans wouldn't enjoy many of the freedoms that make ours the greatest nation on earth. In many cases during the deinstitutionalization process, states "matched" someone leaving the institution with someone at home waiting for services. These institutions closed and others are continuing to close because it is the right thing to do.

Most of those providing services to people with disabilities in Illinois are not-for-profit agencies. Most rely on the generosity of donors and corporate partners to supplement the reimbursement that the state provides and do so for far less then the cost of state operated institutions.

As for cost, most studies show that while the cost of providing services within the community is the same or less as institutionalization, cost is not the reason to move people from institutions. Almost every study following people leaving institutions has demonstrated – by every quality of life indicators – that they are happier, healthier, and their families are more satisfied. The private (non-profit) sector can and does provide these services better then government. Government should stick to what it does well: funding, monitoring, and regulating service provision.

There are also significant resources in Illinois for training and technical assistance. Truth be told, most of the expertise and capacity is in the community, not at Lincoln. This is just a ploy to keep an outdated and outmoded facility open. Building small homes on the institution does not fool anyone, it is still an institution and is still a top-down state government program. Much less flexible than what is done daily, across Illinois, by the private sector.

The disability field has, over the past three decades, learned to separate “level of care” from real estate. They are two separate issues. Where the needed supports for a person take place and the frequency, intensity, and duration of those supports are two separate issues. There are no services available in large buildings that can't be provided more effectively in our neighborhoods, among family and friends.

The Arc as well as almost two hundred other organizations are part of a national movement to promote the “Community Imperative.” The “Community Imperative” states, in part:

- *All people have fundamental moral and constitutional rights.*
- *These rights must not be abrogated merely because a person has a mental or physical disability.*
- *Among these fundamental rights is the right to community living.*
- *All people, as human beings, are inherently valuable.*
- *All people can grow and develop.*
- *All people are entitled to conditions that foster their development.*
- *Such conditions are optimally provided in community settings.*

In fulfillment of fundamental human rights and in securing optimum developmental opportunities, all people, regardless of the severity of their disabilities, are entitled to community living.

Does it make sense to label and categorize people on the basis of some characteristic and treat them as if the condition they have is the most important thing about them? So important, in fact, that it is a legitimate interest of the state to offer alternatives for the provision of needed care and support that, in fact, force people to trade their human and civil rights for services? Doesn't our nation's Constitution have something to say about this?

If it is agreed that people should not have to essentially leave society in order to receive the basic support they need to live their lives, then it does not make sense to offer needed supportive services outside of the community setting. Again, this is not an issue of cost; it is an issue of civil rights. Other than in the criminal justice system, there is not another situation where such restrictions take place in our country, nor one that tolerates the effective control of one group by another.

Lincoln should be permanently closed. The people who lived there, with close cooperation of families or advocates, should be given choices of places to live in the wonderful communities of Illinois. The time has come.

Sincerely,

A handwritten signature in black ink, appearing to read "S. M. Eidelman", with a long horizontal flourish extending to the right.

Steven M. Eidelman
Executive Director

October 15, 2003

The Honorable Robert Ehrlich, Governor
State House
Annapolis, Maryland 21401

Dear Governor Ehrlich:

The Arc of Maryland applauds the legislative directive requiring a report from the Department of Health and Mental Hygiene for closure of a state residential center operated by the Developmental Disabilities Administration. We eagerly anticipate the Department's recommendation so that the civil rights of individuals living at these centers can be restored by responsible action to end the segregation that exists because of these institutions.

The Arc's national and state position statements call for the right of all persons with mental retardation to live in their community, with responsible closure of state institutions that includes individualized planning for quality community supports. Study after study concludes that the vast majority of individuals with developmental disabilities are living fuller, more socially interactive and productive lives in their communities than those in institutions.

As you know, Maryland closed Great Oaks Center seven years ago. Despite heated political debates, Great Oaks was closed. Individuals with complex medical needs who require ongoing medical and nursing attention moved to small community settings, supported by a network of community agencies and medical supports in local communities.

The Arc opposes "Community Resource Centers" located at state institutions for respite care, recreation, and medical services for people with developmental disabilities living in the community. Public dollars should not be spent repackaging segregated centers. Maryland rejected this concept thirty years ago and instead wisely chose to invest in building the infrastructure needed in the community. Public funds must be invested to strengthen the community infrastructure and supports, not for segregated, disabled-only centers.

The Arc advocates for responsible public and fiscal policy. However, public dollars should be invested in those human services that are cost-effective and reflect contemporary best practices, not in furthering or expanding large institutions. The state must not shirk its responsibility to make reasoned public and fiscal policy that balance the needs of people waiting for services with the demands of a few who either do not know what is possible for their loved one or reject their adult family member's right to new opportunities.

We offer our support and assistance to your Administration in your leadership efforts to ensure that all persons with mental retardation currently residing in state institutions have the opportunity for a quality life in the community.

Sincerely,

Ed Worff
President

Cristine Marchand
Executive Director

November 12, 2001

Mr. Nelson,

I appreciate your taking the time to respond to my letter of October 31. It's clear that you are giving the Lincoln Developmental Center issue a great deal of consideration. But I take exception to several points made in your column.

First, you state that your premise is "don't close the facility, fix the problem." The Arc believes that *the facility is the problem* – closing the facility is the only way to fix it. Scholars at Syracuse University have developed the Community Imperative, which The Arc endorses wholeheartedly. The Community Imperative states that all people are entitled to a full life within the community, *regardless of the level of disability*. No matter how idyllic a portrait you may paint of life at LDC, it is not life in the community. It is life apart from families, friends, and neighbors – and that is unacceptable.

As for your comment that I have "no clue about the resident population at LDC," I respond that I don't need to know anything other than that they have mental retardation or related developmental disabilities, and are therefore The Arc's constituents. It matters not one iota whether their disabilities are profound or whether they are functional enough to meet your acceptable standards. You argue that some of the population with mental retardation has been granted release from the institution. That's not good enough. LDC and other institutions like it should be closed, period. People who need a lot of supports can get them in the community. The level of support a person receives is not related to the size of the buildings in which they live. Anything you can do in big buildings, you can do in family-scale environments.

And incidentally, I am the parent of a son with a diagnosis of severe mental retardation, who has lived in his community with family and friends for his entire life. I feel that I do indeed "have a clue" about these matters. I have been a special educator for more than 20 years and have seen many institutions in those years. Being president of the largest volunteer-based advocacy organization for people with mental retardation has given me the opportunity to see programs across the United States in which people with mental retardation are living full and rich lives in their communities.

I'm pleased to learn that your newspaper employs several of our constituents. That's a good start. The next step is to school yourself in people-first language. You write about "retarded people" and people "impaired by mental retardation." The acceptable language in this day and age is "people with mental retardation." They are not "impaired by" or "afflicted with" or "suffering from" the condition. Please visit our web page at www.thearc.org and read through the Press Room section, where you'll find helpful language guidelines.

Lastly, the reason why my e-mail address is not listed in the staff directory on The Arc's web page is because I am not part of the staff. As president, I am a volunteer, as are the members of our board of directors and members of the boards of many of our state and local chapters. For those wishing to contact me, I can be reached at info@thearc.org.

Sincerely,

Karen L. Staley, President
The Arc of the United States

October 29, 2001

Dear Editor,

As president of The Arc of the United States, I read with stunned disbelief your editorial on the proposed closing of Lincoln Developmental Center (*Would We Close a Prison?*). The theme of the column – comparing people with mental retardation to criminals sentenced to prison – is so extreme and outdated that it could have been written at the beginning of the last century.

I take issue with a number of the specific points mentioned in the editorial. First, it is not a valid argument to say that people with mental retardation should remain institutionalized because “there is nowhere else for them to go.” This is reflective of a perverse “I don’t want them in my neighborhood” mentality that has led to years of discrimination and bigotry toward people with disabilities.

It is true that some people need full-time supervision and round-the-clock care, but you are confusing real estate with the need for support and care. There is nothing that is magic about big, old buildings. Anything that you can do there can be done better in highly individualized places near where families reside. We should be allocating resources to create community living opportunities where these services can be provided. The new jobs created in ensuring these services should allay your columnist’s fears about losing the jobs provided by the institution. The institution existed to serve people and we now have a better way of doing that. It never existed to be an employment program or a market for vendors in the community.

Study after study shows that people who leave institutions fare better than those who remain. When done properly, reuniting people with mental retardation and their communities is a thing of beauty. In fact, Illinois lags behind most states in the move toward community living and the people of Illinois should be outraged that so many of their sons, daughters, sisters, and brothers remain institutionalized.

Citing the impact of an institution on the local economy is as illogical as it is outrageous. Plenty of illegal activities – drug trafficking, prostitution, weapons sales – have been outlawed in this country despite the “jobs” and billions of dollars they generate. Institutionalization of people with disabilities is not a financial or economic issue. It is a question of each individual’s right to a full life in the community and the right to enjoy the freedoms our nation promises its law-abiding citizens.

In addition, the argument that residents of LDC would only be moved to another institution reflects the narrow thinking that has perpetuated institutionalization as a viable option for people with mental retardation. Ten states have no institutions at all, and the residents of those states are no more or less disabled than the people now trapped at LDC.

I can imagine no other explanation for supporting the continued operation of LDC than an irrational fear that people with disabilities might one day live in our neighborhoods. It

is that sort of bigotry that contributes to racial and ethnic discord in our country and others. Why is it assumed that the only other option is another prison-like institution? Why would residing in the community not be considered an option?

Lastly, and perhaps most incomprehensibly, the editorial states: “Would the state close a prison over similar allegations? Of course not. Because prisoners need to be in prison. It’s the same with LDC residents.” It’s hardly necessary for me to point out the foolishness of that statement. It is stated very clearly: People with mental retardation should be treated as criminals. And in fairness to prisoners in Illinois prisons, I would trust that “life-threatening conditions cited by state and federal inspectors” would indeed result in a discussion of whether or not to move those prisoners to another location.

I look forward to your next editorial. Here are a few suggested headlines: “Suspending Civil Rights – Why It Makes Sense”; “It’s Time To Arrest People Different From Us.”

Sincerely,
Karen L. Staley, President
The Arc of the United States

Voice of the People
Chicago Tribune
435 N. Michigan
Chicago, IL 60611
tribletter@tribune.com

As president of The Arc of the United States – an organization whose mission is to advocate for full inclusion in all communities – I am writing in response to an editorial submitted by Voice of the Retarded supporting institutionalization (December 16). That editorial contains the usual misleading assertions put forth by those who would keep people with disabilities locked away from their families and our communities.

The most glaring falsehood is that the population in institutions has “fallen under the radar.” To the contrary, this population is at the center of The Arc’s advocacy and has not for a moment been forgotten.

It’s likely that very few of readers of the Chicago Tribune have ever actually been to an institution for people with developmental disabilities. Even so, all Americans can appreciate our right to live in any neighborhood we choose, as equals. Assertions that institutional care has improved over the years are highly suspect, but more importantly, they are irrelevant. None of us would want to live in a “country club prison,” even if we were assured the accommodations were comfortable. Freedom means choices, and institutionalization bars even the most basic of these.

Deinstitutionalization has been taking place in the United States for the past three decades. In the 1990s alone there was a 44 percent decline in the number of persons in state-operated institutions. It’s critical to note that primarily potential cost savings did not drive these reductions. Indeed, if cost were the only consideration, then we as Americans wouldn’t enjoy many of the freedoms that make ours the greatest nation on Earth.

The Voice of the Retarded submission to Voice of the People questions the motives of those of us who want to reunite people with disabilities and their families. As a nonprofit organization, The Arc clearly has no financial motive. Our motive is to fulfill the mission of inclusion dictated by our constituents, the very people whose lives are in question here. Indeed, our motive is to work toward the day when an advocacy organization like The Arc is no longer necessary. We hope to one day work ourselves out of business.

In the interest of accuracy, here are a few facts: no person with a developmental disability has become homeless due to moving from an institution or from the closure of a group home; we advocates view occasional closures as a good sign, as it’s appropriate that those failing to deliver quality services are forced out of business; state institutions continue to operate regardless of their performance – and without regard for the families that have been torn apart by institutionalization.

The Voice of the Retarded also raises the issue of cost, another favorite argument of those supporting institutionalization. The truth is, most studies show that while the cost of providing services within the community is the same or less as institutionalization, cost is not the reason to move people from institutions. Almost every study following people leaving institutions has demonstrated – by every quality of life indicator – that they are happier, healthier, and their families are more satisfied. Why use taxpayer funds for services that families don't want, which produce poor results, and are outdated?

The disability field has, over the past three decades, learned to separate “level of care” from real estate. Where the needed supports for a person take place and the frequency, intensity, and duration of those supports are two separate issues. There are no services available in large, old buildings that can't be provided more effectively in our neighborhoods, among family and friends.

If Americans can agree that people should not have to essentially leave our society in order to receive the basic support they need to live their lives, then it does not make sense to offer needed supportive services outside of the community setting. Again, this is not an issue of cost or motives; it is an issue of civil rights. Other than in the criminal justice system, there is not another situation where such restrictions take place in our country, nor one that tolerates the effective control of one group by another.

Freedom is priceless and the desire to be free is a motive that cannot be questioned.

Sincerely,
Lorraine Sheehan, President
The Arc of the United States

**Joint Letter from The Arc
For Legislators, Governor and Media**

October 15, 2003

Dear :

We write as volunteer and staff leaders of The Arc at the national, state, and local levels in Maryland. Many of us are parents of individuals with mental retardation and related developmental disabilities.

The Arc applauds the legislative directive that calls for a report from the Department of Health and Mental Hygiene regarding closure of a state residential center operated by the Developmental Disabilities Administration. We eagerly anticipate that Maryland's legislature will recognize that the civil rights of the individuals now living at these centers can be restored by responsible action to end the segregation that exists because of these institutions. The Arc's national and state position statements call for the right of all persons with mental retardation to live in their community, with responsible closure of state institutions that include individualized planning for quality community supports.

But some voices in the public today advocate for the continued support of these same institutions. These voices express concern that being allowed to live in the community will compromise the safety and well-being of their family members. In contrast with their concerns, we offer the following data and observations.

Study after study concludes that the vast majority of individuals with developmental disabilities are living fuller, more socially interactive and productive lives in their communities than those in institutions when they have competent staff and receive appropriate supports. All of the studies published in 1990 or later reported significant improvements in challenging behaviors of individuals who moved from institutions to community settings. The research overwhelmingly concludes that adaptive behavior was almost always found to improve with movement to community settings from institutions. Moreover, family members, who were often as a group initially opposed to deinstitutionalization, were almost always satisfied with the results of the move to the community after it occurred. (Larson & Lakin, 1991). Studies based on over 2,600 subjects demonstrate strongly and consistently that people who move from institutions to community settings have experiences that help them to improve their adaptive behavior skills. People living in community programs funded by the Maryland Developmental Disabilities Administration have lower mortality rates than persons in the general public and than persons in state-operated institutions.

But we don't need to look further than Maryland to see this in practice. Seven years ago, Maryland closed Great Oaks Center, the state residential center located in Southern Maryland. Despite the anguish and heated political debates at the time, Great Oaks was closed. Individuals with complex medical needs that require ongoing medical and nursing attention moved to small community settings, supported by a network of community agencies and medical supports in local communities. Today, the Riderwood Retirement Village exists on the property, employing local workforce and contributing to the economy of the local community.

No parent really chooses to put his or her child in an institution. It is only when no other options are presented that a family “chooses” to take this heart-wrenching step. And no person with mental retardation “chose” to go to a state institution.

Many of us were told to forget we ever had a child with disabilities and to place them in an institution. Instead, we took our child home and raised him or her (typically with little or no public support or services), formed The Arc and got federal and state laws passed to educate our children in public schools. We sued for our children’s right to a public education. The Arc went on to get legislation passed for vocational rehabilitation, community services, Medicaid home and community programs, housing, and nondiscrimination and rights protections.

The 2000s are a different time for people with developmental disabilities. Thanks in large part to The Arc’s national, state and local advocacy, people with developmental disabilities and their families today have many more promising options. **Today, with a wide array of community alternatives, no parent has the right to deny an adult son or daughter the right to greater opportunity, growth and inclusion in our society. Moreover, the state acts irresponsibly – and violates the fundamental civil rights of people with disabilities - if it is coerced by a small, vocal group of parents to keep people in state institutions in the name of “parent choice” when appropriate, less restrictive community supports are possible.**

There are nearly 10,000 people with developmental disabilities waiting for services funded by the Developmental Disabilities Administration. What about “parent choice” for these families – many of whom have no choice but to wait for years for some help? It would be outrageous to allow a small number of parents or family members (with the support of institution employees who believe their current jobs are at stake) who are demanding their “choice” for institutions to force the state to admit people who are now living in the community with no services into an institution.

The Arc opposes the development of “Community Resource Centers” located at state institutions. Proponents of such centers want to locate respite care, recreation programs, and medical services for people with developmental disabilities living in the community at the state institution’s Community Resource Center. Public dollars should not be spent repackaging segregated centers. Maryland rejects this concept for such centers thirty years ago and instead wisely chose to invest in building the infrastructure needed in the community. Public funds must be invested to strengthen the community infrastructure and supports, not for segregated, disabled-only centers. Why should an individual be offered segregated, disabled-only recreation programs at a state institution when locally sponsored community leisure and recreation programs are available closer to or in people’s own neighborhoods? And why should a person go to a state institution for their medical care or treatment given the wealth of knowledge and experience that exists at facilities such as Johns Hopkins and the network of physicians and clinics throughout our communities?

The Arc has long advocated for responsible public and fiscal policy. The Arc at all levels has worked tirelessly and creatively to expand federal Medicaid revenues to states and particularly to the State of Maryland for DDA services. The Arc of Maryland is on record supporting tax measures, if necessary, to continue important services and programs. However, tax dollars should be wisely invested in those human services that are cost-effective and reflect contemporary best practices, not in furthering or expanding large institutions. The state must not shirk its responsibility to make reasoned public and fiscal policy that balances the needs of people waiting for services with the demands of a few who either do not know what is possible for their loved

one or reject their adult family member's right to new opportunities. It is inconceivable that this state would deny persons the opportunity for richer lives in the community by bowing to the wishes of a small vocal group of parents!

The Arc calls upon the Governor and State Legislature to fulfill the promise of existing Maryland State statute: "To promote, protect, and preserve the human dignity, constitutional rights and liberties, social well-being, and general welfare of individuals with developmental disabilities in this State." We offer our combined resources to provide any further information to you and invite you to visit people with multiple and profound disabilities living in your community.

Sincerely,

Lorraine Sheehan, President
Steve Eidelman, Executive Director
The Arc of the United States

Ed Worff, President
Cristine Marchand, Executive Director
The Arc of Maryland

David Rosenthal, Vice President
Kate Rollason, Executive Director
The Arc of Anne Arundel County

Eugene Mark, President
Fred Baughman, Executive Director
The Arc of Montgomery County

Ed Nolley, President
Stephen Morgan, Executive Director
The Arc of Baltimore

Steve Pyles, President
Mac Ramsey, Executive Director
The Arc of Prince Georges County

Tim Atkinson, Executive Director
Vikay Koontz, President
The Arc of Carroll County

Charles Reese, President
Harriet Yaffe, Executive Director
The Arc of Southern Maryland

Michael Shank, President
Joanna Pierson, Executive Director
The Arc of Frederick County

Roger Rima, Executive Director
The Arc of Talbot County

Nancy McKee, President
Tim Quinn, Executive Director
The Arc Northern Chesapeake Region

John Follet, President
Bob DeHaven, Executive Director
The Arc of Washington County

Tracy Eberhardt, President
Carol Beatty, Executive Director
The Arc of Howard County

Starr Todd, President
The Arc of Worcester County

"Draft letter to the editor written by Nancy Weiss of TASH in support of efforts to close an institution in Maryland."

Sample Paragraphs for a Letter to the Editor

(this letter would be too long for a letter to the editor but you may be able to use, or adapt parts for a letter that fits the situation in your state)

Dear Sir/Madam:

I've been closely involved in the efforts to close the Rosewood Center in Maryland. Recently, about 200 people took part in a rally to keep Rosewood open. About a quarter of the protestors were family members of Rosewood residents; more than half were employees and union members out to assure that their jobs remained secure; none were Rosewood residents expressing their own views on what the future should be for this institution.

I know hundreds of people with developmental disabilities and communicate regularly with many more. I don't know one person who lives in or has lived in an institution who would say that the institution was a good place. I know parents who want to keep their sons and daughters in places like Rosewood because it is what is known and what feels safe, but what is more important is hearing from adults with disabilities themselves. If it were true that the people who live at Rosewood choose to live there and don't want to move (as supporters for keeping the place open say) -- why have none of *their* voices been heard? You'd think at least a few residents who really want to see the place stay open might have been at the rally or have been interviewed since (because I don't believe that they are "too disabled to have a voice" as some people have implied).

A saying among advocates with disabilities is "Nothing About Me Without Me". Lots of people are happy to speak for and about residents of institutions. One group even calls itself "Voice of the Retarded" -- although not one person with a cognitive disability sits on their board or is represented among their leadership. No Rosewood resident was at the rally or has said since, "this is where I want to be". To me, that absence speaks volumes.

About half of the 200 or so people at the rally to keep Rosewood open were employees and members of the union (AFSCME). I suppose some employees may be fighting to keep Rosewood open because they truly believe it is what is best for the residents, but most of the employees made it very clear that they were there for their own interests, not those of the residents. The message of the union (and that of many of the politicians) was concern over the possibility of lost jobs. But as one State delegate said, "while jobs are important, lives are more important". It is indefensible to keep a portion of our citizenry locked up so that others can keep their jobs.

Institutions are not good places, or in the case of most of them, even benign places. By necessity they are regimented and are run to meet the needs of many, rather than the needs of each person for freedom and recognition. I hear enough horror stories to know that very often they are inhumane places. I do not think for a moment that everyone who works in an institution is a cruel, inhumane person -- probably exactly the opposite. Most people who work in these places are likely caring people who want to

be helpful; then there's a portion of people who are neither caring nor cruel but just show up and do their job; and then there are some who get a thrill out of being in charge, bossing people around -- staff who lack the maturity to separate out what's personal and what's not personal when the people they are supposed to care for are difficult and even aggressive (and this kind of behavior is clearly caused by stifling environments that rob people of their ability to have impact on their worlds). Responses to challenging behavior in places like these are often coercive, restrictive, and serve only to escalate already difficult situations.

It is a sad paradox that the individuals who have the most severe disabilities are the most likely to be placed in environments that directly produce the types of behaviors for which they are then punished and controlled. The sad reality is, the more people dislike living in institutional settings and having every aspect of their lives regimented, the more likely they are to attempt to protest against such treatment. The more demonstrative their protest, the more likely it is that their behavior will be viewed as an expression of their continued need for institutionalization and the less likely it is that their protest will be heard. When will we realize that when you deny an individual basic respect and freedoms, he or she is given little choice but to rebel?

Some (albeit likely a small minority) of the people who work in these places do things to innocent people that would make you cry. People are locked in closets; denied food; hit and pinched; tied up for days on end; paraded naked; sprayed with hoses; left in the dark; taunted and tormented; denied the use of bathrooms; subjected to water spray to the face, jalapeno pepper sauce to the mouth, or ammonia to the nose; subjected to sexual abuse; humiliated and dehumanized -- and much of this in the name of treatment. These are not things that happened in the forties, or that happened once, or even rarely. They are things that happen when people are put in places in which they are isolated not only from the pleasures of life but from the public scrutiny that serves to protect vulnerable people

Bad stuff is done to people when they are hidden from the public eye. Institutions are not OK, not for awhile, not for some people, and not just until we have something better. They should be closed and resources and expertise shifted to community settings.

At the Fairview Developmental Center (a state-run institution) in Huntington Beach, California, a staff person killed a fourteen year old young man who had autism and mental retardation by rolling him inside an exercise mat in an effort to control his behavior. The staff person was arrested. Testimony showed that as punishment for "non-compliant behavior" she had put a diaper across the young man's face to block his vision, rolled him in the mat, sat on the folded end of the mat and kept him there for more than ten minutes until he stopped kicking. The staff person's attorney argued that lay people might consider her reaction "improper" but that a room full of autistic students is "a different world". "These are socially undesirable people" the attorney went on to argue, "sometimes what a person has to do may seem strange and distasteful to others". The judge dropped charges and dismissed the case saying that he had no doubt that the staff person had caused the boy's death but that her actions were "between her and her conscience and not something for a court of law".

Across the country, individuals with disabilities as severe and health care needs as complex as the individuals continuing to reside at Rosewood, are being well supported

in the community. Nine states have closed all of their state institutions and are providing quality supports to all of their citizens with disabilities, even those with significant behavioral challenges and complex medical needs, with a range of services in the community.

The movement toward community living started over thirty years ago and research is unequivocal regarding which type of support results in better lives. People with disabilities living in the community experience improved quality of life in areas such as:

- opportunities for integration and social participation;
- contact with friends and relatives, participation in employment;
- opportunities for choice-making and self-determination;
- quality and duration of services received, protection from abuse and neglect; and,
- other indicators of a quality life.

Prior to community placement, many parents oppose the move to the community -- change is understandably worrisome. But research shows that almost without exception, once their sons and daughters are living in the community, their parents report increased satisfaction with the quality of supports and support for community placement for their loved one.

There is no other example in this country of people being locked up and segregated from society – except for prisoners incarcerated for their crimes. It is not just or reasonable to deny people the right to real lives in the real world when the success of community supports has been demonstrated across the country.

It is one of our country's greatest shames that we continue to keep people in institutions and an even greater disgrace that we try to convince ourselves and others that this removal from society and denial of rights is in the best interest of the people still in these places. It is time to end this era of segregation and begin one characterized by valuing and including all members of our communities.

Nancy Weiss
Executive Director, TASH

POSITION STATEMENTS

Position statements on issues can advance your cause in many ways:

- Developing position statements helps to achieve consensus among the members.
- Position statements guide the actions of everyone involved in the organization.
- Organization members evaluate their activities based on whether they fulfill or contradict the organization's positions.
- Advocates use position statements of their own or of other organizations when they approach legislators and other decision-makers.
- Jointly signed positions allow different organizations to come together in a united front.

This section of the tool kit provides sample position statements that your organization can endorse (such as *The Community Imperative*), adopt (such as The Arc/AAMR position on housing), or adapt for your own purposes. We include the positions of a number of Maryland organizations as an example of the pro-community work of people in one state. We also include the position taken by the national self-advocacy organization, Self-Advocates Becoming Empowered (SABE).

THE COMMUNITY IMPERATIVE A STATEMENT AGAINST INSTITUTIONALIZING ANY PERSON BECAUSE OF A DISABILITY

Center on Human Policy
Syracuse University

In Terms of Human Rights:

- All people have basic human and legal rights.
- These rights must not be taken away just because a person has a mental or physical disability.
- Included in these basic rights is the right to live in the community.

In Terms of Education and Support Services:

- All people are valuable.
- All people have strengths and abilities.
- All people have the right to services in their lives that support these strengths and abilities.
- These supports are best provided in the community.

So:

To meet basic human rights and get the best services, *all* people, no matter what their abilities, have the right to live in the community.

This version of *The Community Imperative* was developed by and for self-advocates in March 2000.

The preparation of this statement was supported in part by the National Resource Center on Supported Living and Choice, Center on Human Policy, School of Education, Syracuse University, through the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133A990001. Members of the Center are encouraged to express their opinions; however, these do not necessarily represent the official position of NIDRR and no endorsement should be inferred.

THE COMMUNITY IMPERATIVE A REFUTATION OF ALL ARGUMENTS IN SUPPORT OF INSTITUTIONALIZING ANYBODY BECAUSE OF MENTAL RETARDATION

**Center on Human Policy
Syracuse University**

In the domain of Human Rights:

- **All people have fundamental moral and constitutional rights.**
- **These rights must not be abrogated merely because a person has a mental or physical disability.**
- **Among these fundamental rights is the right to community living.**

In the domain of Educational Programming and Human Services:

- **All people, as human beings, are inherently valuable.**
- **All people can grow and develop.**
- **All people are entitled to conditions which foster their development.**
- **Such conditions are optimally provided in community settings.**

Therefore:

In fulfillment of fundamental human rights and in securing optimum developmental opportunities, all people, regardless of the severity of their disabilities, are entitled to community living.



POSITION STATEMENT



HOUSING

POLICY STATEMENT

All people with mental retardation and related developmental disabilities¹ have a right to live in communities of their choosing and be fully included with people who do not have disabilities. Children belong with their families. Adults should control where and with whom they live, with increasing opportunities to rent or buy their own homes.

ISSUE

Public policy has not kept pace with changes in what people want and need in housing. Historically, families that had a child with a disability either had to do without supports at home or place the child in an institution to get help. Institutions enforce an unnatural, isolated, and regimented lifestyle that is not appropriate or necessary. They also consume a disproportionate share of limited public resources.

As people left institutions and their family homes, they were placed into group homes, often larger than family-sized, owned by provider agencies or other entities. They still lacked control of where and with whom they lived. It is now clear that with carefully tailored and individualized supports and services people can grow and develop in housing they control, be it a house, an apartment, or a condominium, no matter how significant their disabilities.

However, people with disabilities who receive SSI cannot afford housing because they are among the poorest in the nation. They are, in fact, the low-income group with the highest level of unmet need for housing assistance. To add to the problem, Medicaid, the principal source of funding for services and supports, does not allow for its funds to be used for housing-related costs. In addition, a serious lack of accessible and affordable housing throughout the nation limits our constituents' ability to find a home.

POSITION

Our constituents should be empowered to live in accessible and affordable housing similar to that of people without disabilities. Necessary individualized supports and adaptations should be of their choosing and under their control or the control of their substitute decision-maker.

¹ "People with mental retardation and related developmental disabilities" refers to our constituency, *i.e.*, those defined by the AAMR classification and the DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.

Community over Institutional Placement

- Large congregate facilities are unnecessary and inappropriate for our constituents, regardless of type or severity of disability.
- People must receive individualized supports, including housing, as they leave institutions, and public funds must be shifted from institutions to the community so our constituents can transition successfully to community life.
- The health and safety of people must be safeguarded wherever they live, including when a facility is closing, and whenever a person is transitioning from one living environment to another.

Children

- All children need a home with a family that provides an atmosphere of love, security, and safety.
- Many families need individualized accommodations to enable them to provide a home for the child with a disability.

Adults

- People with disabilities should no longer be "placed" or made to fit into a program or facility. Rather, flexible supports and services must follow the person to the location he or she chooses, including their family home.
- People must be empowered with the opportunity to control their housing by renting or buying their own homes, whether a house, apartment, or condo. Thus public policies must ensure that they receive their fair share of all local, state, and national housing resources.
- Individuals with disabilities should live together only when they freely choose to do so.

Adopted: Board of Directors, AAMR
May 28, 2002

Congress of Delegates, The Arc of the United States (Provisional two-year adoption)
November 9, 2002



Contact Information:
John Sorensen or Missy Perrott
410-571-9320 or 410-974-6139
john@thecdrc.org
missy@thecdrc.org

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Position Statement from the Cross Disability Rights Coalition

The Cross Disability Rights Coalition (CDRC) is a group of people with disabilities, from Maryland ADAPT and People On the Go of Maryland. The CDRC is funded by a three-year grant from the Maryland Developmental Disabilities Council

The CDRC advocates for all people with disabilities to live in the community, not in nursing facilities or state residential centers. We are working on a goal of freeing people from nursing facilities and institutions and improving supports in the community so that people can have more control of their lives. Currently there is a funding bias in Maryland that favors institutionalization and segregation of people with disabilities. We are working to correct this outdated idea.

In addition to building CDRC into an influential and powerful group, we have two main goals: to get people out of nursing facilities or state residential centers, with full funding for community services; and to change the current system to one that ensures people who transition from nursing facilities or state residential centers do so with tools of self-determination.

Working for
communities that include
and support everyone



MARYLAND
DEVELOPMENTAL
DISABILITIES
COUNCIL

Position Statement on *Community Living*

All people with developmental disabilities, including people with the most intensive support needs, belong in our communities with the support they need.

Institutionalization is not justified when experience and research provide evidence that people with significant disabilities -- including individuals with intensive support needs and complex health issues -- can be supported successfully in the community.

This is not a vision statement -- it is reality.

We know this because:

Individuals with the same type of needs as people currently in institutions like Rosewood Center are being supported safely in the community now -- by their families and in community programs. This includes people with trachs, g-tubes, people who don't speak, and people who rely on others for support with all activities of daily living.

- Nine states have closed all of their institutions for people with developmental disabilities.

Experience and research demonstrate that community placement has been successful and yields greater benefits and quality of life than institutional placement.

We no longer segregate any other group of people from society unless they have committed a crime. It is not acceptable to segregate people with disabilities in institutions when we know their needs can be met in the community.

Contact: Brian Cox, 410-333-3688 ext 2

The Maryland Developmental Disabilities Council advocates for public policy and supportive practices and opportunities that promote the full inclusion of all people with developmental disabilities in community life.

300 W. LEXINGTON STREET, BOX 10, BALTIMORE, MD 21201
410-333-3688 • 800-305-6441 • FAX: 410-333-3686 • MD RELAY: 711 • www.md-council.org

JEFF RIVES, CHAIRPERSON • BRIAN COX, EXECUTIVE DIRECTOR

THE ARC OF MARYLAND'S POSITION STATEMENT
REGARDING
"RESIDENTIAL OPPORTUNITIES"

- o The Arc of Maryland believes that all persons with mental retardation, regardless of the nature or severity of their disability, can live in and contribute to their communities.
- o The Association believes that the individuality of persons with mental retardation is best fostered in integrated settings in regular neighborhoods where life experiences follow the normal flow of community life.
- o The Association believes that persons with mental retardation have a right to necessary support through comprehensive community services that promote independence, integration, and productivity, and health and safety.
- o The Association believes that citizens with mental retardation should play an integral role in community life and that through their experiences, we are all enriched.

Therefore, The Arc of Maryland strongly supports and will advocate for the full inclusion and participation of all persons with mental retardation into the community in small, typical housing arrangements in regular neighborhoods.

National studies on residential opportunities support the premise that persons with mental retardation who receive services at home or in community settings make more progress toward integrated, independent and productive living than those who live in large institutions. Research and innovative examples indicate that, given the proper supports, persons with mental retardation can lead successful lives in their communities.

Consistent with this policy, the Association supports the responsible closure of state residential centers within a five year period. This must include a flexible approach that takes into account the individual's needs. The Arc of Maryland believes that the following principles should be applied to ensure responsible closure of state residential centers:

- o Thoughtful and definitive planning must occur to ensure that persons are transitioned only to quality and appropriate community services.
- o Administrative decisions that close state residential centers by shifting individuals from one institution to another and further remove people from their families against their wishes are unacceptable.
- o Comprehensive placement plans, consistent with the individual's needs, should be developed for each person to ensure that services are provided in accordance with that person's needs and requirements. No person should be relocated in the absence of such a comprehensive plan.
- o Public officials, advocates, families and service providers have a responsibility to persons moving to the community. In the event of projected closure of a state residential center, a task force representing these interests should be established to ensure a thorough and effective planning process.

June 21, 1991 Adopted by the Arc of Maryland's Board of Directors



Mid-Atlantic Chapter of TASH - Maryland, Washington D.C.

MASH is the Mid-Atlantic chapter of TASH, an international membership association of people with disabilities, their family members, other advocates, and professionals leading the way for over thirty years to inclusion, opportunity, equal access, and best practice based on research for people with disabilities. TASH calls for funding and public policy that enables people with disabilities to have the supports they desire and require while living in their own home, in the community of their choice.

MASH members are working to change systems so that people with disabilities and their families are in control of the funding and the choices that ensure a successful life in the community. MASH supports the full inclusion of people with disabilities internationally. Full inclusion is not a privilege for people; it is a right and supported effort on the part of the entire community. People's communities offer them real choices for home, family, employment and the range of value that most citizens enjoy.

Therefore, MASH believes that opening, operating, and accepting enrollment in segregated institutions denies citizens with disabilities their fundamental rights, and is counter to the movement to ensure equal access and community participation.

MASH inherits the positions of TASH on Choice, Community Living, Supports in the Community, Deinstitutionalization, and the Cessation of Capital Investment in Segregated Settings (see attached).

MASH joins many other Maryland Citizens, with and without disabilities, to fully support the continued downsizing and eventual closing of Rosewood and other institutions in Maryland. We, in fact, refute statements that see segregated facilities as "vital and deserving" with facts, financial information, opportunities, technical resources and most importantly by stories of many, many citizens with disabilities and intense medical and support needs living successfully in the community.

Community services in the state of Maryland have been designed to support people in community settings, regardless of their disability label or level of required services and assistance. To most of the public's surprise, these services cost less or are relatively equal in cost to keeping institutions open.

MASH urges the citizens of Maryland to support citizens that challenge our society in having meaning and quality in their lives by assuring that public dollars are spent to support people to live in the community with the support that they need.

MASH supports the meaningful and careful planning, transition and consideration for people in institutions as they move into their communities and exercise citizenship.

MASH members offer support and facilitation to the residents of institutions, friends, families, legislators, etc., so that they may meet other citizens in Maryland whose lives, with the support necessary, are those of value and quality. MASH also offers facilitation to assist in the process of moving out of institutions; and selecting community based services and supports.



ADVOCATES CALL FOR BUILDING COMMUNITY CAPACITY
TO SERVE PEOPLE WITH DISABILITIES AND ENDING
SEGREGATION IN INSTITUTIONAL SETTINGS

For Immediate Release
September 29, 2003

People On the Go of Maryland
Phil Weintraub, Chair
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Cross Disability Rights Coalition
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Mid-Atlantic Chapter of TASH
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People On the Go (POG), Maryland's Statewide Self-Advocacy Group; The Cross Disability Rights Coalition (CDRC) an advocacy group of persons with disabilities; and MASH, the Mid-Atlantic chapter of TASH, an international membership association of people with disabilities, their family members, other advocates, and professionals; The Arc of Maryland; and the Maryland Developmental Disabilities Council (MDDC) call for the end to funding bias in Maryland that favors institutionalization and segregation of persons with disabilities. Members of these groups will attend a Rally in the Rosewood Gymnasium at 7:00 PM tonight to oppose efforts aimed at preserving the viability of the Rosewood Center, one of the State's four remaining institutions for people with disabilities.

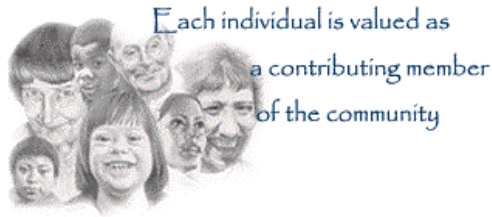
It is the position of these statewide advocacy groups that all individuals, regardless of disability, have the right to live in the community and that **all people** with disabilities, with the proper supports and planning, can live in the community.

POG, CDRC and MASH, The Arc and MDDC join many other Maryland citizens, with and without disabilities, to fully support the continued downsizing and eventual closing of Rosewood and other institutions in Maryland. We, in fact, refute statements that see segregated facilities as "vital and deserving" with facts, financial information, opportunities, technical resources and most importantly by stories of many, many citizens with disabilities and intense medical and support needs living successfully in Maryland's communities.

POG, CDRC and MASH, The Arc and MDDC believe that people with disabilities should be able to live, work and worship in the community like everyone else, and support the meaningful and careful planning, transition and consideration for people in institutions as they move into their communities and exercise citizenship.

For more information please refer to position statements attached, and/or contact one of the above representatives.

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January 2004

Community Supports Fact Sheet

Deinstitutionalization has been taking place in the United States for over three decades. In the 1990s alone there was a 44 percent decline in the number of people in state-operated institutions. Potential cost savings did not drive these reductions. These institutions closed and others continue to close because it is the right thing to do.

In FY 2004, Maryland Developmental Disabilities Administration (DDA) funds 22,000 persons with developmental disabilities in a comprehensive array of home and community-based supports. These include in-home family support, daytime therapeutic and medical day care programs, employment and supported employment, respite care, and out-of-home residential services ranging from a few hours a day to 24-hour awake, overnight staff. Nearly 11,000 people are on the Waiting List for community services.

The 22,000 people receiving DDA-funded community services comprise a wide range of ages, family situations, and level and type of disability. Some individuals need a few hours a week to help them live independently and keep a job. Others receive intensive medical interventions, life-sustaining therapies and technologies, ongoing therapeutic services like physical therapy, and emergency medical support.

- **Health and Safety**

In Maryland, persons with developmental disabilities receiving DDA-funded services in community programs have lower mortality/death rates than the general public. Despite sensational propaganda by some groups that community programs are not safe, vulnerable individuals receiving community services in Maryland are actually safer than the general Maryland populace.

<u>Death Rate/ Per 1,000¹</u>	<u>2000</u>	<u>2001</u>	<u>2002</u>
General Population	8.2 per 1,000	8.1 per 1,000	8.2 per 1,000
DD Community	7.6 per 1,000	5.9 per 1,000	7.2 per 1,000

- **Quality of Life**

Community living affords greater opportunities for full participation in the social and economic life of our communities, is effective and yields demonstrably greater benefits for individual with disabilities than institutional careⁱⁱ.



People living in community-based residences had larger social networks than did people living in state-operated residential campuses... People living in community-based residences had more people...in their social networks than did people living in state-operated residential programs.ⁱⁱⁱ

Research overwhelmingly demonstrates that the vast majority of individuals are living fuller, more socially interactive, productive, and independent lives in their communities than those in institutions when supported by competent staff and receive appropriate supports.^{iv}

Parent's views – Prior to community placement, many parents oppose community placement for their son/daughter. However, following placement, surveys report increased satisfaction and support for community placement for their loved one.^v

- **Market Demand**

10,865 people are on DDA's Waiting List for services and have requested over 17,000 community services.^{vi} They want services in their local communities, where their loved ones can be close to family and friends. There is a question of fairness when "choice" is used to justify the most costly services in institutions, while others have nothing.

- **Invest in Services not Buildings**

There is nothing magical about the services provided within the four walls of an institution that cannot be provided in a community program that is smaller and more like a real home.

The cost of physically maintaining institutions is inordinately expensive given the number of people who benefit. For example, \$4.3M proposed in 2003 to update one institution's electrical system averages over \$20,000 per person living there.^{vii}

\$4.3M could buy:

- Community services (including residential, day and resource coordination) for one person on the waiting list for 62 years. Or one year of service for 62 people.^{viii}
- Intensive community services for a person with significant, multiple needs for 31 years.^{ix}

ⁱ Source: Maryland Department of Health and Mental Hygiene

Note: General Population Rates for Calendar Year 2002 being compiled; General Population statistic anticipated to be similar as for 2002 and 2001.

ⁱⁱ Lakin, K.C. (1999). *A review of literature of home and community services for persons with mental retardation and related conditions*. Minneapolis: University of Minnesota, Research and Training center on Community Living, Institute on Community Integration.

ⁱⁱⁱ *Social Networks of People with Mental Retardation in Residential Settings*. Robertson, J. et al. June 2001. Mental Retardation – American Association on Mental Retardation.

^{iv} *Status and Changes in Medicaid's Intermediate Care Facility for the Mentally Retarded: Results from Analysis of the Online Survey Certification and Reporting System*; Larson, S.A. and Lakin, K. Charlie. Minneapolis: University of Minnesota, Center on Residential Services and Community Living/Institute on Community Integration, 1995.

^v Conroy, J. & Bradley, V. *The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis* (1985). Temple University, Philadelphia, PA.

^{vi} Source: DDA, August 2003

^{vii} \$4,300,000 divided by 213 people (average client population at that institution) = \$20,188

^{viii} Average cost of community services = \$68,669 (source: DDA budget, FY2004)

^{ix} Based on the average cost of institutional care = \$137,595 (source DDA budget, FY2004)



MARYLAND DEVELOPMENTAL DISABILITIES COALITION

People on the Go of Maryland • The Arc of Maryland

Maryland Association of Community Services

Maryland Developmental Disabilities Council • Maryland Disability Law Center



Position Statement on Closing Institutions

We believe that all institutions,
both private and public should be closed.
All people regardless of the severity of their
disability should live
in the community with the support they need.

by Self-Advocates Becoming Empowered
Adopted April, 1995



Self-Advocates Becoming Empowered:

SABE is a coalition of state and local advocacy organizations, directed by regional representatives, and its purpose to ensure people with disabilities are treated as equals and that they are given the same decisions, choices, rights, responsibilities, chances to speak up to empower themselves, opportunities to make new friendships, and learn from mistakes as everyone else.

*Self-Advocates Becoming Empowered (SABE) is the US national self-advocacy organization. It was formed in 1991 and describes itself as an "active organization that is like a family." It has 18 elected board members who meet four times a year in different cities. Some of the things that the board does to forward the movement include: *Advocacy Action*—keeping members up-to-date of various advocacy opportunities; the *Campaign for Freedom*—working to push for closing institutions; *Self-Advocacy Development*—supporting people who want to find out more about self-advocacy and start state organizations; and *Public Relations*—putting out newsletters, membership information, making videos, and most recently a music CD.*

THE OLMSTEAD DECISION

For years, advocates have filed lawsuits and promoted legislation to close institutions and to establish rights to community services. While the results of such efforts have varied, there are now many precedents for use by advocates. The most promising of these, the Olmstead decision, is described below. Advocates can use this decision in many ways, whether on behalf of one individual or on behalf of the cause of institutional closure.

The Olmstead Decision

On June 22, 1999, in a 6-3 opinion written by Justice Ruth Bader Ginsburg, the Supreme Court affirmed a ruling by the United States court of Appeals for the Eleventh Circuit that **unjustified isolation of individuals with disabilities is properly regarded as discrimination based on disability.**

The Court ruled in Olmstead v. L.C. & E.W. that “[U]nder Title II of the ADA, States are required to provide community-based treatment for persons with mental disabilities when the State’s treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.”

While the Olmstead decision does not state that institutions must be closed or depopulated, it provides very strong leverage to advocates who know that individuals with significant disabilities can live in the community, with the appropriate mix of supports. It establishes that all people have civil rights and that there are legal requirements that must be met by states. It gives people with disabilities and their advocates the legal right to request community services and to waiting lists that move at a reasonable pace.

Your own state may have developed a plan to implement the decision, as was recommended by the Court and the Department of Health and Human Services. The plan should include information on how many people currently in institutions want to move out, and should set timetables for getting people out of institutions. In states with a good Olmstead plan, advocates can review the plan and assess whether the state’s actions and policies are in accordance with the plan. In states with an inadequate plan, or with no plan, advocates should refer policymakers back to the decision itself and insist that the rights it establishes are not to be abridged due to economic considerations, bad or no planning, or any other excuses. So-called “Olmstead planning” is not required by the Olmstead decision. In fact, if little change has occurred in a state in the years since the decision, it is reasonable to assume that a plan will not make the difference. Instead, advocates should look at how their states spend their money. Are they building capacity for serving more people in the community? Are they developing policies and funding streams so that people can more easily

move into the community? Are the state waiting lists shrinking? Use these and other such questions to bring attention back to the issue of whether states are meeting the mandate posed by the Olmstead decision.

Note: a section on litigation will be developed at a later date. It will be available on the Tool Kit web site and by contacting the organization that provided you with a copy of the Tool Kit. Please let them know if you wish to have the litigation section when it has been completed.

RESOURCES:

There are many resources now available about the Olmstead decision:

- The National Council on Disability report, *Olmstead: Reclaiming Institutionalized Lives*, can be found at <http://www.ncd.gov/newsroom/publications/2003/reclaimlives.htm> (abridged and full-length versions both can be downloaded).
- The National Council of State Legislators has a site from which one can access its publications about states' Olmstead issues and implementation, <http://www.ncsl.org/programs/health/Onews.htm> and one that can be searched for information on how each state is dealing with long term care: http://www.ncsl.org/programs/health/forum/lc/LTC_draft.htm
- For the decision itself, go to <http://supct.law.cornell.edu/supct/html/98-536.ZS.html>
- The Centers for Medicaid and Medicare Services, CMS, presents the position of the federal government at <http://www.cms.hhs.gov/olmstead/default.asp>
- Freedom Clearinghouse is a project of Free Hand Press, publisher of *Mouth* magazine. Tap its Olmstead information and find hundreds of strategies, mounds of information, and lots of encouragement: <http://www.freedomclearinghouse.org/know/olmstead.htm>

INCLUDED WITH THIS SECTION AS BACKUP DOCUMENTS:

Community Integration/Medicaid. (2004, May 26). Washington, D.C.: National Association of Protection and Advocacy Systems (NAPAS). Available: <http://www.napas.org/l-3/l-3-D/community%20integration-medicaid%20home.htm>

National Council on Disability. (2003, September 29). Executive summary. In *Olmstead: Reclaiming institutionalized lives* [Abridged Version] (pp. 1-8). Washington, D.C.: Author. Available: <http://www.ncd.gov/newsroom/publications/2003/pdf/reclaimabridged.pdf> or <http://www.ncd.gov/newsroom/publications/2003/reclaimabridged.htm>

NAPAS

The Association for the
Nation's P&A/CAP Network

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Community Integration/ Medicaid

Page last updated: 5/26/04

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[Statutes and Regulations](#)

[Resources](#)

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Executive Summary¹

The extent of unnecessary institutionalization of people with disabilities in the United States is daunting. Research and experience have shown that the great majority of people who live in large congregate settings could be supported safely and effectively and enjoy a higher quality of life in a typical home in the community. Longitudinal studies of community placement document their more favorable outcomes and furthermore establish that persons with significant disabilities benefit the most from community placement. Similarly, comparing residents of nursing facilities with elders, children with complex health needs, and adults with physical disabilities living at home shows that nursing facility residents are not more severely disabled than those who receive support in their own homes. Yet, 106,000 persons with developmental disabilities lived in public and private institutions and more than 1,300,000 elders and persons with disabilities lived in nursing facilities in the year 2000. In addition, data on the outcomes of consumer-directed mental health services and intensive case management models show that most of the 58,000 persons currently confined in psychiatric institutions could be supported in their own homes in the community. The persons who fill the more than 800,000 licensed board and care beds in the United States could also live in the community.

In this report, the National Council on Disability (NCD) assesses the nation's response to the United States Supreme Court's decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999) that the unjustified institutionalization of people with disabilities is a form of discrimination. NCD's research reports on the extent of unnecessary institutionalization in the United States, the continuing barriers to community placement, and resources and service models that facilitate community integration. NCD examines the Federal Government's implementation efforts and the strategies states and key stakeholders are using to (1) develop consensus on a coordinated action plan, (2) identify and commit the necessary resources for community-based service options, and (3) sustain collaborative action toward creating real choice for people with disabilities living in institutions. NCD collected extensive information, available online in the electronic version of this report at www.ncd.gov/newsroom/publications/reclaimlives.html, on the states' experiences in the planning and implementation of the *Olmstead* decision.

¹National Council on Disability. (2003, September 29). Executive summary. In *Olmstead: Reclaiming institutionalized lives* [Abridged Version] (pp. 1-8). Washington, D.C.: Author. Available: <http://www.ncd.gov/newsroom/publications/2003/pdf/reclaimabridged.pdf> or <http://www.ncd.gov/newsroom/publications/2003/reclaimabridged.htm>

The *Olmstead* Decision

In 1999, by a clear majority, the United States Supreme Court held in *Olmstead v. L.C.*, 527 U.S. 581 that, under the Americans with Disabilities Act (ADA), undue institutionalization qualifies as discrimination by reason of disability and that a person with a mental disability is “qualified” for community living when the state’s treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the individual, and the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities.

Whereas the justices agreed that the state is not required to provide immediate relief in the form of community placement where such relief would represent a “fundamental alteration” of the state’s programs, the majority did not agree on what constitutes a “fundamental alteration.” Only four justices agreed on the interpretation of the fundamental alteration defense set forth in Justice Ginsburg’s opinion: that the defense should be construed to “allow the State to show that, in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities” (527 U.S. at 604, emphasis added). Justice Ginsburg added that demonstrating that it has “a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings” is one method a state may use to show that it already has reasonably modified its programs and that no further alteration is necessary. This statement became the basis for the *Olmstead* planning initiatives.

Barriers to Community Integration in the United States

Representatives of all disability groups agreed that lack of affordable and accessible housing is the single biggest barrier to community integration in the United States. Persons with disabilities whose incomes depend on government benefits need housing subsidies or shared housing to live in the community. Unfortunately, because of systemic barriers, people with disabilities tend not to receive their fair share of the approximately \$7 billion in federal housing subsidy programs, and the various Section 8 housing subsidy programs targeted to persons with disabilities are funded at a relatively modest amount (\$271 million in 2001) in comparison. An additional barrier is the lack of meaningful collaboration between human services agencies and housing agencies. High unemployment rates for persons with significant disabilities (typically 60 to 90 percent) maintain dependence on public benefits.

Low wages and benefits severely limit the availability of personal assistants and other direct support professionals. In turn, low wages are the result of low reimbursement rates for community services. Lack of quality health care and dependable transportation are also significant barriers.

The institutional bias of the Title XIX (Medicaid) program, in which home- and community-based waiver-funded services and personal care are optional whereas nursing facility services are required and financial eligibility rules for institutional residents are more generous than those for people living in their own homes, greatly compounds the problem. Title XIX waivers have significantly expanded available funding for home- and community-based services but have not leveled the playing field; because state governments do not recognize home- and community-based waiver services as entitlements, waiting lists for waiver services are long in most states. The unavailability of Title XIX reimbursement for services to adults below the age of 65 in Institutions for Mental Diseases (IMDs) poses a significant barrier to the use of home- and community-based waivers to fund community mental health services.

Delivering on the Promise

On June 18, 2001, President George W. Bush, pursuant to his New Freedom Initiative, issued Executive Order No. 13217, committing the Administration to implement the integration mandate of the ADA as interpreted in *Olmstead*. The Executive Order required federal agencies to promote community living for persons with disabilities by providing coordinated technical assistance to states; identifying specific barriers in federal law, regulation, policy, and practice that impede community participation; and enforcing the rights of persons with disabilities. Pursuant to the Executive Order, federal agencies evaluated their own programs to identify barriers and issued their final reports on March 25, 2002.

Altogether, the reports acknowledged the many barriers to community integration of persons with disabilities, including the institutional bias of the Medicaid program, unaffordable and inaccessible housing, a critical shortage of personal assistance and direct support professionals, and the unavailability of supported employment. However, most of the proposed agency actions consisted of technical assistance, training, research, demonstration, policy review, public awareness campaigns, outreach, enforcement of existing regulations, information dissemination, convening of advisory committees, and interagency coordination and collaboration. Systemic solutions, measurable goals, timelines, deliverables, and outcomes were lacking.

In early 2003, President Bush's Administration announced a five-year program beginning in FY 2004, the "Money Follows the Individual" Rebalancing Demonstration, to enable people with disabilities to move from institutions to the community. The program would provide 100 percent federal funding for home- and community-based waiver services for one year for a person leaving an institution, after which the state would agree to continue to provide services for the person at the regular Medicaid matching rate.

The States' Response

After *Olmstead* was decided, the Department of Health and Human Services (HHS) provided guidance to the states concerning the development of "comprehensive, effectively working plans" in increasing community placements. In addition, *Olmstead* stakeholders concluded that state implementation plans could have value both as an organizing tool for achieving deinstitutionalization and as a method to persuade states to commit to numerical targets, timelines, and allocation of resources. Although the experiences of states and stakeholders in implementing *Olmstead* varied widely, NCD's evaluative study documents some key overarching findings, including the following:

- Plans do not consistently provide for opportunities for life in the most integrated setting as people with disabilities define "the most integrated setting."
- The majority of states have not planned to identify or provide community placement to all institutionalized persons who do not oppose community placement.
- Few plans identify systemic barriers to community placement or state action steps to remove them and few plans contain timelines and targets for community placement.
- State budgets often do not reflect *Olmstead* planning goals.

Lessons Learned: Good Practice in Community Services and What Works

The following are some of the many examples suggested by this report of promising practices in the design, delivery, and financing of community services.

- **Good practice in *Olmstead* planning.** Indiana's recent plan assigns each recommendation to one of three categories: those that should be implemented quickly and with little or no fiscal impact or regulatory requirements; those that should be implemented quickly but have a fiscal impact or require regulatory changes; and those that are more complex, costly, or difficult and will require

more time to develop and implement. Indiana's plan should serve as a model for other states. Nevada's *Olmstead* plan is commendable for its candid analysis of the state's compliance with *Olmstead*.

- **Overcoming incentives to unnecessary institutionalization.** Methods include Maine's use of pre-admission screening by an independent agency prior to nursing facility placement, Minnesota's legislation encouraging nursing facility operators to take beds out of service, and Washington's system for tracking reduction targets for nursing facility placements.
- **Identification and transition of people with disabilities from institutions.** In Colorado and Kansas, disability rights advocates are doing the work of identifying people in nursing facilities who could move to more integrated settings.
- **Use of trusts and fine funds to finance transition costs and start-up of community services.** A creative and underappreciated set of strategies for financing transition costs, providing "bridge funding," and funding new community services involves the creation of trusts and fine funds dedicated to the needs of people with disabilities. North Carolina, Oregon, and Washington have used the proceeds from the sale of state facilities to establish trusts to generate funds for people with disabilities.
- **Housing strategies.** Commendably, and in large part because of the influence of the technical assistance provided by the Department of Health and Human Services' (HHS') Office of Civil Rights (OCR), the more recently developed plans tend to reflect the input of housing agencies. Provisions for requiring universal design in new units that state housing agencies fund or finance; ensuring that all existing publicly financed housing has completed Section 504/ADA self-evaluations; conducting utilization reviews to ensure that targeted Section 8 programs are fully used; and including home modifications and home repair in the services provided under home- and community-based waivers and independent living programs are examples of housing-related recommendations in state *Olmstead* plans.
- **Single point-of-entry systems.** Single point-of-entry systems have the potential to reduce unnecessary institutionalization by providing easier access to a wider array of community services. Single point-of-entry systems that separate "assessment" and "service brokerage" from "service provision" are also responsive to the Centers for Medicare and Medicaid Services (CMS) findings in a number of states that Medicaid beneficiaries' right to choose among qualified providers was violated.

- **Beyond institutional closure: Increasing community integration.** Developmental disabilities services in Vermont and New Hampshire show that, more than placement in a residence outside an institution, “the most integrated setting” is a continuous process of increasing community inclusion. These states’ service systems have progressed far beyond institutional closure and are eliminating group homes in favor of living in a companion home or a home of one’s own and working at a real job with support.
- **Self-determination.** Self-determination and consumer-directed service models have been so broadly tested and practiced that they have emerged as fundamental principles in human services.

Recommendations

On the basis of its research, NCD recommendations for the Federal Government include the following:

- HHS and CMS should provide more explicit guidance on implementation of *Olmstead v. L.C.*
- CMS should determine whether the states are adequately identifying residents of Medicaid-funded and -certified facilities that can handle and benefit from community living.
- HHS should refocus its Real Choice Systems Change grant program as a true system-change project by shifting from funding demonstration projects to funding change that affects entire service systems.
- HHS should require the states to identify all institutionalized persons in the state and their need for community services.
- CMS should use its waiver approval authority to require the states to minimize “institutional bias” in the choice between institutional and home- and community-based waiver services.
- HHS should provide federal financial assistance to states to provide small grants to people with disabilities for transition costs from institutions to community.

Conclusion

The *Olmstead* decision has become a powerful impetus for a national effort to increase community-based alternatives and eliminate unjustified institutional placements. Ultimately, only comprehensive amendments to Title XIX of the Social Security Act, similar to the amendments proposed in MiCASSA (the Medicaid Community-based Attendant Services and Supports Act), will overcome the institutional bias within

the Medicaid program. In the meantime, however, federal agencies have many measures, short of a thorough revision of Title XIX, they can and should undertake. We must continue to empower *Olmstead* stakeholders in their state “systems change activities,” that is, in their efforts to redesign the state service systems to enhance choice, independence, self-determination, and community integration. Our nation will be much more prosperous when it makes real the right of people with disabilities to live in the most integrated setting.

V. Personal Stories

- a. Stories Collected in Anaheim, CA, May 2004
- b. Stolen Lives Campaign Stories – May 2003,
“Seeking Ways Out Together” (S.W.O.T.)
Team, Titusville, New Jersey
- c. Liz’s Story

PERSONAL STORIES

Advocates can often make their point most powerfully through the personal stories of people who have lived in institutions, in the words of the person if at all possible, and/or of family members who are pleased with life in the community for their loved one. Most convincing are the stories of people who live in the state or locality of the institution being considered for closure (or re-opening). We strongly encourage the local collection of such stories; listed below are some tips for "story-collectors," with an emphasis on the stories of people with disabilities.

How Can Personal Stories be Used by Advocates?

People's stories, or collections of stories, can be used in many ways. They can be given to the media, with an invitation to meet with the narrator(s). They can be given to legislators and policymakers. They can be submitted as testimony during hearings and public forums; even more powerfully, the people can give their testimony in person, submitting their narratives (written or video) as part of their testimony. They can be used to educate parents, people with disabilities, and people in institutions about possibilities in the community. For example, a woman in New York testified at a public forum with her son with a disability, on the topic of a proposal to make drastic cuts in Medicaid-funded services. She asked the legislators present to look him in the eye and picture his future if his services were to be cut back to the extent proposed, and ended her testimony with a handout that included pictures of him and their family.

What Can Story Collections Look Like?

Most commonly, personal narratives are collected in written form, often accompanied by photographs of the people who are featured. Some people have written books about their lives (Johnson, 1999), and the stories of many others have been published in collections (Campaign for Freedom Team, 2000; Hayden, 1997; Pratt, 1998). Increasingly, stories are being put on the World Wide Web (http://www.selfadvocacy.com/Jerry_Smith_article.htm), sometimes with audio components. Story collections have also been captured on videotape and even audiotape, as in the case of Roland Johnson's book, Lost in a Desert World, which is available on audiotape for nonreaders and lovers of books-on-tape (Johnson, 1999).

How Can Advocates Collect Personal Narratives?

Some tips for collecting personal stories are:

- Find a variety of people whose stories should be told. You want to show that everyone can live in the community, so feature stories by people with a variety of challenging circumstances (medical, behavioral, familial, etc.) as well as people without so many challenges.

- Make sure the stories of people who don't use speech are told. Some such stories can be written by a person who uses augmentative, assisted, or facilitated communication. Others can be told by family members, friends, or direct support workers of people who don't use speech.
- In the narratives, there is no need to represent the community as a utopia, perfect and without problems. The stories should reflect people's real lives.

Many resources can be approached for the purpose of collecting one or more personal stories, if you and your organization don't have the time to do so. Self-advocacy groups and their advisors are often very willing to work on a project of this type, for example, as are parent groups. University students and faculty members may wish to collect stories (a graduate student may wish to take this on as a research project, for example). People who work in direct support organizations may be interested in collecting narratives of people with whom they work. And occasionally, a journalist may write an article about one or more people who once lived in an institution.

Stories can be collected one by one, and this is the most common approach. Or, a group of people can be called together (like a focus group) to reply to interview and impromptu questions. The common themes that emerge from their discussion can form the basis of an article or paper that tells a collective story. The writer can elaborate on each theme, using the words of a focus group member whenever possible.

The stories that follow were collected at a national self-advocacy conference in Anaheim, California, held late in May, 2004. The people who gave their stories were busy with many other things, but all of them felt strongly about community living for all people. Afterwards, the interviewers wished that we had asked more pointed questions about why people felt as they do. In your own state, you can direct your questions to issues that will have the greatest impact on decision makers.

RESOURCES: PERSONAL STORIES AVAILABLE IN PRINT, ON THE WEB, OR ON AUDIOTAPE:

Campaign for Freedom Team. (2000). *Out of institution & you're home: Success stories*. Plymouth Meeting,

PA: Speaking for Ourselves.

Crossley, R., & McDonald, A. (1980). *Annie's coming out*. Australia: Penguin Books.

Hayden, M. F. (1997). *Living in the freedom world: Personal stories of living in the community by people who once lived in Oklahoma's institutions*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration (UAP).

Hoyt, T. (1998). *The right thing to do*. Topeka: The Kansas Council on Developmental Disabilities.

Johnson, R. (as told to Karl Williams) (1999). *Lost in a desert world: An autobiography*. Plymouth Meeting,

PA: Speaking for Ourselves.

Pratt, J., Ed. (1998). *On the outside: A look at two decades of deinstitutionalization in West Virginia through the eyes of people with developmental disabilities*. Charleston, WV: West Virginia Developmental Disabilities Planning Council.

Sienkiewicz-Mercer, R., & Kaplan, S. B. (1989). *I raise my eyes to say yes*. New York: Avon Books.

PERSONAL STORIES

Collected in Anaheim, CA, May 2004

Paul Nichols, from Vermont

I lived in Brandon Training School. I was placed there when I was 3 years old because the doctor told my mother to do that. It wasn't so great. You had to eat liver. I was there 14 years and got out in 1979. It was a dump, not nice at all. My old teacher knows. We did have education classes—reading, writing, 'rithmetic. We had to share our bedroom with other people. We all had to go to bed at the same time.

I live in Burlington now. I was doing fine until I had to have surgeries on my hip. I live in my own apartment now, and it's a lot different than living in Brandon. I don't eat liver now. I got a job at the airport, at the observation tower. If it wasn't for my support people I couldn't do what I do. I have my own van, and my support staff drive it. I hire my support staff. I became my own guardian, too. Champlain Vocational Services helps me with my job and they also give me residential and community supports. I do so many things now—I write for the Green Mountain Self-Advocates newsletter, for example.

Rick Hodgkins, from Sacramento

I was placed in the California School for the Blind in 1992, when I was 13 ½ years old. It was a school run by a partnership between the CA Department of Educ and the CA Department of Rehabilitation. While I was there, I gained a bunch of weight because of medical conditions I have, and I was put on a really restricted diet where I could eat only one serving of everything, and I had no right to object to it. After 3 months, I had to sign away my rights in order to stay at the school. I was put under a conservatorship, as were all the other students at the school. I wasn't allowed to say "no" or object to anything I didn't like, or to eat when I was hungry. Whenever I did something wrong or had problems in school, I'd get yelled at. I lived in a dormitory, and same thing there—I got yelled at for things. People would yell their heads off. One teacher thought I was unteachable, and a lot of people thought I could not travel independently. Even when I was a grown man, between the ages of 18 and 20, I was still treated like a kid. At 20 years of age, I decided that that was enough, and I got a certificate of completion from the State Department of Education, special education curriculum, and left there. I wasn't able to get my GED because it wasn't provided in Braille.

I now have a job as a telemarketer. I make good money at that. I live in Citrus Heights, CA. I live in a townhouse that I own. I rent a room there to my grandfather. That was my decision. In the community, I have my own choices. I may be going for my GED in an adult school this fall, near where I live.

I have other disabilities besides blindness, so I have rights under the Lanterman Act. I'd like to see the act changed so that people who are blind have the same rights as those with developmental disabilities. I happen to know a researcher in San Francisco who may be able to help me get the laws changed.

That school in Fremont still exists, to this day!

Frank Vinciguerra from Concord, New Hampshire

I was in Laconia State School from the time I was 12 years old. I was treated like a prisoner. People were unhappy there. They were putting us in straitjackets, throwing cold water on us, and giving us no privacy. People would get locked in a room. We lived in big dormitories. We didn't get a chance to vote, or a chance to speak up for ourselves. They didn't serve enough food to the patients, and they didn't teach us how to be independent, how to read and write, how to work at a job.

I was in one of the oldest buildings on the grounds. They didn't think we could learn anything like the brighter people could. After my mother got me out of Laconia State School, I didn't know much of anything, but I lived with her and got a job in a grocery store. I had been in Laconia State School 3 years. She got me out because she wanted to take care of me and be with me before she passed away. I wasn't happy with the way Laconia State School was run, and I wanted my mother to have a chance to take care of me. After she passed away, I went to a group home to learn how to be independent, because I didn't know much about being independent. Before I went to Laconia State School, I was in an orphanage in Rochester (Rochester St. Charles Orphanage) for 8 years. I could not stay there any longer because you had to leave there when you were 12. In the institution, we didn't get enough education and they didn't teach us how to be more independent. The state of New Hampshire didn't investigate how it was run.

Now I'm 57 years old. I'm a member of Knights of Columbus, and a representative of the Self-Advocacy group of Carthage, and of People First of New Hampshire. I also am a member of the Granite State Independent Living Center and a member of the Democratic Party. I work at Yankee Book Binding 2 days a week for 3 hours each day. I am involved in the community a lot—Capital Center for the Arts and the Chamber of Commerce. I'm learning how to read and

write through a literacy volunteer who comes to my apartment once a week to teach me. I have a power of attorney who helps me make the right decisions so that people don't take advantage of me, and a conservator who helps me pay my bills. I live in my own apartment by myself, and I have someone who comes over and takes me shopping and cooks for me.

Roberta Gallant, Concord, New Hampshire

I live and vote in Concord, New Hampshire. On Oct. 27, 1956, my parents admitted me to the Laconia State School and Training Center, a residential placement for people with mental retardation, because of a birth defect. For 25 years, I lived at the Laconia State School and Training Center. I hated leaving my mother and father's house in Berlin, New Hampshire. When my mom and dad placed me in Laconia State School I became homesick. I constantly cried, sobbed, and threw severe temper tantrums.

What I would like to talk about next is the bad things there. Many other adult citizens and I lack some basic math, reading and writing skills. While they and I were children living at the Laconia State School and Training Center, New Hampshire deprived them and me of opportunities to receive proper elementary and secondary school education. Laconia State School itself also never offered private tutoring, which we needed.

The staff people used to physically abuse me. The staff and other residents always ignored and neglected me.

When I went out to the community on June 22, 1981, I left Laconia State School and entered the community to live a better life.

Kimberly Horton, Sylmar CA

My parents divorced when I was 5 years old, and my father got custody of the kids and me. I have two brothers, and because I have a physical disability, my father, even at the age of 5, was questioning, "What am I going to do when she becomes a teenager?" So he turned me over to the custody of the state, and they suggested that I should be put in an institution.

I was put in the first institution when I was 6, after two foster homes. I lived in those homes while they were trying to find a place. However, the institution I was in first was not chosen because it would be best for me. They just stuck me in one. It was filled with unwanted kids, runaways, kids with problems, disabled kids, kids who were in trouble with the law, things like that.

When I was 8, 9 years old, I knew that there had to be someplace out there that deals with someone like me. I explained to my social worker that I needed to be in a place for physically disabled kids. She said, "As long as you're a minor, you do what I say." I didn't get out of that institution until I was 17, and that was because I got a new social worker then. My new social worker shocked me by asking me what I wanted. I said, "But you're the social worker!" She said, "I don't care, you're old enough to tell me what you want." So I told her, "Get me out of here!" I didn't care who came by my room or who heard it. And within a week, I was gone.

The experience was totally different in the second place. The second institution dealt mostly with physically disabled kids. Some were both physically and mentally disabled. We had PT, OT, swimming, once a week, and some kids, I think I may have been one of them, had these things twice a week. I didn't like doing these things, but I knew I had to learn to do them if I wanted to live on my own. Within 5 months, they had taught me how to transfer out of bed, go to toilet, and how to move my body. I was only there from age 17 to 21. The whole atmosphere was different. They did a panel on me with the different department heads, where they decided whether I should stay there and whether they could help me, and while they did that I hung out with the other kids. Within half an hour, I knew I wanted to stay there if I had to be anywhere. I kept saying, "I should have been here 10 years ago!"

I remember calling my mother after I had been there two weeks, because they did have a period where you were not supposed to have any contact with anyone from the outside, so you could adjust. She was going crazy, because she didn't know where I was. I remember saying, "Don't worry about it, Mom, it's fine here."

She was worried because she didn't have custody and she didn't know what was going on. At the first place, there were numerous abuses. I have one major example: one time I had to go to the bathroom, but I had to call the nurse. They didn't have railings, and they wouldn't allow you to go by yourself. They said, "You're going to have to wait. You just went two hours ago." The supervisor, who was buddy-buddy with the person who was working with me that evening, said, "You're gonna wait, and if you have an accident, you're going to go to bed early for a week, and you're going to get a cold shower." Finally I wet myself, and they punished me. I got that cold shower, and they left me in there for a long time. They took away my therapy toys, and my legs atrophied. I'm just showing you the kinds of abuses that happened. They got away with so many abuses. I saw them do terrible things to kids with mental disabilities, like flicking the lights to upset them and then punishing them. They didn't have programs except when the state came in. We just watched TV and listened to the radio.

I went to a special school for the disabled in Ontario, California. I loved it because it was my outlet, even though I had to be bussed there. I had a favorite teacher who knew I didn't like where I was living. He did everything in his power to show me that even though I lived like I did, I could participate. He'd take me places even if the home wouldn't give me a ride. He taught me about baseball, and I became a big Dodgers fan. He would let us watch baseball games.

I moved from Angelview when I was 21 to my own place, and that was very scary. I got so paralyzed with fear that I got sick. On the first day in my own apartment I passed out. They moved me into a group home, and then later into an apartment. I was in the first place from 1968-1979, and in Angelview from 1979-1984.

Now I am married, and I live in Sylmar with my husband Randy.

But I also want to tell you about my friend Barbara. She was nonverbal, but we were such good friends that it was like, "If you want to find Kimberley, go to Barbara's room." She's still in a facility, in Sacramento. She can't get out because her mother is her conservator. I saw her a few months ago, after 25 years. I hadn't written to her, because I knew she couldn't write back. The only way that she communicates is by looking up if she means, "Yes," and down if she means "No." She is still in a place, and she should have the chance to get out just like I did.

James R. Meadours, from Louisiana

Before I moved to Louisiana, I lived in Oklahoma. I lived in a group home from 1987 to 1992, and that seemed to me like an institution.

When I was a young child, I never heard the word "institution" or any word like group home until we moved to Oklahoma. I think that was because my mother believed in me and my brother, and had confidence in us, and wanted us to believe in ourselves. My brother has a disability, too. My mother passed away right after we moved to Oklahoma. We moved there in September of 1983, and my mom was pregnant with my younger brother. She died after she had the baby, because the placenta went to her heart for 45 minutes. She had major brain damage and died.

My father remarried in 1985. A lot of people told my stepmother and my father to put me in a group home, and after I graduated from high school they put me in a group home.

I had a hard time with it because no one asked me what I thought about going. They didn't ask me what I wanted for myself, or ask me what's wrong with me, because I was still upset about my mom's death. No one took the time to take me to counseling or help me to deal

with it. They just put me in a group home instead. At the group home, I didn't have control over my life. The staff had the control.

I never learned about self-advocacy until then. I had some friends at church, and one year we were watching the Super Bowl together, and I said "Next year we'll watch this at my place." They thought I meant at the group home, but I said I wanted my own apartment. A week later my friends helped me look for an apartment, searching for the right place, and the last place was a good match for me. It was very neat because three weeks later I got out.

The sad part was that my dad and my stepmom were totally against it and thought I should keep living in the group home. They had small expectations on me, and that was very hurtful for me. I proved...well, I don't like to prove myself to anyone, but it is very hurtful when our parents think we cannot do anything for ourselves. And even our policymakers, when they think we can't do anything for ourselves.

Stolen Lives Campaign Stories - May 2003
"Seeking Ways Out Together" (S.W.O.T.) Team
Titusville, New Jersey

I lived at Vineland State School for 15 years. I went there when I was five years old. When I was a teenager they let me go to public high school so I got my high school diploma. When I was 20 years old I was moved to a group home. I knew that I wanted to live in my own place, have a real job, learn new things, and be on my own. So I learned everything at the group home, found a job as a janitor on my own, and then moved into my first apartment with my friend Josephine.

Josephine & I just moved into a brand new apartment. I am no longer a client. I travel all over the state by public transit working for self-advocacy. I have a state job helping people with developmental disabilities understand their health insurance rights. I keep busy serving on boards, committees. Life changed for the better the day I walked out of the institution. I had a dream. I am living my dream come true. I like to tell people to have a dream & believe in yourself. No matter what.

Barbara Coppens, Cherry Hill, NJ

When I was a very little girl I was put in Vineland State School because my mother was sick and they said I was retarded. When I was 12 years old I went home to live with my mother and I went to public school. But my mother was too sick to take care of me so I was sent to Edward R. Johnstone Research & Training Center when I was 14 years old. I lived there for five years.

Then they put me in a boarding home. They beat me there so I ran away. When they found me they sent me to a group home. It was the best place I had ever lived. I was glad to be there. I met my best friend Barbara there. I learned how to take care of myself, how to keep house, cook, shop. It was the first time I had freedom.

Barbara & I have been roommates for years. We just moved into a new apartment. I have a job. Barbara & I have been very active in self-advocacy. We like to travel. We went to the TASH conference in Boston in December. We are helping to start a NJ TASH.

People should not live in institutions. People should have a choice where they want to live. Anybody with a disability can live out in the community if they get the help they need. Listen to us President Bush.

Josephine Messina, Cherry Hill, NJ

I am a man with Cerebral Palsy. In my life I have lived in a boarding house, a developmental center, and three group homes. I have been restrained, starved, burnt with cigarettes, and abandoned for dead.

I use a wheelchair and I communicate via an electronic language board called a liberator. Technology has changed my life. I now live in a condominium and work with preschoolers.

I work as a volunteer to help other people move out of developmental centers.

I have my freedom.

To President Bush I ask you if one of your daughters had a disability would you put her in an institution? PLEASE, PLEASE help us get people out of institutions and help get institutions out of our great nation.

Robert Fesel, Robbinsville, NJ

In 1963 I was put away at the New Lisbon State School for Boys. My mother didn't want to send me there but I have Cerebral Palsy and a lot of brothers and sisters and she didn't have a choice. But she came to visit me almost every Sunday. I saw a

lot of abuse, sexual and physical. The staff used to get the stronger boys to beat up on the weaker ones. It happened to me. If you didn't do what they said there were consequences.

When I got out I lived in a group home but now I live in my own apartment. I wish my mother could see me. I make my own decisions and the support staff is better than in the institution. I work, I like to play bocce, and I am very active in the self-advocacy movement in New Jersey.

I go back to institutions including the State School (now New Lisbon Developmental Center), to help people get out. I wish someone could have helped me when I was getting out. That's why I do it. I will do it as long as I am needed.

I want to tell President Bush that all people with disabilities need to be in the outside world. No one really knows how institutions really are, only the people who live there. If a person needs help it can come to the person in the community.

Bernard King, Mapleshade, NJ

I was 16 years old when I was sent with my mother to live at the Village for Epileptics near Princeton. My mother and I had seizures and my father was told to put us there. She and I lived in different parts of the village but we would meet at the bridge near the barn (my job was to milk the cows) almost every day and I saw her at dances, on visitor's days, and the such. My mother got a job as a live-in maid with one of the staff and I didn't see much of her. Then she died.

I left in the late 1970s. I can't remember exactly when.

My dream was to get my high school diploma, get a job and see America. I did all those things and then some.

I retired from my job as a janitor when I became 84 years old. I have seen the Pacific Ocean, traveled to Florida, Rhode Island, Virginia, just to name a few and have been to Washington, D.C. several times to testify on behalf of people with disabilities. I'll be going to Washington, D.C. in May for MiCASSA.

I want to tell President Bush to sign a law to close all institutions. That's my dream now.

John Kover, Barrington, NJ

I was sent to live at Edward R. Johnstone Training & Research Center because I use a wheelchair and I am blind. My mother didn't know what it was like in an institution. When the state announced they were going to close Johnstone I wrote to the governor and told him to keep it open because I didn't know what it was going to be like to live on the outside and I was scared. So were my friends. My mother had died and a lot of the staff told us scary things about the community. But they closed Johnstone and now I am glad!

In the institution you couldn't say how you felt about things, you had to do what you were told, you couldn't speak up. I had friends who were handcuffed and locked up for doing those things in the institution.

Now I live in my own condo with my housemate. I have good support to help me. I work at a copy center and I travel. I love to travel and visit new places. I make my own decisions. I vote, I worship. In 2001 I testified in Washington D.C. at the New Freedom Initiative Hearings and this past January I testified at our State House against restraints and aversive treatment for institutionalized children and adults. I would never put a member of my family in an institution. I will never go back.

Ed Palermo, Robbinsville, NJ

I live at three institutions. When North Princeton Developmental Center closed in 1998 I moved into an apartment but I didn't like living alone so now I share a home with two housemates. It was hard adjusting to the community. I went through a lot of changes. They had misdiagnosed me in the institutions. I got help learning how to cook and houseclean when I moved into the house with Robert & Chris. Now I cook for all of us. Right now I am learning how to manage my own medication. I have a lot of medicine to take.

I do volunteer work. I have made friends and I go to church, which is something I couldn't do in the institutions. I have freedom. I can go where I please. In an institution they keep you locked up.

The institution was not good for me. There were mean people there. You feel like a prisoner.

I say to President Bush - "No one: should have to live in an institution. Everyone deserves a chance to live in the community. All the institutions should be closed."

Darlene Fulton, Hammonton, NJ

When I was a teenager in Totowa State School for Girls, now called North Jersey Developmental Center. I have 3 brothers and 2 sisters and my mother was sick and they said I was retarded so they put me away. I was badly treated, beat up by the staff and other girls, and accused and punished for things I didn't do. I was there for five years.

I say that getting out and living in the community is 100% good. I have made good friends. I am happy to be free. I learned to be independent. I got to take care of

my mom when she was sick and dying. Last year I went to my family reunion. It was great.

I became a self-advocate to help others. I help other people get out of institutions. I tell them they will do new things, make new friends and have more control over their lives out where it is free. I am happy. I have my apartment. I have my job. I have my cat. I have my boyfriend.

If I could talk to President Bush I would say to him - "Free my brothers and sisters."

Adelaide Daskam, Elizabeth, NJ

Hi! I'm Todd Leroy Emmons. When I was about 13 years old I went to live at New Lisbon State School in New Lisbon, NJ. When I was 15 years old I went to Edward R. Johnstone Training & Research Center. I helped take care of the blind boys. I left Johnstone on June 16, 1976. Johnstone closed for good in 1991.

Since I have been living in the community I got my high school diploma, I am very active in the church, Special Olympics, self-advocacy, and I have a good job at the mall.

Thank you very much for listening to me.

Todd Emmons, Mapleshade, NJ

There are seven developmental centers still open in New Jersey. In my lifetime I have lived in five of those seven institutions. I was institutionalized when I was 2 years old. My mother couldn't take care of me and they said I was retarded. I was sexually abused when I was a little girl in the developmental center. I know they abuse and kill people in institutions and the food is terrible. I have been put in

straightjackets and tied down. While I was in North Jersey Developmental Center I found out about self-advocacy. Steve Gold & Tim Cook came and helped me and some other women get out and move into a group home but they sent me back because I had behaviors.

I finally got out of Vineland Developmental Center in 1999. I now live in a supervised apartment. I have my privacy, I can watch TV when I want, and buy my own food. I am a member of a group of self-advocates that help other people get out of institutions. Self-advocacy helped me to understand that I have rights and I want to help other people living in institutions understand that they have rights!

Bonnie Schuller, Vineland, NJ

LIZ'S STORY

When people think of institutions, they often think of big ones like Fernald in Massachusetts or Rosewood in Maryland. However, I have learned and know in my heart that I was sent to an institution by my parents in the mid eighties. First of all, I want to say that my parents are so wonderful to me, and they would do almost anything for me. However like most parents they listened to the professionals when it was suggested that I should go to Bancroft, a private institution in New Jersey.

I stayed at Bancroft for nine years. Yes, most of that time I was in the community, but the first six months I was in what I called a "mini-institution." You entered this place by a long driveway and at the bottom was a cluster of 10-15 small houses. I lived with two other people, but all of my neighbors were people with disabilities. I remember one night when I came home, my roommate threw out my dinner because I was ten minutes late from my job. When I first got to this place, my parents and the staff at Bancroft called this place "the community." I ask you: does this sound like a community that you would like to live in?

I wrote this because I wanted you as the reader, to know that there are many different kinds of institutions. The big public ones like Fernald, and smaller private ones like Bancroft. I think the definition of an institution is how the person defines one.

Right now, I live in Rockville, Maryland working for The Council on Quality & Leadership doing training and consultation for organizations around the issue of advocacy and how people with disabilities should have input in their services and how the organizations should listen to them. My fiancée and I both get the services that we both need and want.

Liz Obermayer
Quality Consultant

VI. Resources

- a. Packets Prepared By Groups Advocating For Institution Closure
- b. Web Sites
- c. Bibliography

RESOURCES

This section contains three different types of resources for advocates:

- Packets prepared by groups advocating for institution closure. We include these as examples of the kinds of information your organization may want to prepare. As you can see, the packets typically are made up of one-page fact sheets on various issues that always come up in debates about institution closure. You may use the information in this tool kit to create your own set of fact sheets.
- A list of web sites that provide more information and resources for your advocacy for institution closure.
- A bibliography of studies, articles, chapters, newsletters, policy briefs, etc. that are included in or that shed light on the issues covered in this tool kit. For other references, see the articles included in the tool kit.



**CLOSE THE DOORS
CAMPAIGN FOR FREEDOM PACKET**

Self-Advocates Becoming Empowered



Position Statement on Closing Institutions

We believe that all institutions,
both private and public should be closed.
All people regardless of the severity of their
disability should live
in the community with the support they need.

by Self-Advocates Becoming Empowered
Adopted April, 1995

CLOSE THE DOORS: CAMPAIGN FOR FREEDOM HELPING PEOPLE LEAVE AN INSTITUTION

How to help people while they are in the institution:

1. Help people get used to moving a little bit at a time.
2. Get people moral support, training, someone to talk with, and help from case managers.
3. People First members can help by:



- a. get people to come to a local chapter
- b. visiting people in the institution—meet people in institutions before they move, be a friend to people, take them places, i.e. your home, churches, show them what the community looks like
- c. start chapters in institutions—help people learn how to speak up for themselves and learn about moving, make visits, talk about living in the community
- d. make presentations to people in the institution about advocacy and independence and living in the community



How to help people after they move out of the institution:



1. Visit people in their new places and check on them to be sure they are o.k.
2. Call them on the phone.
3. Help them join a People First Chapter. Take them to a local chapter and help them learn for themselves and become more independent.
4. People should be able to learn from their own mistakes.

**CLOSE THE DOORS: CAMPAIGN FOR FREEDOM
OUTLINE OF PRESENTATION AND SUGGESTED MATERIALS AND
TIPS TO BE USED IN MAKING THE PRESENTATION**

1. INTRODUCTION OF YOURSELF

2. PURPOSE OF THE CLOSE THE DOORS CAMPAIGN

- Overhead: Position Paper

3. VIDEO/VISUAL PRESENTATION OF AN INSTITUTION THAT HAS CLOSED

- Laconia Video or Pictures
- Tell About the Video
- Ask the Group to Think About the Following: Would they live in some type of institution where they have no control? Would you choose this?
- Overhead/Fact Sheets: Answers To Top 10 Arguments of Why People Think Institutions Should Not Be Closed

4. STORIES OF LIVING IN INSTITUTIONS

- Panel members or participants in the group will tell their stories or read stories about their friends or other self-advocates who live or have lived in institutions.

5. STORIES OF LIVING IN THE COMMUNITY

- Panel members or participants in the group will tell their stories about living in the community.
- You may want to talk about freedom, choices, jobs, friends, and living in your own place.
- You need to talk about the types of support and services you and your friends receive.
- Tell stories for your friends who cannot tell their own stories.
- A video may be used to tell a story of a friend who cannot tell his or her own story.
- Overheads/Fact Sheets: Community for All
 Stories of How People Who Have Lots of
 Needs for Support Can Live in
 Communities

6. WHAT CAN YOU DO?

- Overhead/Fact Sheets: Actions that Local and State Self-Advocacy Groups Can Take To Close Institutions
Lawsuits--What are They?

7. RESTATE THE GOAL OF NATIONAL ORGANIZATION CLOSE THE DOORS

- Overhead: Position Paper
Rev. Martin Luther King's "Free at Last" Quotation
- Tape: Close the Doors, Stand Together
Don't You Want to Do Right
Promote Symbols, T-Shirts, Ribbons, Bracelets
Ask for Support by Signing the Petition

CLOSE THE DOORS: CAMPAIGN FOR FREEDOM SUGGESTED THINGS STATE CHAPTERS CAN DO

1. Be educated on the issues
2. Talk to your Governor
3. Support local efforts: create a help-line for local chapters to call, provide emotional support to local chapters
4. Develop a formal policy or position paper
5. Make sure the state president is supported by national and local people
6. Find out ways to state your position to State Government
7. Bring the powers that be together to tell them what is your position and host roundtables or coalition building
8. Identify people who lived in institutions to help write letters about what it was like
9. Attend your state's Arc conferences and talk about community living and closing institutions
10. Use yellow ribbons, buttons, friendship bracelets, keys, t-shirts or other items to show your support
11. Demand Department of DD and Governor to develop a plan to close institutions
12. Put CTD articles and success stories in your newsletters
13. Get information about inspections and surveys (i.e., Justice Department or HCFA reports)
14. Have Close the Doors training for local chapters
15. Talk about which institution(s) to focus on
16. Get your DD Council, State Arc and P&A to adopt a closure position
17. Learn about direct action and lawsuits
18. Have a state leadership retreat to come up with a plan on how your state chapter will work on this goal

CLOSE THE DOORS: CAMPAIGN FOR FREEDOM SUGGESTED IDEAS FOR LOCAL CHAPTERS TO DO

1. Recruit members from institutions
2. Visit people who live in institutions to get to know them; get to know the individuals who live at the institutions on a personal level and develop friendships
3. Learn about the issue of closing institutions
4. Get people who have lived in institutions to tell their stories
5. Get people who are experts to come to talk to the group
6. Ask administrators of institutions pointed questions about how the institutions work, why do people live there, what kind of choices/decisions are they allowed to make, do they get to be included in the community
7. Visit institutions, ask to come unannounced, ask to eat with the people who live there
8. Help people who live in institutions to learn how to speak up for themselves
9. Volunteer to help people who live there
10. Local chapters could approach local Arcs, Student CEC, TASH, AAMR, Civitans, civic groups, other professional groups about closing down institutions and get them to support the movement
11. Local media coverage
12. Talk with local community providers of services and supports to enlist their support
13. Celebrate successes for people
14. Have local Close the Doors Training for members
15. Local chapters meet with the local politician in his/her office or home
16. Use videos that show personal stories to educate local members and others what is going on in institutions
17. Group act on rights issues (i.e., staff reading and not giving out people's mail in institutions)
18. Start a scrapbook about institutions in your area
19. Have members wear buttons, ribbons, friendship bracelets, or other things to show they are working on this goal

**CLOSE THE DOORS: CAMPAIGN FOR FREEDOM
TOP TEN ARGUMENTS YOU WILL HEAR
AGAINST CLOSING INSTITUTIONS**

1. They won't make it in the community because they have too many disabilities and can't take care of themselves.

If they have the supports and services in the community, they can move. They can make it. The state should be responsible to do this.

2. Institutions should be a choice: people like living in the institutions.

Nobody has had the option to live other places with the supports they really need. How can they make a choice without experience? Would you choose to live there?

3. People will end up on the streets.

We don't want anyone to move until we are sure that the supports and services are in place for them.

4. The people are perpetual children, they only have minds of two year olds.

Since when do we lock up our two year olds?

5. Parents and families don't want them to move.

Research shows that families who are against people moving change their minds afterwards because they see the real good positive things that can happen.

6. This is a good institution, everything they need is right there, like doctors and nurses in case of an emergency.

You can get the same things in the community. The community has good medical and other services for people.

7. The community system isn't ready and won't be accountable for what happens.

As more people move, the community system will have more resources to help people. People will have more people in their lives to look out for them.

8. There's no guarantee the money will be there.

People have been living in good community services for many years. The same funds that pay for the institutions can pay for the community.

9. Society isn't ready, they'll be made fun of and won't have friends.

There will be more opportunities for people to make friends because research shows people go more places and do more things.

10. The employees will lose their jobs and it will hurt the community where the institution is.

It's the state's responsibility to plan what will happen to the employees. Experience shows that state employees get other jobs in state agencies.

THE BOTTOM LINE: This is a human rights and constitutional rights issue. People have the right to live in the community.

**Close the Doors: Campaign for Freedom
Community for All!!!!**

**EVERYBODY WHO LIVES IN INSTITUTIONS TODAY
CAN LIVE IN THE COMMUNITY
WITH THE SUPPORTS THEY NEED
NO ONE SHOULD BE LEFT BEHIND**

HOW DO YOU MAKE THIS HAPPEN?

Supports must be in place that are individualized and flexible.

WHAT ARE THE SUPPORTS THAT NEED TO BE IN PLACE?

Supports that need to be in place are:

- Communication Supports to help encourage people's own ways of communicating. This includes assistive devices, interpreters, and other communications assistance devices.
- Supports To Get Around in our communities. This includes wheelchairs designed for the person, accessible transportation and access to transportation to get to recreation, leisure, work, school and medical appointments.
- Educational and Personal Growth Supports that assist people in learning new things, such as how to manage our money, use computers, take care of our home, and cook our meals.
- Personal Care Assistance to help people get up in the morning, bathe and get out of the house.
- Homemaking Assistance that help people take care of their home.
- Employment Supports that include career planning and job coaches.
- Supports That Connect Us with our communities through circles of friends, personal friendships, self-advocacy groups, churches, recreational and civic groups.

- Housing that is affordable, safe and accessible.
- Advocacy Supports that promote learning to make decisions, assertiveness and protection of rights. These supports can be provided through self-advocacy groups, as well as personal and legal advocacy.
- Access to Medical, Health and Other Specialized Supports.

HOW DO YOU MAKE SURE THESE SUPPORTS ARE PROVIDED?

A Case Manager or Service Coordinator assists in coordinating these supports. This person makes sure a person gets the supports needed and teaches a person to coordinate their own supports.



CLOSE THE DOORS: CAMPAIGN FOR FREEDOM USING THE COURTS TO HELP PEOPLE MOVE OUT

What kinds of lawsuits are there? There are two kinds of institution lawsuits. There are lawsuits brought by the U.S. Justice Department and there are lawsuits brought by advocates. Sometimes these lawsuits are joined together but sometimes they are separate.



What laws are involved? The first “claims” that are used in lawsuits are violations of people’s rights under the U.S. Constitution. Other laws that are brought up include the Americans with Disabilities Act, IDEA, Section 504 and the Social Security Act.

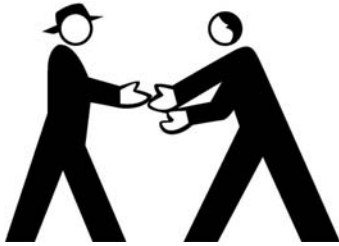
How will we get a lawyer? We can ask other states who are involved in lawsuits to recommend a lawyer to see. Ask organizations like The Arc, Protection and Advocacy or Legal Aid.

What’s involved in a lawsuit? You will need to make sure everyone in your group wants to do it. You will need information about the bad things that are happening to people at the institution. You will need to work closely with your lawyers to talk about what papers to file at the courthouse. You will need to go to the courthouse for hearings, trials and other meetings. You will need people to testify about what has happened and what needs to be done. You will need ways to support each other and keep people interested in what is happening. You will need to use the media to help state your position.



Should we go to state or federal court? When the Constitution and Federal Laws are violated, you go to federal court to file your “claims” and ask for relief.

Who should be involved? Members, people on the inside, family members who agree with you, and other disability organizations who believe in this issue.



Who can we trust? In a lawsuit everything between you and your attorney is confidential. Sometimes things need to be a surprise so the other side will not be able to come up with a defense for what they are doing. For example, if you are going to talk about somebody's abuse, you don't want the other side to know and maybe put pressure on that person to not talk about it with you. You need to make sure that everyone involved can be trusted to keep things confidential. It is really true that people's lives can depend on trust in institution lawsuits.

How will people react? State government, family members, legislators, employees and other people might be really angry when you file a lawsuit. You might get ugly remarks, phone calls, and mail. People might try to retaliate against you for taking a stand. You will need to let your lawyers know about this if it happens. Also, you will need to help your members know what to do when they get negative feedback. People who were your friends or even members might quit and not talk to you anymore.



How much does it cost and how long will it take? It depends on the agreement you have with your attorney. Some attorneys will not charge you and will ask the court for attorney fees if you win. But, you will still need some money to pay for things like getting people to the courthouse, faxes, phone calls, media campaigns, etc. Lawsuits can take a very long time. It can take anywhere from 3 to 10 years to resolve problems in court.

Where can we get more information? You can get more information about lawsuits self-advocates have filed from:

People First of Tennessee, Inc. (615) 256-8002
People First of Connecticut, Inc. (203) 792-3540

CLOSE THE DOORS: CAMPAIGN FOR FREEDOM PARENT ATTITUDES TOWARDS CLOSING INSTITUTIONS

Many parents who have children living in institutions are happy to see their family members moving out of these places. Others are concerned about them moving to the community. Common questions that they ask include the following: “Will my son or daughter be safe in the community?,” “Will they have friends?,” “Will I be able to visit them in the community?,” “Will they always have a home to live in?”

A lot of professionals asked parents what they thought about their sons and daughters before and after they moved. Two of these professionals (Larson and Lakin, 1991) reviewed 21 studies that looked at parental attitudes and expectations about their children moving out of institutions. From these studies, the following conclusions were made:

- **The vast majority of parents were satisfied (secure, content, and comfortable) with their family member living in an institution.**

Eleven of the studies asked parents questions before their son or daughter moved. Ninety-one percent said they were somewhat or very satisfied with the institution. Only 21% of the parents supported the idea of having their son or daughter move to the community.

- **The vast majority of parents changed their attitudes about community placement after their family member moved.**

Four studies surveyed parents before and after their family member moved. Only 15% of these parents had a positive reaction about their son or daughter moving before the move. After the move, 62% of the parents expressed a positive opinion about the move to the community.

Before the move, 83% of the parents reported satisfaction with the institution. After the move, 87% were satisfied with the community.

- **After experiencing community services, parents viewed the institution less positively than they did when their family member lived there.**

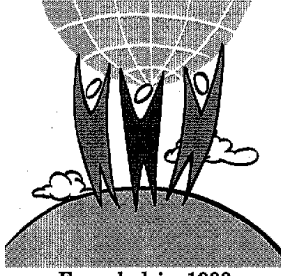
Seven studies interviewed parents whose sons or daughters had moved into the community about their satisfaction with the institution, the community, and their opinion of the move. Only 51% said they had a positive reaction about their family member moving to a community home before it happened. This compares with a 83% pre-discharged rate of satisfaction with the institution and a 15% rate of support for the move. The same parents reported an 88% rate of satisfaction with their children's community living experience.

- **Parents observed improved quality of life and relationships for their family members after the move.**

In five studies, more than 65% of the parents reported after the move that their family member was happier, that relationships between their son or daughter and other people improved, that needed services were available, and that staff members in the home were fine. Fewer than 12% reported negative changes in these areas.

SOURCE: Larson, S. A., & Lakin, K. C. (1991). Parent attitudes about residential placement before and after deinstitutionalization: A research synthesis. *JASH*, 16(1), 25-38.

Building Leadership
Around Wisconsin



Working Together
For Change

Founded in 1999

People First Wisconsin

More Reasons
than You Ever Needed
for Why the State Centers
for People with Developmental
Disabilities in Wisconsin
Need to Close

Marian Center, 3195 South Superior Street, Milwaukee, WI 53207
Voice (414) 483-2546 Toll Free 1 (888) 270-5352 Fax (414) 483-2568
<http://www.peoplefirstwi.org>

More Reasons
than You Ever Needed
for Why the State Centers
for People with Developmental
Disabilities in Wisconsin
Need to Close

Reason 1. The Dollars & Cents Story

844 people with developmental disabilities still live in the State Centers. We think that is 844 too many, but we also know that this is just 2% of all people with developmental disabilities who get services in Wisconsin.

This 2% costs 123 million dollars a year. The other 98% who live in the community cost 330 million dollars. This means 27% of the total money spent is spent on only 2% of the people. Some will tell you this is because this 2% have high needs but a big chunk of the cost is due to the fact that these people live in the State Centers rather than in smaller living arrangements.

It now costs an average of \$400. a day for a person with a developmental disability to live in a State Center. This means that each year, it costs \$146,000. for one person to live in a State Center.

The Department of Health & Family Services knows that 90% of all the residents of the State Centers could live in the community at a cost of \$300. per day. That means if these people lived in the community instead of living in the State Centers, it would save taxpayers 27.7 million dollars each year!

But the Department of Health & Family Services will tell you it costs more - not less - for people to move to the

community. That is because they won't make a plan to close the Centers. So every time someone leaves the Center, even though it costs less for that person to live in the community, the State must keep paying the Center \$200. a day or \$73,000. a year for that person, even though he or she doesn't live at the Center anymore!

If the Department would make a plan to close the Centers, then all that money paid to the centers for people who don't live there anymore would stop once the Centers closed. After that, taxpayers would save 30.8 million dollars every year, which they would have been paying if all 844 residents kept living in the State Centers.

The Department currently proposes relocating 35 people each year of the next biennium. At this rate, it would take 24 years or until 2025 for the Centers to close. This is too long!!!

If the Department won't close the Centers, we figured out what it will cost for one person to live in the Center in the future, based on the Department's relocation rate (35 residents each year) and the current Center reduction rate (\$200. per day, per relocated resident) that the Department is proposing. (Please turn to next page.) Remember, the cost of these same people living in the community is \$300. per day or \$109,500.

Cost Per Person Who Lives In State Center

	<u>Per Day</u>	<u>Per Year</u>	<u>How much more than community</u>
Year 2003	\$427.	\$155,887.	\$46,387.
Year 2005	\$447.	\$163,113.	\$53,613.
Year 2007	\$469.	\$171,185.	\$61,685.
Year 2009	\$494.	\$180,310.	\$70,810.
Year 2011	\$522.	\$190,530.	\$81,030.
Year 2013	\$555.	\$202,575.	\$93,075.
Year 2015	\$595.	\$217,175.	\$107,675.

By the year 2015, it costs twice as much for a person to live in a State Center than it does for that same person to live in the community.

By the time all residents would move out of the State Centers, this is what it would cost:

Year 2023	\$995.	\$363,175.	\$253,675.
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This is over three times what it would cost for a person to live in the community!

Reason 2. People don't need to live in the State Centers.

It is a myth, a lie, and an old wives tale that the size and location of the building someone lives in determines the amount and type of care they receive from support staff.

The fact is that any amount of assistance and supervision can be provided in any setting, as long as the money to pay for that assistance and supervision is available. We have many stories of people with complex needs for assistance and supervision who are living good lives in small community settings.

Reason 3. People Who Have Lived in the State Centers are Passionate About Them Closing Because of What They Experienced There.

People First Wisconsin could pull in over 100 of its members to tell you stories about the abuse and neglect they have witnessed or experienced while living in the State Centers. It doesn't just happen in Wisconsin's institutions, it happens all over the world.

History tell us that it is when these stories end up in the newspapers that states or countries make policies to close these institutions. But when these stories end up in the newspapers, it is too late for the residents who have suffered.

We hope the State of Wisconsin will start listening to the stories that ex-residents of the State Centers have to tell, and that they will believe these people. We hope the State of Wisconsin won't wait for things to come out in the press before they act to close the State Centers.

It has been proven that people are safer living in community settings because there are more people who see them everyday, especially other community members and family members who can notice when something is not right.

No matter how many rules and regulations are made for institutions, the likelihood of abuse and neglect doesn't go away. The problem is the institution itself...and the fact that the community has little or no contact with the people who live there.

Reason 4. Living in the State Centers is Not a Right.

Institutions for people with developmental disabilities have only existed for the last 200 years. Wisconsin's State Centers are 106 years old. For at least 1,600 years before that, people with developmental disabilities did not have the "choice" to live in an Institution. Just because we have had State Centers in Wisconsin for the last 106 years doesn't mean that the State must provide this option for eternity.

If people with disabilities, their families & their communities survived without the option of institutions for 1,600 years and more before these institutions were built, they can survive without these institutions again.

The Olmstead decision concluded that the ADA could not be used to forcibly remove people from institutions. However, it did not require States to offer institutions as an option. There are 10 states that no longer have any people with developmental disabilities in state institutions. The Olmstead decision did not say they had to build institutions again so people in those states could have that placement option.

The Olmstead decision stated that institutions "may" remain open without violating the ADA. The decision did not say that states "must" keep institutions open (if they have them) in order to comply with the ADA.

The Olmstead decision also said that people with disabilities do not have the right to insist that the State pay for them to get service in a certain way, if the State cannot afford the cost of that service. Surely this decision must also apply to State Centers as well as community placement.

If a state decides that its Centers cost too much, they have the right to choose to close those Centers.

The Olmstead decision allowed "comparative placement cost" to be a factor in determining whether people be placed in institutions or the community. People First Wisconsin believes it is time for the State of Wisconsin to compare the cost of the State Centers and decide they are not a fiscally responsible option for people with developmental disabilities. The Centers already cost 31 million more dollars than it would cost to serve the 844 residents in the community. That works out to \$36,500. more per person, per year.

At current relocation rates, by 2025, placement in the State Centers will cost \$253,675. more per person, per year.

Reason 5. The Employment Rights of One Citizen Should Never Be Given Priority Over the Human Rights of Another Citizen.

We know that many people who work in the State Centers belong to Unions. They will not have jobs at the State Centers if they close. We don't want these workers to be unemployed. But we also know that Wisconsin state government is very big, and there are lots of jobs working for the state that people could have if they didn't work at the State Centers. Plus, there are more than enough personal care jobs waiting for them in the community.

The most important thing is that the State of Wisconsin should never put the employee rights of one citizen above the human rights of another citizen. And the decision to keep people with developmental disabilities in state institutions denies those people their human rights more than it could ever advance the employment rights of the people who work at these institutions.

Reason 6. The Federal Department of Health and Human Services Has a Goal that People Should Not Have to Live in an Institution if They Can Live in the Community with the Right Support.

Voice of the Retarded is trying to convince people that the residents of state institutions around the country are extraordinary people who can't live in the community, even with lots of support. VOR members are saying that no matter how much money is available, these people could never live anywhere but in these institutions. There's an old saying, "Never Say Never...".

How does *Voice of the Retarded* know this if they won't give these people a chance to try living in the community? If we can find ten people with similar needs who are living in the community, why isn't this enough proof that these individuals in the institutions can live in the community, or at least should try it?

Voice of the Retarded is cashing in on the fact that legislators and other citizens don't really know these people who live in State Centers. VOR members are counting on you believing them without questioning them.

Reason 7. Wisconsin Can Build Stronger Communities Only By Including All of Its Citizens Within Them.

Some people who talk about the Olmstead decision say that we can't end institutional settings for people "unable to handle or benefit from community settings." Again, what did they do before the 1800's, when there were no institutions to put people in? What they did is work together as a community to include and support people with special needs. They didn't just abandon their fellow citizens in exchange for paying a few more dollars in taxes!

If there is one thing that is true about people with developmental disabilities, we always go beyond what everybody expects of us. This is especially true for people who have left the State Centers. We show that the impossible in people's minds can become the possible in our lives.... All we need is an opportunity and support from our fellow citizens!

We'd like to point out one last thing (you can hang the next page in your office):

If there really is
a
"voice of the retarded",

WE -
self-advocates
and
People First -
are that voice,
and we say NO to
institutions!

Close Wisconsin's State Centers Now!!!

Closing State Centers Could Help Under-Funded Community Services

Over 800 people are still lodged at the three State Centers for people with developmental disabilities. **The State Center system uses 38% of the available funding for disability services to serve 2% of the total population of Wisconsin citizens with disabilities. (YOU MAY WANT TO CHECK THIS WITH MARY GREEN – THE NUMBERS KEEP CHANGING)** The state agency that administers the State Centers reported that every current resident could be supported in the community if the money available to the Centers could be used to fund community-based supports for these individuals. The Department of Health and Family Services estimates that only a small number of residents would require the average daily rate of \$400.00 currently being spent on each **(I TOOK OUT THE WORD CURRENT)** resident of the Centers.

Over 35,000 people with developmental disabilities rely on and prefer our community service system. This group includes many people once deemed to be in need of institutional care. This overwhelming majority of Wisconsin citizens with developmental disabilities depend on a community support system that is currently under-funded. **(YOU MIGHT WANT TO MENTION THE 6,000 ADDITIONAL FOLKS ON THE WAITING LISTS TOO – AGAIN NOT SURE IF 6,000 IS THE RIGHT NUMBER)**

The Problem

The State Center system is funded and operated as a distinct system separate from the county-administered community support system. Although the community system serves many more people--including people with support needs similar to residents of the Centers--the community system is significantly under-funded. Evidence of under-funding is documented by long waiting lists and low-wage jobs. The Center system is not under-funded but is budgeted based on actual costs. The average cost to house one person at a State Center is \$400.00 a day. When a Center resident moves out, \$190.00 a day is available for the cost of community support. The remainder, \$210.00 a day, stays in the Center budget despite the fact that the person no longer generates costs to the Center. The budget proposed by the Governor makes a very small adjustment in this formula. It would increase the amount available for community support (CIP 1A) to \$200.00 a day and reduce the amount retained by the Centers to \$200.00 a day. Half the money would be used to cover actual costs of support; the remaining half would stay to pay for buildings and staff the person no longer uses.

The Solution

The Wisconsin Council on Developmental Disabilities, the Survival Coalition, **AND CAPOW** endorse the closing of Northern Wisconsin Center and Southern Wisconsin Center within five years. People First Wisconsin calls for closing all three Centers within ten years. The state should budget sufficient funding for quality support in the community by increasing the CIP1A rate to \$300.00 per day. These increases should continue in future budget periods as needed to insure the efficient transfer of Center residents to supported community settings. For each Center closed, the state will net a projected savings of \$10 million a year. **(THIS IS STATE/FEDERAL MATCH COMBINED)** These savings should be used to strengthen the community support system. As each Center is closed, residents should move to the community settings that meet their support needs and not simply be transferred to a remaining State Center or other institutional setting.

Closing Wisconsin's Three State Centers Dollars & Cents Fact Sheet

- The 3 State Centers cost taxpayers 30 million dollars more than what it would cost if the 844 residents lived in the community. This saved money could be used to help with waiting lists and paying direct support staff in the community better wages.
- We can only get the savings if the legislature decides to close the Centers.
- The reason the Centers cost so much is because every time someone moves out of a Center, the state has to keep paying that Center \$73,000. a year for that person, to cover the overhead costs of keeping those big buildings open.
- We know community services for people with developmental disabilities don't have enough money. We know this State budget is really tight. So closing the State Centers now is the right thing for Wisconsin and for people with developmental disabilities.
- The cost to the State for closing the 3 State Centers is around 4.5 million dollars over 10 years. Over that 10 year period, the net savings to the State is 55.5 million dollars. From the 11th year onwards, the savings for the state is 15 million dollars every year. If you add to that the federal match money, the total savings is 30 million dollars every year.
- We need legislators to find the courage to joint together to close the State Centers and spend funding for people with developmental disabilities more fairly and wisely. Closing the Centers will bring back many millions in savings for Wisconsin.

Closing Wisconsin's Three State Centers Human Rights Fact Sheet

- 844 people with developmental disabilities still live in these institutions.
- They are separated from their home communities and their families. They are cut off from the world.
- They are denied many rights and opportunities the rest of us have.
- These Centers are not safe places to live, where residents get better care than they could get in the community.
- People who have lived in the Centers talk about how they were treated badly when they lived there, and how they had no rights at all.
- Department of Justice investigators found many, many problems with the care being provided at the State Centers.
- Some people say the residents of the State Centers can't live in the community. That is not true. The Department of Health & Family Services believes that all residents of the State Centers can live in the community. There are people with the same needs who are living good lives in Wisconsin communities.
- 10 other states have closed their state institutions, including Minnesota. If they can do it, why can't Wisconsin?

End the Institutional Bias in Wisconsin

What is the institutional bias?

Right now, the state will pay \$400. a day for someone to live in a State Center; but the state will only pay \$200. a day if that same person wants to live in the community.

This is an institutional bias that means over 800 people with developmental disabilities are denied the right to live in the community because their support services cost more than \$200. a day.

Why does this blatant institutional bias exist?

Because Wisconsin continues to value institutions more than community services, even though federal laws and policies and court decisions repeatedly tell us that people with disabilities should have an equal right and opportunity to live in the community.

Because Wisconsin values institutions more than community services, it spends 27% of all funds for people with developmental disabilities on its state-run institutions, but these places serve only 2% of Wisconsin citizens with developmental disabilities.

According to Department of Health & Family Services data, the residents of the State Centers could live in the community at a cost of about 30 million dollars less than it costs for them to continue to live in the State Centers. The institutional bias not only denies choice, it wastes precious tax dollars.

How to End the Institutional Bias:

Fund all services for people with developmental disabilities at the same daily rate. Set that rate based on individual need. Stop under-funding community services and over-funding institutional services.

Natural Environments For All!

The Birth to Three Program for infants and toddlers with developmental disabilities is a wonderful program that Wisconsin legislators have rallied around.

One of the key principles of the Birth to Three Program is a requirement that infants and toddlers with developmental disabilities receive services in natural environments.

The federal government made this a requirement of the Birth to Three Program to ensure that segregation and institutionalization would not be an option.

People First Wisconsin wants this philosophy to run through all programs for people with developmental disabilities. No matter what their age, we believe people with developmental disabilities have a right to receive services and supports in the same places everyone else gets them - in the community!

In the Birth to Three Program, if people do not wish to receive services and supports in natural environments, they have the option not to participate in the program. The same should apply to adult services.

Long ago, we realized that segregating people of color was wrong. It is time we recognize that segregating people with disabilities is just as wrong.

**Apply the Principle of Natural Environments to
All Publicly Funded Programs for People
with Developmental Disabilities.**



STATE CENTERS INITIATIVE

People Can't Wait to End the Institutional Bias Favoring State Centers

ISSUE LEADERS: Lisa Mills, People First of Wisconsin, 414/483-2546, lmills@execpc.com; Steve Verriden, ADAPT, 608/249-4308, adaptsteve@charter.net

The number of institutional closures continues to rise dramatically across the nation. Thirty-eight states have closed or begun to close at least one large state-run institution for people with developmental disabilities. Ten states have closed all such facilities. Wisconsin doesn't even have a plan to close any of its three State Centers.

ISSUE:

Just 800 people with developmental disabilities now live in the three State Centers.

- The Centers' population continues to decrease every year because our community service system can now support people with significant disabilities to live alongside other citizens in our communities.

The daily cost for residents in State Centers has skyrocketed, currently averaging \$477 per day or \$174,100 per year.

- This is \$53,000 more per person per year than the national average spent on this type of institutional care, and \$80,000 more per person per year than the average spent on Wisconsin's alternative community program, CIP1-A.

99% of the State Center residents could live in the community for an average rate that is less than the \$477 per day the state spends to keep people in the State Centers. Most could get services for much less.

State law must change to make sure people are not unnecessarily kept in the State Centers, and that enough of the money being spent on them in institutions can follow them to fund their community services. To make this happen, more efforts must be made to down-size and close the State Centers. If the Centers were closed, projected savings could be used to provide desperately needed increases in community service funding.

Moving out of the State Centers and being served in the community under the CIP 1-A program has been proven to be the right thing to do. While only 75% of State Center guardians are satisfied with the placement of their loved one in a State Center, 96% of guardians for individuals who have moved out of the State Centers are satisfied with the quality of the community services they are receiving through the CIP 1-A program.

GOAL:

Start a process that will move Wisconsin toward a single, high quality support system for people with developmental disabilities. This system must be community-based, with adequate funding and an adequate workforce. Stop running three State Centers as a separate - and very high cost - system.

2003 - 05 ACTION PRIORITIES:

- 1) Direct the Department to develop a plan to **close Northern and Southern Center in 3-4 years**, and transfer \$23.6 million in savings to community services.
- 2) Direct the Department to **create a downsizing plan for Central Center**, which ensures that residents' needs are met.
- 3) Level the playing field between the State Centers and community services and make community a real choice. **Increase the CIP 1-A rate to \$325 per day.**
- 4) **Increase the CIP 1-A rate in a way that is cost neutral to the state.** Fund the CIP 1-A rate increase by increasing the Center Reduction Rate to \$325.
- 5) When a person dies in a State Center, the Center currently has the option to keep the entire rate (\$174,100/year at present) in its budget. **Adopt a policy that would require that at least 75% of these funds be used to help others move out or to prevent people from moving into the Centers.**
- 6) **Put safeguards in place so people moving to the community have all the supports they need to succeed.** CIP 1-A rates should be adjusted periodically to ensure that rates match costs of placements.

For more information about the Survival Coalition or other Survival Coalition issue papers, visit the DAWN website at: http://www.dawninfo.org/co/sc/survival_coalition.cfm

DECEMBER 2002

U.S. Department of Justice Report on the State Centers
September, 1994

Summary of the Findings

- There is excessive restraint usage.
- The environment fails to meet the needs of residents – it has no stability, is non-stimulating, is unsafe and is overly restrictive.
- Residents are subject to harm due to inadequate supervision.
- There are inadequate behavioral programs.
- Training programs are inadequate and do not facilitate individual growth, independence, & functional skills.
- Emergency care is lacking and critical care is deficient.
- Medical record keeping is seriously deficient.
- Administration and monitoring of psychotropic medications are grossly deficient.
- There is deficient monitoring of seizure disorders.
- Diagnosis & treatment of illness does not meet professional standards.
- Monitoring & follow-up of medical care received at hospitals are insufficient.
- Psychiatric services are inadequate.
- There are shortages of trained medical staff.
- Psychological services do not meet professional standards.

Value All Wisconsin Citizens!

Leave no person's door to the future
locked in State Centers.

Close the Centers.

Use the 30 million dollars in savings to
build stronger community services.

A message for Wisconsin Legislators from People First Wisconsin, a statewide self-advocacy organization made up of people with disabilities, many of whom are former residents of the State Centers. For more information, please contact People First Wisconsin at (414) 483-2546 or 3195 S. Superior Street, Milwaukee, WI 53207.

We Need Your Help!

Support Wisconsin Taking a Serious
Look at the State Centers!

Support AB 473 and SB 231

These bills would create a
taskforce to develop a plan for
the future of the State Centers.

A message for Wisconsin Legislators from People First Wisconsin, a statewide self-advocacy organization made up of people with disabilities, many of whom are former residents of the State Centers. For more information, please contact People First Wisconsin at (414) 483-2546 or 3195 S. Superior Street, Milwaukee, WI 53207.

There is an institutional bias in funding for people with developmental disabilities: the 2% that live in the State Centers for the Developmentally Disabled get 27% of the funding while the 98% that live in the community get only 73% of the funding!

Despite this, we are very worried about the care people are getting at the State Centers.

We believe all people should be able to make their own choice of where to live.

People living in the community can realize their dreams. Community members' lives are enriched by living alongside people with developmental disabilities.

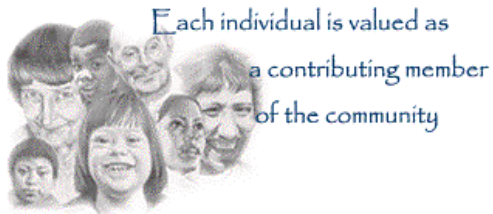
Allow all people with developmental disabilities to live near their family and friends. Support the State Centers Taskforce Bill (Senate Bill 231 and Assembly Bill 473) and move toward closing the State Centers.

A message for Wisconsin Legislators from People First Wisconsin, a statewide self-advocacy organization made up of people with disabilities, many of whom are former residents of the State Centers. For more information, please contact People First Wisconsin at (414) 483-2546 or 3195 S. Superior Street, Milwaukee, WI 53207.

What Do The State Centers Have To Do With Building Stronger Community Services for People with Developmental Disabilities?

- The community service system is millions of dollars short of what it really needs to support people with developmental disabilities to live good lives in the community.
- If the State budget is tight, we need to be looking for other ways to find that money.
- The State Centers cost \$30 million dollars more than what it would cost to support the 844 residents to live in the community.
- Closing the State Centers is the only way to capture those savings for community services.
- Money is not the only answer to building a stronger community service system. The other thing Wisconsin must do is recognize that we will never have a strong community service system as long as we have an institutional service system competing for our time and resources.

If we make the community service system the only service system for people with developmental disabilities, we can focus all of our energy and resources on making it the best it can be!



March 2004

Federal, State and Case Law Regarding Institutionalization of People with Disabilities

What Does the National Conference of State Legislators (NCSL) State About Olmstead and its impact on Deinstitutionalization and Waiting Lists?

NCSL NEWS (March 29, 2001):

"In June 1999, The Supreme Court ruled in *L.C. & E.W. vs. Olmstead* that it is a violation of the Americans with Disabilities Act for states to discriminate against people with disabilities by providing services in institutions when the individual could be served more appropriately in a community-based setting."

NCLS State Legislative Report (March 2002), Volume 27, Number 7:

The Court suggests ways by which a state can show compliance with Olmstead.

1. A state may develop a comprehensive, effective working plan, including timetables and progress reports, for placing qualified people in community-based settings.
2. A state may maintain a waiting list for community-based services, but the list must move at a reasonable pace and may not be motivated by a desire to fill institutions.

What Does *Olmstead v. L.C.*,¹ Find?

- "Unjustified isolation...is properly regarded as discrimination based on disability."²
- Affirms the Department of Justice's stance that "undue institutionalization qualifies as discrimination 'by reason of ... disability.'"³

¹ 527 U.S. 581 (1999). *Olmstead* is a landmark Supreme Court Case that serves to advance the rights of people with disabilities. In *Olmstead*, the Supreme Court held that the Americans with Disabilities Act required that individuals with disabilities be placed in the community rather than in institutions. *Id.* Lower courts (federal and state) have interpreted *Olmstead* as a prohibition, mandated by federal law, against "avoidable" and "unnecessary" institutionalization of individuals with developmental disabilities, and as a requirement that states make "reasonable efforts to place institutionalized individuals with developmental disabilities in the community." *Id.*

² See *Olmstead*, 527 U.S. at 597 (discussing unjustified isolation in terms of institutionalization).

³ See *id.*, at 597-598.

- “...Confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”⁴
- “...Under Title II of the ADA, States are required to provide community-based treatment for persons with mental disabilities when the State’s treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.”⁵

What Does The Developmentally Disabled Assistance and Bill of Rights Act⁶ Say About Institutionalization of People with Developmental Disabilities?

- “Treatment, services, and habilitation for a person with developmental disabilities ... should be provided in the setting that is **least restrictive** of the person’s personal liberty.”⁷

What Do Federal Regulations Say About Institutionalization of People with Disabilities?

- "A public entity shall administer services, programs, and activities in the **most integrated setting** appropriate to the needs of qualified individuals with disabilities.”⁸

What Does The Americans with Disabilities Act⁹ Says About Institutionalization of People with Disabilities?

- "Historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem;
- Discrimination against individuals with disabilities persists in such critical areas as . . . institutionalization. . .;

⁴ See *id.*, at 601.

⁵ See *Olmstead*, 527 U.S. at 607.

⁶ 42 U.S.C §6001 (2000).

⁷ 42 U.S.C. § 6010(2) (1976 ed.) [Emphasis added].

⁸ See 28 C.F.R. 35.130(d) (1998) [Emphasis added].

⁹ 42 U.S.C. §12101 (1990).

- Individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, . . .failure to make modifications to existing facilities and practices, . . .[and] segregation" ¹⁰

What Does Evolving Case Law State About Institutionalization?

- If an individual opposes community placement, does the individual have a right to remain in an institution?

NO. This issue came before the Pennsylvania District Court which ruled that Olmstead does not give a person the right to remain in an institutional. Advocates for institutionalization sought to intervene in *Richard C. v. Houstoun*, (W.D.Pa. September 29, 1999). The proposed interveners argued that the facility's residents have a right to remain in the facility if they oppose community placement. The District Court rejected the proposed interveners' argument and made it clear that nothing in the Olmstead decision precludes a state from closing or downsizing institutions or placing individual residents into the community and that the ADA does not confer on individuals the right to veto such actions. ¹¹

What Does Maryland Law Say About Institutionalization of People with Developmental Disabilities?

Maryland Health-General Article 7-102. Legislative Policy states: "To advance the public interest, it is the policy of this State:

- "(4) To foster the integration of individuals with developmental disability into the ordinary life of the communities where these individuals live.
- (5) To support and provide resources to operate community services to sustain individuals with developmental disability in the community, rather than in institutions.
- (6) To require the Administration to designate sufficient resources to foster and strengthen a permanent comprehensive system of community programming for individuals with developmental disability as an alternative to institutional care."¹²

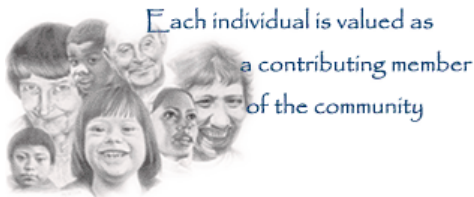
MARYLAND DEVELOPMENTAL DISABILITIES COALITION

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Maryland Developmental Disabilities Council • Maryland Disability Law Center**

¹⁰ See 42 U.S.C. §§12101(a)(2), (3), (5).

¹¹ NAPAS, Washington, D.C.

¹² See §7-102(4-6) (2000).



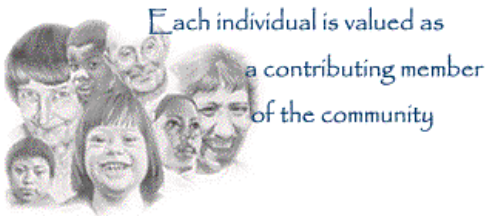
March 2004

Outcomes for People Leaving Institutions: What Research Tells Us

A review of all reports published between 1980 to 1999 about behavioral changes when people with intellectual disabilities move from institutions to community settings found the following¹:

- Studies of over 2,600 subjects demonstrate strongly and consistently that people who move from institutions to community settings have experiences that help them to improve their adaptive behavior skills. This is a robust array of research whose findings are remarkable for their consistency
- Individuals who left institutions used significantly more community places, engaged in significantly more social activities, experienced significantly more personal integration, had significantly more family contacts, and made significantly more choices at an adjusted expenditure that was 66% of that of their counterparts who remained in institutions.
- All of the studies published in 1990 or later reporting significant findings regarding changes in challenging behavior reported significant improvements.
- Many studies have examined changes in adaptive or challenging behavior associated with movement from institutions to community settings. Summaries of this research noted that, overall, adaptive behavior was almost always found to improve with movement to community settings from institutions, and that parents who were often as a group initially opposed to deinstitutionalization were almost always satisfied with the results of the move to the community after it occurred.

¹Source: Lakin and Larson, 1999, Research & Training Center on Community Living, University of Minnesota. "Behavioral Outcomes of Deinstitutionalization for People with Intellectual Disabilities: A Review of Studies Conducted Between 1980 and 1999."



**ROSEWOOD CENTER SHOULD NOT REMAIN OPEN AND BECOME A
“COMMUNITY RESOURCE CENTER”**

WHY?

Do we need a “Community Resource Center” at Rosewood Center to provide optimum health care for persons with developmental disabilities?

No.

- The Baltimore Area is nationally recognized as having the most advanced health care in the nation. The Johns Hopkins Medical Center and the University of Maryland Medical Center are teaching hospitals that attract specialists who are widely respected in their field.
- These Teaching Facilities eagerly accept persons with complex medical needs and pride themselves on finding answers that improve the lives of all persons who need their services.

Are community Physicians, Dentists and other Health Care Providers ill equipped to provide care to persons with intensive needs?

No.

- Community health care providers are very capable. Sometimes additional training and coordination is needed; however training at an institution is not the answer. One proven approach is occurring in the Philadelphia area. The Commonwealth of Pennsylvania has established Philadelphia Coordinated Health Care that provides technical assistance and training for medical personnel, including physicians, dentists and medical students; individuals with developmental disabilities and their families; and community support staff. Collaborative efforts result in accessible quality medical, dental, and behavioral health care. PCHC works with each county to develop a plan to address disability priorities in the health care arena.

Is a “Resource Center” located at an institution necessary to train staff of community service providers?

No.

- The Developmental Disabilities Administration requires intensive training of community staff. Adult training is best done in an experiential manner and not in an artificial setting such as the buildings of an institution. Training can always be improved, but it is best done in the community where people are living. It should be done by those who receive services, their families, and professionals in the field.
- In the last few years, some agencies have pooled their resources and enlisted the assistance of local community colleges to enhance the professional standards for staff. We must build upon existing community and college resources, rather than establishing a new bureaucracy and program housed at an institution.

Do we need Rosewood Center to provide respite care and other services to people who live in the community?

No.

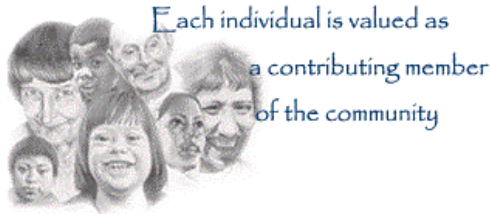
- Families overwhelmingly report that they want access to respite care and other supportive services in their home or home community, rather than traveling to an institution. The market demands quality respite care and other services in the community.
- Individuals living in the community are not attracted to large segregated sites for respite or other services. Community respite services have been provided in more inclusive settings for more than 15 years. Younger families are more comfortable with community settings.
- Maintaining and improving increasingly deteriorating buildings at state institutions is expensive and unnecessary.

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January 2004

Shattering Myths *about* **Choice**

Q: Should a continuum of services include institutions?

A: No.

- Society has no responsibility to subsidize segregation.
- Society's values change as civil rights, contemporary technology, and new medical and health approaches are incorporated into mainstream society. Outdated technologies and treatment approaches are then replaced by more advanced practice. Institutions are no longer the contemporary approach for the way individuals with disabilities seek to live and receive treatment and supports.

Q: Should parents have the choice to place or keep their child in an institution?

A: No.

- None of us, whether we have a disability or not, has unlimited choices in life.
- Governmental and societal strictures do not allow any of us to choose anything we wish. Some options are excluded or forbidden, either in the interest of the community's overall welfare or as a result of government responsibility to set priorities and allocate its resources.

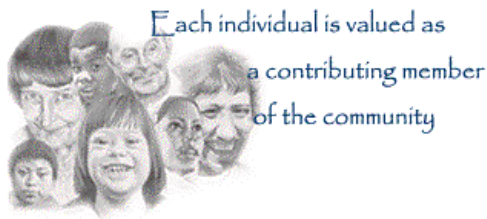
It is NOT reasonable to segregate people in institutions when experience and research prove that even people with significant disabilities and intensive needs can be supported in the community.

It is NOT reasonable to continue to invest scarce public dollars operating large, inefficient congregate settings.

It is NOT reasonable to deny even one person the right to live among us in the community, where services and supports can be provided.

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March 2004

Shattering Myths *about* **Closure Impact on the Local Economy and Workforce**

Q. Is the local economy & workforce negatively impacted when a State Residential Center closes?

A: No.

The Great Oaks State Residential Center was closed seven years ago. All residents were transitioned to individually designed community residential and day supports. The Center's buildings were demolished. The property was sold to Erickson Retirement Community who constructed Riderwood Village on the property that formerly housed the Great Oaks Center.



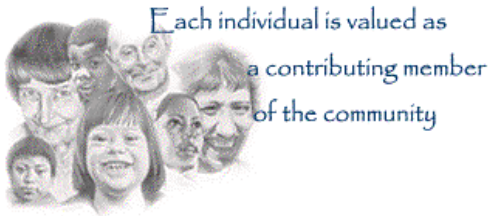
Construction Investment: \$560 Million in Private Investment

- **Annual Operating Budget: Approximately \$60 Million**
- **Local Taxes: \$1.4 Million per year**
- **Number of Employees: 712**
- **Annual Payroll: 2003 - \$12.3 Million; As of Completion in 2006: \$23.8 Million**
- **Median Income of Residents Served: \$48,168**

Riderwood Village, upon completion in 2006, will include approximately 2,000 independent living units, 250 assisted living units and 400 skilled nursing units. The Project also includes four community buildings and related support facilities and common areas, e.g. dining rooms, convenience stores, bank branches, beauty salons, game rooms, aquatic center, classrooms, woodworking shop, in-house cable television station, non-denominational chapel, walking paths, nature trail and health club. Services provided in the common facilities include an on-site medical center and services for resident organizations.

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October 2003

Shattering Myths *about* **Community Placement**

Q: Can institutions serve people on DDA's Waiting List?

A: No.

- “*Over my dead body.*” ~ quote from Waiting List families.
Families on the Waiting List have struggled for years to meet their loved one's needs with little or no outside help. They did this so their son or daughter with a disability could remain a part of the family and community. That's what they want to continue, with adequate community supports.

Q: Will people lose their jobs if an institution closes? Will hundreds of people become unemployed if an institution closes?

A: This should not even be a consideration.

- We shouldn't keep people institutionalized just so others can keep their current jobs.

A: Many staff could find work in community programs.

- In fact, many institution staff are already working in community programs.

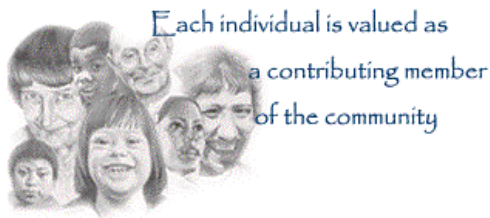
It is NOT reasonable to segregate people in institutions when experience and research prove that even people with significant disabilities and intensive needs can be supported in the community.

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January 2004

Shattering Myths *about* **The Cost of Services**

Q: Should people move to the community only if the State can save money?

A: No.

- Moving people to the community is not an issue of cost; it is an issue of human and civil rights.
- In fulfillment of human rights and in securing optimum opportunities for development, all people, regardless of the severity of their disability, are entitled to community living.ⁱ

Q: Is there a cost savings when an institution closes?

A: Yes.

- The proceeds from the sale of institutions go into Maryland's Community Services Trust Fund. Investment earnings generated by the Fund are used to support more people with developmental disabilities and their families in critical need of community services. In addition, closure of an institution means that the state can stop spending scarce public funds on costly maintenance and upkeep of antiquated buildings.

Q: Are institutions cost-effective?

A: No.

- Recent cost comparisons of community and institutional services refute claims that institutions offer "economies of scale" or that the centralization of services at institutions is more cost-effective.ⁱⁱ
- The cost of community services depends on each individual's needs and may or may not cost less.

Q: Why not operate an institutional system and a community system?

A: This is not fiscally or socially responsible.

- More than 11,000 people are on DDA's waiting list for community services. Policymakers must take their needs into account. Limited public resources must be spent in a fiscally and socially responsible manner.

It is NOT reasonable to segregate people in institutions when experience and research prove that even people with significant disabilities and intensive needs can be supported in the community.

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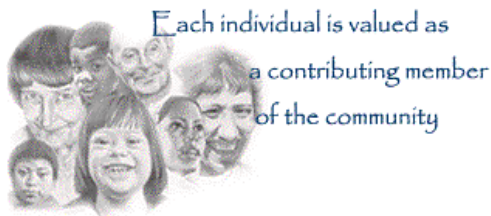
ⁱ *The Community Imperative: A refutation of all arguments in support of institutionalizing anybody because of mental retardation* (1979). Center on Human Policy at Syracuse University.

Established that all human beings, regardless of nature and severity of disability, are inherently valuable, have fundamental rights, and are capable of learning, growth, and development.

ⁱⁱ Taylor, S.J. (2003, June) *The Editor's Perspective on Institutional and Community Costs*. *Mental Retardation*, 41,125-126

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Shattering Myths
about
**People with Intensive Needs
Living in the Community**

Q: Can everyone with a developmental disability be served in the community? Are there individuals who are not able to live outside of an institution?

A: All people currently in institutions can live in the community.ⁱ

- Former Great Oaks Center residents who rely upon ventilators and portable oxygen, require positioning every two hours, and need suctioning are now living safely with home and community supports in Maryland.
- Nine states, plus the District of Columbia, have closed all state institutions: Alaska, Hawaii, Maine, Minnesota, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia. People are living successfully in the community.
- People are receiving 24-hour care and support, 365 days a year, when needed, to be safe in the community. They also have a better quality of life.

Q: Are people in institutions more challenging and disabled than people living in the community?

A: No.

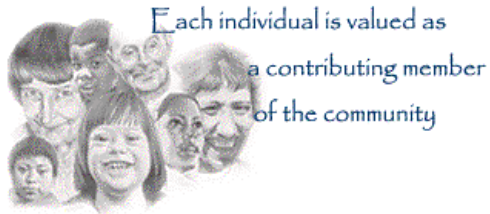
- While many people remaining in institutions do have multiple disabilities and extensive support needs, there are people with similar disabilities and more intensive needs who are living with their families or are supported in community programs throughout Maryland.

It is NOT reasonable to segregate people in institutions when experience and research prove that even people with significant disabilities and intensive needs can be supported in the community.

It is NOT reasonable to continue to invest scarce public dollars operating large, inefficient congregate settings.

It is NOT reasonable to deny even one person the right to live among us in the community, where services and supports can be provided.

ⁱ Some people in DDA institutions are there under a court order because of involvement with the criminal justice system. They are referred to as the forensics population. Whether or not they can be served in the community is under the jurisdiction of the court, and therefore, not a part of this discussion.



January 2004

Shattering Myths *about* **Quality of Life & Quality of Services**

Q: Has moving from institutions to small community homes been successful? Are outcomes for people better in the community?

A: Yes.

- Research demonstrates that moving people from institutions to the community has been extremely successful and that outcomes for people in the community are better than for individuals segregated in institutions.ⁱ Recent research has also found this to be true of people with very serious challenges.ⁱⁱ In fact, from the large body of research evidence now available, researchers make this statement: “*Deinstitutionalization of people with developmental disabilities in America has been one of the most successful and cost-effective social experiments in the past two decades.*”ⁱⁱⁱ

Q: Do parents who fear their loved ones will not be safe and will suffer in the community continue to feel this way after their family member leaves the institution?

A: No.

- Research shows that family member attitudes change dramatically after community placement. Before community placement, less than 20% of families agreed with community placement and 58% strongly opposed community placement; However, after placement, 66% of families strongly agreed with community placement and less than 5% opposed.^{iv}

Q: Is community living a “one size fits all” approach?

A: No.

- Smaller community settings are more likely to address unique needs and preferences than larger institutions. Community programs, including staff training, are designed around the needs of the person.
- Everyone who leaves a DDA institution does so ONLY after thorough individualized team planning and when all needed community-based services and supports have been identified. In addition, everyone leaving an institution is assigned a resource coordinator to monitor and assist in carrying out his or her plan.
- It is actually institutions – with large numbers of people and set routines – that epitomize “one size fits all.”

Q: Is there widespread abuse in community programs? Are institutions safer?

A: No.

- Institutions and community programs in Maryland are licensed and certified by the same state and federal agencies. When people live in the community, neighbors, friends, and the public

can see and report any abuse--something less likely to happen for an individual living in an isolated setting.

- A recent study found allegations of abuse actually decreased after community placement.^v
- Direct comparisons of the number of abuse allegations in institutions and community programs are misleading, as they must be considered in the context of the total number of people served -- 22,000 people with developmental disabilities are supported in community programs while about 400 people live in institutions.
- Abuse, unfortunately, also occurs in institutions.

Q: Aren't institutions home-like?

A: No.

- “As much as we try to create a home-like environment in an institution, institutions are not homes. You cannot take 200 people and create a home. It’s not individual. And you just cannot measure the importance of environment.” ~ Bill Brooks, retired superintendent of Winfield State Hospital^{vi}

It is NOT reasonable to segregate people in institutions when experience and research prove that even people with significant disabilities and intensive needs can be supported in the community.

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ⁱ Lakin, K.C. (1999). *A review of literature of home and community services for persons with mental retardation and related conditions*. Minneapolis: University of Minnesota, Research and Training center on Community Living, Institute on Community Integration.

ⁱⁱ Conroy, J., Spreat, S., Yuskas & Elks, M. (2003). The Hissom Closure Outcomes Study: A Report on Six Years of Movement to Supported Living. *Mental Retardation*. 41, 263-273.

ⁱⁱⁱ Conroy, J., Garrow G., Fullerton, A., Brown, M. & Vascile, F. (2003). *Initial Outcomes of Community Placement for the People Who Moved From Stockley Center*. Completed for the Delaware Division of Developmental Disabilities Services.

^{iv} Conroy J. & Bradley, V. (1985). The Pennhurst Longitudinal Study: A Report of Years of Research and Analysis.

^v Conroy J., et. al (2003). *Initial Outcomes of Community Placement for the People Who Moved From Stockley Center*.

^{vi} *The Right Thing To Do*. 1998. The Kansas Council on Developmental Disabilities.

MARYLAND DEVELOPMENTAL DISABILITIES COALITION

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"SEEKING WAYS OUT TOGETHER" TEAM (SWOT)

In 1991 a small group of self-advocates was invited by the state of New Jersey to help persons prepare to return to the community during the closure of Johnstone Training & Research Center.

From this small group of pioneers came a team of experienced, dedicated, volunteer self-advocates called the "Seeking Ways Out Together" Team or the S.W.O.T. Team. These self-advocates hail from all parts of New Jersey, many have been institutionalized, a few of us still live in developmental centers. We are **all** disabilities and backgrounds. We are not a self-advocacy group. We all hold an abiding belief that all people, no matter the degree or type of disability, have the right to live in their communities with dignity. The work of the team requires hard work, courage, and a commitment to a cause. Members return to developmental centers, many had once called "home." They go back to inform, counsel, befriend, share personal testimony, advocate and support their brothers and sisters still kept inside these institutions, still waiting to return to the community, still waiting to be free.

During the years we have witnessed the liberation of our members from institutions, have mourned the passing of other members and greeted new ones. We have celebrated birthdays, anniversaries, weddings and more. We have protected each other during public demonstrations and hearings. We have also argued mightily among ourselves and we have had our differences. We are proud to have played a part in the closing of two developmental centers, and the release of dozens of our brothers and sisters from other state institutions.

In 1999 the Supreme Court of the United States made the Olmstead Decision. It says people with disabilities have the right to live where they want to live. The Olmstead Decision helps us to continue our work.

We are a group of people with disabilities with a strong belief in the power of self-advocacy and working together for a cause. We believe in the work we do. We believe in each other. We are family.

SWOT LIVES!

COMMUNITY LIVING REQUEST FORM



NAME _____

ADDRESS _____

PHONE _____

1. DO YOU WANT TO KNOW MORE ABOUT COMMUNITY?

_____ YES _____ NO _____ MAYBE

2. DO YOU WANT TO LIVE IN THE COMMUNITY?

_____ YES _____ NO _____ MAYBE

3. NAME TWO THINGS YOU WANT TO LEARN ABOUT LIVING IN
COMMUNITY:

1. _____

2. _____

4. TELL US TWO THINGS ABOUT YOURSELF:

1. _____

2. _____

5. HOW CAN WE HELP YOU?

_____ LEARN ABOUT THE COMMUNITY

_____ LIVE IN THE COMMUNITY

_____ UNDERSTAND & SPEAK UP AT MY IHP MEETING

_____ SOMEONE TO TALK TO/PHONE BUDDY

_____ LEARN MORE ABOUT SELF-ADVOCACY

6. DO YOU HAVE A FRIEND OR STAFF WHO HELPS YOU HERE?

_____ YES _____ NO _____ MAYBE

WOULD YOU LIKE TO BE A TELEPHONE BUDDY OR A
PEN PAL TO SOMEONE LIVING IN AN INSTITUTION IN NEW
JERSEY?

JUST FILL OUT THIS FORM AND MAIL TO:

SWOT TEAM
C/O PEOPLE SUPPORT NETWORK
P.O. BOX 58
TITUSVILLE, NJ 08560

NAME _____

ADDRESS _____

PHONE _____

YOUR INTERESTS/HOBBIES _____

WOULD YOU LIKE TO BE A PAL TO A:

FEMALE _____ MALE _____

OR CALL KATE AT 609-737-8926 OR 609-633-3782

PEOPLE SUPPORT NETWORK
& SEEKING WAYS OUT TOGETHER TEAM
PO BOX 58
TITUSVILLE, NJ 08560

1. Arrange to visit self-advocacy groups in institutions (developmental centers) and talk about living in the community.
2. Have your group invite people from an institution to your self-advocacy meetings.
3. Become a "buddy" to some people or a self-advocacy group in an institution.
4. Plan an event with a self-advocacy group in an institution (party, voter registration, speakers' night).
5. Become a telephone or pen pal.
6. Arrange for people to visit your homes, attend church or synagogue, go to a sports event.

REMEMBER: All of these ideas take a lot of planning, but all of these ideas have worked for other self-advocates who decide to help people leave an institution and become part of the community. Please call the SWOT Team at 609-737-8926 if you have questions or call NJUSA!

PEOPLE SUPPORT NETWORK &
SEEKING WAYS OUT TOGETHER TEAM
2001 -2004
NJ OLMSTEAD INITIATIVE

Support Services & Activities

1. Community Living Meetings
2. 'Welcome to Your Neighborhood' Kits
3. Community Self-Advocacy Host Groups
4. Staff Trainings
5. Transitional Support Groups (Anger Groups)
6. Open House:
 - Weekends & Evenings
 - Refreshments
 - 2 to 3 hours
 - Self-advocates are hosts. Provide peer counseling & information
 - Community Living Guest Speaker
 - Music
 - Videos
 - Lending Library
 - Information Table for Staff
 - Games about Community Living
 - Accessible Room
 - Open to all residents
 - Newsletter

OTHER SUGGESTIONS:

1. Community Visits (include people with significant disabilities)
2. Bridging

What PSN & SWOT TEAM has done in the past:

1. Initiated self-advocates (former center residents) as guest speakers and peer support for transitioning residents.
2. Interviewed residents about their concerns, emotions, needs during transitional period.
3. Provided information about the Olmstead Decision & referrals for persons not on Olmstead Initiative list.
4. Initiated self-advocates as members of relevant policymaking and planning bodies.

5. Developed support techniques, ex. newsletter, video, community visits (Bring in community/take residents out to community).
6. Established Consumer Support Office & paid internships for residents.
7. Supported individuals at IHP & other relevant meetings.
8. Established Community Living Office @ New Lisbon Developmental Center.
9. Conducted voter registration drives at centers.

COMMUNITY



NEWS

NEWSLETTER # 4

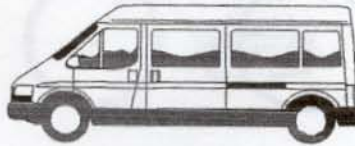
THE SEEKING WAYS
OUT TOGETHER
(S.W.O.T.) TEAM
SPRING, 2004

THE SWOT TEAM
NEWSLETTER,
COMMUNITY NEWS,
IS MADE FOR
PEOPLE WHO LIVE
IN A
DEVELOPMENTAL
CENTER AND
WANT TO KNOW
MORE ABOUT
LIVING IN THE
COMMUNITY.

THE NEXT
OPEN HOUSE
WILL BE HELD ON
MARCH 13TH
FROM 1:30 TO 3
AT THE
COMMUNITY CENTER.
ENJOY A GAME OF
COMMUNITY BINGO,
WATCH A VIDEO,
DO AN ACTIVITY, AND
CELEBRATE
ST. PATRICK'S DAY

How Do People Get Around In The Community?

VAN



What To Expect When Traveling by

VAN

- Usually has from 6-10 seats
- Always buckle your seat belt

BUS



BUS

- Usually has 20 or more seats
- County Transit or City Bus Line

TAXI



TAXI

- Usually has 3 or 4 seats
- Call for Cab to pick you up

TRAIN



TRAIN

- Door slides open & step inside car
- Scheduled stops at train station

**COUNTY TRANSIT
MINI-BUS**

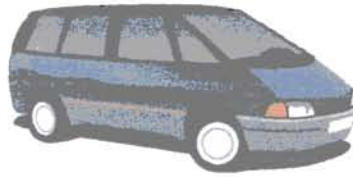


PEOPLE WALKING,

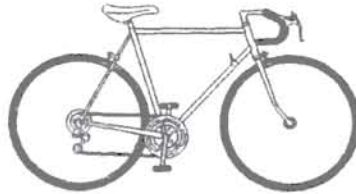


TRANSPORTATION

VAN

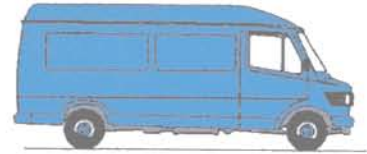


RIDING A BIKE,



**WATCH CARS OR
RISK AN ACCIDENT**

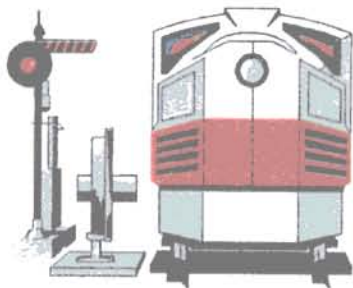
**CALL TO PLAN A
DAY AND TIME**



AND JOGGING ALL



TRAIN



PASSENGER



**A PASSENGER
IN THE BACK
SEAT OF A TAXI**



**PEOPLE WHO
WANT A 'BUDDY'**



**LET US KNOW IF YOU
WANT A S.W.O.T.
TEAM MEMBER TO
WRITE TO YOU.**

CHARTER BUS



S.W.O.T. TEAM

**Call: 609-434-1212
Write: PO Box 58
Titusville, NJ 08560**



**MORE
CONTACTS**

**Self-Advocacy Project
732-926-8010**

**Monday Morning
Network
1-800-216-1199**

WEB SITES

This list includes web sites that have been listed in different sections throughout this tool kit as well as web sites that can provide more information and resources for your advocacy for institution closure.

Advocacy Center, National Down Syndrome Society

<http://www.ndss.org/content.cfm?fuseaction=AdvCen&article=79>

Provides many advocacy tools for anyone's use, including tips for advocates, organizing coalitions, interacting with policymakers, a guide for change agents by Bobby Silverstein, former principal advisor to Senator Tom Harkins and now Director of the Center for the Study and Advancement of Disability Policy (CSADP).

Advocacy Training Materials from The Public Policy Collaboration

<http://www.thearc.org/ga/trainmat.html>

This is the training page of The Arc, and covers how a bill becomes law (national), how to be an effective legislative advocate, tips on writing or emailing a member of Congress, how to have a meeting with a legislator or their staff, general tips on working with the media, and how to write a letter to the editor of your local paper.

American Association on Mental Retardation (AAMR)

<http://www.aamr.org>

Explore AAMR, whose mission is: AAMR promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual disabilities.

Americans with Disabilities Act/Olmstead Decision, Centers for Medicare & Medicaid Services

<http://www.cms.hhs.gov/olmstead/default.asp>

The Centers for Medicare and Medicaid Services are the parts of the US Department of Health and Human Services that deal with Medicare and Medicaid. This site provides an official summary of the Olmstead decision, an invitation to give input or ask questions about the decision, letters that have been sent to state Medicaid Directors about the Olmstead decision, and links to other government sites related to the Olmstead decision.

The Arc of the United States

<http://www.thearc.org/>

Explore the site of The Arc of the United States, whose mission is: The Arc of the United States works to include all children and adults with cognitive, intellectual, and developmental disabilities in every community. Click on Information, then Governmental Affairs, and then Advocacy Center for a host of advocacy tools.

The Arc of the United States Media Guide

<http://capwiz.com/thearc/dbq/media>

Another useful media guide for journalists.

Assistance with Integrity: The Search for Accountability and The Lives of People with Developmental Disabilities

<http://thechp.syr.edu/integri.pdf>

Download this report listed as a resource in the *Choice* section.

Become an Instant Op-Ed Star! How to Write Opinion Articles that Editors Will Actually Use
By Mary Johnson

<http://www.raggededgemagazine.com/mediacircus/opedtips.htm>

Mary Johnson provides great tips on writing op-ed pieces. You may also want to explore the whole *Ragged Edge Magazine* site by clicking on "About Us" at the bottom of the page.

Behavioral Outcomes of Deinstitutionalization for People with Intellectual Disabilities: A Review of Studies Conducted Between 1980 and 1999. Policy Research Brief, 10(1). Minneapolis: University of Minnesota, Institute on Community Integration

<http://ici.umn.edu/products/prb/101/default.html>

Get an online version of the *Policy Research Brief* contained in the *Quality of Life Outcomes in the Community* section.

BEYOND THE AP STYLEBOOK: Language and Usage Guide for Reporters and Editors

<http://www.raggededgemagazine.com/mediacircus/styleguide.htm>

Provides a style guide for journalists.

Capstones Summer 2003 Issue

<http://www.thecouncil.org/council/about/Capstones/summer03.pdf>

This is a link to the Summer 2003 issue of *Capstones*, the newsletter of The Council on Quality and Leadership.

Center for an Accessible Society

<http://accessiblesociety.org/>

Want to know about the ADA, census data on disabilities, and many other disability issues? This site will answer most of your questions.

Center for Health Care Strategies (CHCS)

http://www.chcs.org/info-url_nocat3961/info-url_nocat_show.htm?doc_id=206314

Since 1995, the Center for Health Care Strategies (CHCS) has strived to continuously improve the quality of health and health related services for beneficiaries of our nation's health coverage safety net--Medicaid and the State Children's Health Insurance Program. This page lists and discusses some of their Olmstead work.

Center for the Study and Advancement of Disability Policy (CSADP)

<http://www.disabilitypolicycenter.org/>

Web site of The Center for the Study and Advancement of Disability Policy (CSADP). CSADP provides public education, leadership development and training, technical assistance and information dissemination, and conducts action-research and analysis of public policy issues affecting individuals with disabilities and their families.

The Center on Human Policy

<http://thechp.syr.edu>

Web site of the Center on Human Policy.

Centers for Medicare & Medicaid Services

<http://www.cms.hhs.gov/medicaid/icfmr/default.asp>

This is the CMS web site for the Intermediate Care Facility for People with Mental Retardation Program (ICF/MR).

A Chance to be Made Whole: People First Members Being Friends to Tear Down Institution Walls by People First of Tennessee

<http://thechp.syr.edu/pl1st.htm>

Abbreviated article by People First of Tennessee on their work on getting other People First members out of institutions.

Closing Brandon Training School: A Vermont story

<http://thechp.syr.edu/brandon.htm>

Web version of the full report on the closing of Brandon Training School, listed as a resource in the *State Strategies* section.

Closing the Gap By Zena Naiditch

http://www.equipforequality.org/equalizer_2001closing.html

The newsletter of Illinois' Equip for Equality covers ADA and Olmstead issues in Illinois, among other things.

CLOSING INSTITUTIONS/SUPPORT FOR COMMUNITY LIVING

<http://www.peoplefirstofcanada.ca/archive/pfc/2.html>

Resolutions by People First of Canada having to do with institution closure and supporting people to live in the community.

Closing the State Centers for the Developmentally Disabled

http://www.dawninfo.org/advocacy/issues/state_centers.cfm

This page of the Disability Advocates: Wisconsin Network (DAWN) gives the People First Wisconsin position papers on institution closure plus a great deal of information and research about the topic.

Closing State Institutions, The Center for Community Solutions

http://www.communitysolutions.com/store/item.asp?ITEM_ID=78&DEPARTMENT_ID=38

<http://www.communitysolutions.com/images/upload/resources/sbmissue44.pdf>

Resources by the Center for Community Solutions, an Ohio-based nonprofit focused on policy and system reform.

Closure By Dave Seaton

<http://www.winfieldcourier.com/Closure/closure01.html>

The closing of the Winfield State Hospital left dozens of developmentally disabled individuals without a home. This is the story of how the movement that closed Winfield came to Kansas and how these individuals found new homes in the Winfield area.

The Community Imperative

http://thechp.syr.edu/community_imperative.html

Endorse, on the web, the Center on Human Policy's *Community Imperative* (found in the *Position Statements* section); see who else has endorsed this national statement of principles.

Community Integration/Medicaid

<http://www.napas.org/I-3/I-3-D/community%20integration-medicaid%20home.htm>

Contains information about compliance with Olmstead nationwide; includes the text of the decision and much, much more.

Congress.org Media Guide

<http://congress.org/congressorg/dbq/media/>

Congress.org is a public service of an organization called Capitol Advantage. This page allows one to find media outlets anywhere in the country.

Costs and outcomes of community services for persons with intellectual and developmental disabilities. Policy Research Brief, 15(1). Minneapolis: University of Minnesota, Institute on Community Integration

<http://ici.umn.edu/products/prb/151/default.html>

Download the *Policy Research Brief* on costs and outcome of community services.

The Council on Quality and Leadership

<http://www.thecouncil.org>

The web site of the Council on Quality and Leadership, which provides accreditation, monitoring, evaluation, training, and consultation to human service organizations.

Deinstitutionalization--Keep Focused on How and When, Not Why

<http://www.thearc.org/news/article.asp?ID=610>

An article that originally appeared in the *Durham Herald-Sun* in July, 2003, written by a parent.

Deinstitutionalization of Persons with Developmental Disabilities: A Technical Assistance Report for Legislators

<http://www.ncsl.org/programs/health/Forum/pub6683.htm>

The web page for the report excerpts in the *State Strategies* section. The web site of NCSL, the National Conference of State Legislatures, contains a search engine. Try searching with the key words "Olmstead" or "Long Term Care" for other reports of use to advocates and state officials.

Developmental Disabilities Planning Institute

Provides access to research and progress reports on the closure of two New Jersey institutions:

Background on Closure of North Princeton Developmental Center ([http://www.ddpi.njit.edu/ddpi-](http://www.ddpi.njit.edu/ddpi-publications-state-op.htm)

[publications-state-op.htm](http://www.ddpi.njit.edu/ddpi-publications-state-op.htm)) and Background on Closure of E.R. Johnstone Research and Training Center:

(<http://www.ddpi.njit.edu/ddpi-publications-state-op2.htm>).

Escape! from Tennessee's DD centers

<http://www.mouthmag.com/peoplefirst.htm>

A *Mouth Magazine* article about how People First of Tennessee filed and won lawsuits to close institutions in Tennessee, and how they involved the people living in the institutions in "their own liberation," in the words of PFT advisor Ruthie May Beckwith.

Essential Lifestyle Planning

<http://www.elpnet.net/>

The site of the Essential Lifestyle Planning network gives information, news, and articles about Essential Lifestyle Planning.

Family Futures Project

<http://www.family-futures.org.uk/index.html>

Click on "Planning Tools" for more information on using planning tools such as "Essential Lifestyle Planning," "Person-Centered Planning," "PATH," or "MAPS"

Key Principles of Person Centred Planning, The Family Futures Project

<http://www.family-futures.org.uk/Introduction%20to%20PCP.html>

The title says it all—this is a very nice description of the key principles of person-centered planning, prepared by the Edinburgh-based project of the Scottish Human Services Trust, Family Futures. Visit other parts of their website to learn more about what is going on in Scotland.

IMPACT: Feature Issue on Behavior Support for Crisis Prevention and Response, 14(1). Minneapolis: Institute on Community Integration, University of Minnesota

<http://ici.umn.edu/products/impact/141/default.html>

Download the *IMPACT Feature Issue on Behavior Support*.

IMPACT: Feature Issue on Consumer-Controlled Budgets and Persons with Disabilities, 17(1).

Minneapolis: Institute on Community Integration, University of Minnesota

<http://ici.umn.edu/products/impact/171/default.html>

Download the *IMPACT Feature Issue on Consumer-Controlled Budgets and Persons with Disabilities*.

Issues and Challenges in Developing Individualized Supports By John O'Brien

<http://thechp.syr.edu/nysbisch.htm>

Download the article backing up the *Planning for Quality Community Services* section.

Intermediate Care Facility for People with Mental Retardation Program (ICF/MR), The Centers for Medicare & Medicaid Services (CMS)

<http://www.cms.hhs.gov/medicaid/icfmr/default.asp>

The web site of the ICF/MR Program Information CMS.

The Journalist's Toolbox, Disability/Accessibility Resources

<http://www.americanpressinstitute.org/content/3738.cfm>

Information on disability and accessibility for journalists.

Listen to Me!

<http://www.allenshea.com/listentome.html>

Provides a workbook for planners.

The Media Edge: Feeding the Beast By Jennifer Burnett

<http://www.raggededgemagazine.com/0199/d199me.htm>

A *Ragged Edge Magazine* article about the media and getting your story covered, the way you'd like it covered.

National Association of Councils on Developmental Disabilities (NACDD)

<http://www.nacdd.org/>

NACDD's site provides positions, information, links, and more.

National Center on Disability & Journalism

<http://www.ncdj.org/index.php>

The web site of the National Center on Disability and Journalism (NCDJ), an independent, impartial journalism organization whose mission is to educate journalists and educators about disability reporting issues in order to produce more accurate, fair and diverse news reporting.

NCDJ News

<http://www.ncdj.org/newsletter.php>

Provides online versions of the *NCDJ News*.

NCDJ Style Guide

<http://www.ncdj.org/styleguide.php>

Provides a style guide for journalists.

National Conference of State Legislatures (NCSL) Olmstead Publications

<http://www.ncsl.org/programs/health/Onews.htm>

Read NCSL's publications on Olmstead and long term care for information on how and what the states are doing.

National Down Syndrome Society's Advocacy Center

<http://www.ndss.org/content.cfm?fuseaction=AdvCen.Main>

This section of the NDSS web site has lots of great information for advocates, including tips for advocates, organizing coalitions, interacting with policymakers, and others.

Office for Civil Rights, New Freedom Initiative – Disability, Most Integrated Setting - The Olmstead Decision

<http://www.hhs.gov/ocr/mis.htm>

Read the government's positions on the Olmstead decision, including press releases, grant awards, and much more.

Olmstead: Reclaiming Institutionalized Lives, National Council on Disability

<http://www.ncd.gov/newsroom/publications/2003/reclaimlives.htm>

Get the full report of the NCD report on the Olmstead decision.

OLMSTEAD v. L. C. - Supreme Court Collection, Legal Information Institute, Cornell University

<http://supct.law.cornell.edu/supct/html/98-536.ZS.html>

Cornell Law School's Legal Information Institute presents legal information on the Olmstead decision.

On Choice by Steve Taylor

http://thechp.syr.edu/on_choice.htm

On-line version of the article "On Choice" by Steve Taylor reprinted in the *Choice* section.

People First of Oregon, Fairview: The Closing Chapter

<http://www.open.org/~people1/Fairview/closingcontents.htm>

People First of Oregon talks about the closing of Fairview.

Person Centered Planning and Perversion Prevention By Michael W. Smull and Susan Burke Harrison

<http://www.allenshea.com/perversion.html>

A great article on prevention of perversion of person-centered planning. Describes ways in which what is called "person-centered planning" is misused, and ways in which the process should be implemented.

Public Policy in Action: The Action Starts Here!!

<http://www.tash.org/govaffairs/>

This is the web site of TASH's Governmental Affairs division and has links to help you contact your Senator and/or Representative, along with links to Senate and House Committees that make decisions on policy affecting people with disabilities.

Quality Mall – Closing Institutions Store

<http://www.qualitymall.org/directory/dept1.asp?deptid=32>

A great site for finding materials on or supporting institution closure. Part of the Quality Mall, a site offering person-centered services supporting people with developmental disabilities.

Ragged Edge Magazine Online

<http://www.raggededgemagazine.com/>

Online version of *Ragged Edge Magazine*.

Remembering with Dignity: Leadership Through Activism By Jerry Smith

http://www.selfadvocacy.com/Jerry_Smith_article.htm

The story of how self-advocates in Minnesota obtained a \$200,000 legislative appropriation in 1997 to begin marking 10,000 graves of people buried in state hospital cemeteries, collected oral histories of people who had lived in Minnesota institutions, and did much more to remember with dignity.

Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2002, University of Minnesota, Research and Training Center on Community Living

<http://rtc.umn.edu/risp02/risp02.pdf>

Download the 203-page report whose executive summary is given in the section on *Who are in the Institutions Today?* Gives much data and analysis about state residential institution and community services. Also visit <http://rtc.umn.edu/risp/index.html> which leads to much of the RTC's data and information on community living. A rich resource for advocates.

Resources for Reporters

<http://www.iod.unh.edu/reporters-room.html>

The Institute on Disability's guide for reporters; well worth visiting.

Revisiting Choice – Part 1 & Part 2 - By Michael Smull

<http://www.elpnet.net/choice.html>

The web site for the article included in the *Choice* section.

Safeguards [Policy Bulletin No. 3]

<http://thechp.syr.edu/bullsafe.htm>

The Center on Human Policy's bulletin on Safeguards is on the web.

Self-Advocates Becoming Empowered

<http://www.sabeusa.org/>

Web site of SABE, Self-Advocates Becoming Empowered.

State Long-Term Care: Recent Developments and Policy Directions 2003 Update – National Conference of State Legislatures (NCSL)

http://www.ncsl.org/programs/health/forum/ltc/LTC_draft.htm

Download the NCSL report that examines the specific measures taken by each state in their efforts to reform long-term care.

The State of the States in Developmental Disabilities

<http://www.cu.edu/ColemanInstitute/stateofthestates/>

Download the *new* State of the States in Developmental Disabilities Study Summary 2004 (http://www.cu.edu/ColemanInstitute/stateofthestates/summary_2004.pdf), and examine profiles of disability services in the US, state by state.

Steve Gold's Treasured Nuggets of Information

<http://www.stevegoldada.com/>

Steve Gold is an attorney in Philadelphia who shares tools on how to enforce the ADA with an emphasis on the topics of housing, medical assistance/Medicaid, nursing homes, and education.

Stuff to know about... The Olmstead Decision, Freedom Clearinghouse

<http://www.freedomclearinghouse.org/know/olmstead.htm>

Check this site for great ideas of things to do to implement the Olmstead decision.

TASH

<http://www.tash.org>

The web site of TASH, which supports the inclusion and full participation of children and adults with disabilities in all aspects of their communities as determined by personalized visions of quality of life.

Testimony to: The Special Committee on Appropriations/Ways and Means Senator Morris, Chair, Representative Neufeld, Vice Chair. September 22nd, 2003

<http://www.kacil.org/tm9-22-03.htm>

Provides some compelling testimony in favor of closing the remaining two Kansas institutions, including studies, moral arguments, and more.

Top 10 Arguments Against Closing an Institution

http://www.open.org/~people1/articles/inst_arguments_against_closing.htm

People First of Oregon gives answers to the top arguments against institution closure.

Towards Person Centred Approaches

<http://www.valuingpeople.gov.uk/pcp.htm>

This is a site of the Valuing People Support Team in the United Kingdom. It describes several different person-centered planning approaches.

The University of Minnesota's Research and Training Center on Community Living

<http://rtc.umn.edu/>

The home page of the RTC on Community Living.

What can we count on to make and keep people safe? Perspectives on creating effective safeguards for people with developmental disabilities

<http://thechp.syr.edu/CountOn.pdf>

Web site of the document reprinted in the *Safeguards* section.

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VII. Indexes

- a. Author Index
- b. Topical Index

AUTHOR INDEX

(Index of Authors of Documents Backing up Sections Listed in the Table of Contents)

- Anderson, L. see FAMILY ISSUES
- Bogdan, R. see STATE STRATEGIES
- Braddock, D. see TRENDS IN INSTITUTION CLOSURE
see WHAT IS AN INSTITUTION?
- Cheek, M. see ALL PEOPLE CAN BE SUPPORTED IN THE COMMUNITY
- Community Integration/Medicaid* see *OLMSTEAD AND OTHER LEGAL RESOURCES*
- Coucovanis, K. see COST/ECONOMIC ISSUES
see TRENDS IN DEINSTITUTIONALIZATION
see WHO ARE IN THE INSTITUTIONS TODAY?
- Croser, M. D. see COST/ECONOMIC ISSUES
- Daniels, R. see QUALITY OF LIFE OUTCOMES IN THE COMMUNITY
- Davis, D. see STATE STRATEGIES
- Eidelman, S. M. see COST/ECONOMIC ISSUES
- Federal definitions of "institution"* see WHAT IS AN INSTITUTION?
- Fitzgerald, T. see ALL PEOPLE CAN BE SUPPORTED IN THE COMMUNITY
- Fox-Grage, W. see STATE STRATEGIES
- Gardner, J. F. see COST/ECONOMIC ISSUES
- Gehshan, S. see STATE STRATEGIES
- Hemp, R. see TRENDS IN INSTITUTION CLOSURE
- Hulgin, K. see SAFEGUARDS
see STATE STRATEGIES
- Jesien, G. see COST/ECONOMIC ISSUES
- Kim, S. see QUALITY OF LIFE OUTCOMES IN THE COMMUNITY

Smull, M. W. see ALL PEOPLE CAN BE SUPPORTED IN THE COMMUNITY
see CHOICE

Stancliffe, R. J. see COST/ECONOMIC ISSUES

Swenson, S..... see FAMILY ISSUES

Taylor, S. J. see CHOICE
see COST/ECONOMIC ISSUES
see SAFEGUARDS
see STATE STRATEGIES

Walker, P. see STATE STRATEGIES

TOPICAL INDEX

Abuse and neglect	<i>WHAT'S WRONG WITH INSTITUTIONS?</i>
AAMR	<i>STATEMENT OF PRINCIPLES; POSITION STATEMENTS</i>
Arc of the United States, The.....	<i>STATEMENT OF PRINCIPLES; POSITION STATEMENTS</i>
Arc of Maryland, The	<i>POSITION STATEMENTS</i>
Assistive technology, lack of access to.....	<i>WHAT'S WRONG WITH INSTITUTIONS?</i>
Center on Human Policy.....	<i>STATEMENT OF PRINCIPLES; POSITION STATEMENTS</i>
Challenging behavior	<i><u>ALL</u> PEOPLE CAN BE SUPPORTED IN THE COMMUNITY</i>
Civil rights	<i>WHAT'S WRONG WITH INSTITUTIONS?</i>
Close the Doors: Campaign for Freedom	<i>RESOURCES</i>
Community capacity	<i>WHAT IS THE COMMUNITY?</i>
Community living	<i>WHAT IS THE COMMUNITY?; <u>ALL</u> PEOPLE CAN BE SUPPORTED IN THE COMMUNITY; QUALITY OF LIFE OUTCOMES IN THE COMMUNITY</i>
<i>Community Imperative, The</i>	<i>POSITION STATEMENTS</i>
Cost comparisons	<i>COST/ECONOMIC ISSUES</i>
Criminal justice system, people involved with.....	<i><u>ALL</u> PEOPLE CAN BE SUPPORTED IN THE COMMUNITY</i>
Cross Disability Rights Coalition (CDRC)	<i>POSITION STATEMENTS</i>
Dehumanization.....	<i>WHAT'S WRONG WITH INSTITUTIONS?</i>
Disability issues and the media.....	<i>WORKING WITH THE MEDIA</i>
Dually diagnosed individuals	<i><u>ALL</u> PEOPLE CAN BE SUPPORTED IN THE COMMUNITY</i>
Education, lack of access to.....	<i>WHAT'S WRONG WITH INSTITUTIONS?</i>
Governor and Executive Branch, work with to close institutions	<i>STRATEGIES FOR ADVOCATES</i>
Human rights.....	<i>WHAT'S WRONG WITH INSTITUTIONS?</i>
Individualization in services, lack of.....	<i>WHAT'S WRONG WITH INSTITUTIONS?</i>
Institutional facility use conversion	<i>STATE STRATEGIES</i>
Legislature, work with to close institutions	<i>STRATEGIES FOR ADVOCATES</i>
Letters to the Editor & Op-Ed pieces	<i>STRATEGIES FOR ADVOCATES</i>
Maryland Developmental Disabilities Coalition	<i>RESOURCES</i>
Maryland Developmental Disabilities Council	<i>POSITION STATEMENTS</i>
Medical needs, complex	<i><u>ALL</u> PEOPLE CAN BE SUPPORTED</i>

	<i>IN THE COMMUNITY</i>
Mid-Atlantic Chapter of TASH.....	<i>POSITION STATEMENTS</i>
Mortality studies.....	<i>SAFEGUARDS</i>
Older people with developmental disabilities.....	<i>ALL PEOPLE CAN BE SUPPORTED</i>
	<i>IN THE COMMUNITY</i>
People First Wisconsin.....	<i>RESOURCES</i>
Parents.....	<i>FAMILY ISSUES</i>
People On the Go of Maryland.....	<i>POSITION STATEMENTS</i>
Person-centered planning.....	<i>PLANNING FOR QUALITY COMMUNITY SUPPORTS</i>
	<i>FOR MOVING INTO THE COMMUNITY</i>
Psychiatric and developmental disabilities.....	<i>ALL PEOPLE CAN BE SUPPORTED</i>
	<i>IN THE COMMUNITY</i>
Public forum, on institutional closure or other issues.....	<i>STRATEGIES FOR ADVOCATES</i>
Regulations, the limitations of.....	<i>SAFEGUARDS</i>
Newspaper reporters and editorial boards, work with.....	<i>WORKING WITH THE MEDIA</i>
Segregation and isolation from the community.....	<i>WHAT'S WRONG WITH INSTITUTIONS?</i>
Self-Advocates Becoming Empowered.....	<i>POSITION STATEMENTS, RESOURCES</i>
State government, work with, to close institutions.....	<i>STRATEGIES FOR ADVOCATES</i>
Social Security Act Section 1905(d).....	<i>WHAT IS AN INSTITUTION?</i>
Web-based advocacy materials.....	<i>STRATEGIES FOR ADVOCATES</i>
Workforce issues.....	<i>STATE STRATEGIES</i>