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ABSTRACT

This document is the participant's manual for a 3-day training conference for professionals involved in transition and the independent living movement for individuals with disabilities. Preliminary information includes the conference agenda, background information on the trainers and the sponsoring organizations, and the learning objectives of the conference. The first section examines in some detail the decision in Olmstead v. United States in which the court ruled that unjustified isolation of people with disabilities is properly regarded as discrimination based on disability and requires states to provide community based services. The following sections address: (1) constitutional rights of people with disabilities; (2) outreach and identification strategies; (3) exploring the limits of community living (personal stories); (4) first meeting and initial planning; (5) identification of barriers and advocacy strategies; (6) housing; (7) states' use of home health, the Personal Care Services benefit, and waivers; (8) general guidelines for nursing facility transition; (9) a timeline for activities for transition; (10) developing a safety plan; and (11) cognitive impairment, guardianship, durable power of attorney, and Adult Protective Services. Eleven appendices include a glossary, checklists and forms, planning worksheets; a nursing home transition needs survey, and the texts of four presentations. (DB)

IL NET Presents...

How to Free Our People: Real Life Solutions

May 21-23, 2003
Kansas City, MO

ilnet

Expanding the Power of the Independent Living Movement

IL NET

an ILRU/NCIL National Training and Technical Assistance Project

Expanding the Power of the Independent Living Movement

HOW TO FREE OUR PEOPLE: REAL LIFE SOLUTIONS

A National Conference

Participant's Manual

May 21-23, 2003

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Table of Contents

Appendices:

How to Free Our People: Real Life Solutions

Agenda

Wednesday, May 21

8:30	**Continental Breakfast**
9:00 – 9:30	Welcome, Introduction, and Review of Agenda
9:30 – 10:30	Overview of the Law: Olmstead
10:15 – 10:45	Real Life Stories: Turning the Law into Action
10:45 – 11:00	**Break**
11:00 – 12:00	What prevents CILS from trying and performing nursing home removal and why they should be doing it
12:00 – 1:30	**Lunch on your own**
1:30 – 2:30	Identification and Outreach
2:30 – 3:30	The Limits of Community Living
3:30 – 3:45	**Break**
3:45 –4:30	Initial Meeting with Institutionalized Consumer
4:30 – 5:00	Overview and Introduction to Community Based Services

Thursday, May 22

8:30	**Continental Breakfast**
9:00 – 10:30	Developing a Community Support Plan ▪ Personal assistance services ▪ Waiver services ▪ Medical services ▪ Legal issues
10:30 – 10:45	**Break**
10:45 – 12:00	How to get Housing
12:00 – 1:30	**Lunch on your own**
1:30 – 2:45	Financial Benefits and Other Quality of Life Supports
2:45 – 3:00	**Break**
3:00 – 5:00	Addressing Bureaucratic Barriers and Potential Roadblocks

Friday, May 23

8:30	**Continental Breakfast**
9:00 – 10:00	Day of the Move: Unexpected Pitfalls
10:00 – 10:30	Final Transition Tips and Questions
10:30 – 10:45	**Break**
10:45 – 12:00	Developing an Action Plan for Your Center
12:00 – 1:30	**Lunch on your own**
1:30 – 3:00	Developing an Action Plan for Your Center
3:00 – 3:15	Closing and Evaluations

About the Trainers

Bruce Darling is co-founder and Executive Director of the Center for Disability Rights (CDR), a Rochester-based disability rights organization and Independent Living Center. During his 17-year career he has advocated on a variety of disability issues: fighting for access to public transportation, promoting accessible housing, opposing physician-assisted suicide, and creating community-based alternatives to institutionalization.

During the summer of 2000, without any new funding but a great deal of conviction, CDR began a project to transition people out of nursing homes and back into the community. Since that time, the project has helped over thirty-five people return to community living, and CDR has hired staff dedicated to this transition work. Bruce and the project staff have worked with many other community groups and Independent Living Centers to teach them about the *Olmstead* decision and begin nursing facility transition projects of their own.

Bruce is very proud of his work as a community organizer with ADAPT in New York State. As part of ADAPT, Bruce has met with state and federal officials, led efforts to file complaints with the Health and Human Services Office of Civil Rights, participated in direct action, and been arrested for civil disobedience as part of his efforts to make the *Olmstead* decision a practical reality in New York State.

Kirk W. Lowry is currently employed as General Counsel at the Topeka Independent Living Resource Center, Inc. His duties include lobbying, litigation and general work for the not-for-profit organization. Areas of litigation include ADA, IDEA, Rehabilitation Act, and the Fair Housing Act.

Prior to his current employment, Kirk was partner with Palmer, Lowry, Leatherman & White, LLP for thirteen years. His practice focused on Americans with Disabilities Act litigation, employment law, medical malpractice, product liability, and workers compensation. He has also drafted legislation and testified before the House and Senate Judiciary Committees, House Commerce and Insurance Committee, and House State and Federal Affairs Committee.

Kirk has been an Adjunct Professor at the Washburn School of Law in Topeka, and has produced several publications and presentations related to State, District, Circuit, and Supreme Court proceedings in which he played a central role.

Kirk received his Jurist Doctorate in 1987 from the Washburn School of Law and Bachelor of Arts from the University of Kansas.

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ABOUT ILRU

The Independent Living Research Utilization (ILRU) Program was established in 1977 to serve as a national center for information, training, research, and technical assistance for independent living. In the mid-1980's, it began conducting management training programs for executive directors and middle managers of independent living centers in the U.S.

ILRU has developed an extensive set of resource materials on various aspects of independent living, including a comprehensive directory of programs providing independent living services in the U.S. and Canada.

ILRU is a program of TIRR, a nationally recognized, free-standing rehabilitation facility for persons with physical disabilities. TIRR is part of TIRR Systems, a not-for-profit corporation dedicated to providing a continuum of services to individuals with disabilities. Since 1959, TIRR has provided patient care, education, and research to promote the integration of people with physical and cognitive disabilities into all aspects of community living.

ABOUT NCIL

Founded in 1982, the National Council on Independent Living is a membership organization representing independent living centers and individuals with disabilities. NCIL has been instrumental in efforts to standardize requirements for consumer control in management and delivery of services provided through federally-funded independent living centers.

Until 1992, NCIL's efforts to foster consumer control and direction in independent living services through changes in federal legislation and regulations were coordinated through an extensive network and involvement of volunteers from independent living centers and other organizations around the country. Since 1992, NCIL has had a national office in Arlington, Virginia, just minutes by subway or car from the major centers of government in Washington, D.C. While NCIL continues to rely on the commitment and dedication of volunteers from around the country, the establishment of a national office with staff and other resources has strengthened its capacity to serve as the voice for independent living in matters of critical importance in eliminating discrimination and unequal treatment based on disability.

Today, NCIL is a strong voice for independent living in our nation's capital. With your participation, NCIL can deliver the message of independent living to even more people who are charged with the important responsibility of making laws and creating programs designed to assure equal rights for all.

ABOUT THE IL NET

This training program is sponsored by the IL NET, a collaborative project of the Independent Living Research Utilization (ILRU) of Houston and the National Council on Independent Living (NCIL).

The IL NET is a national training and technical assistance project working to strengthen the independent living movement by supporting Centers for Independent Living (CILs) and Statewide Independent Living Councils (SILCs).

IL NET activities include workshops, national teleconferences, technical assistance, on-line information, training materials, fact sheets, and other resource materials on operating, managing, and evaluating centers and SILCs.

The mission of the IL NET is to assist in building strong and effective CILs and SILCs which are led and staffed by people who practice the independent living philosophy.

The IL NET operates with these objectives:

- Assist CILs and SILCs in managing effective organizations by providing a continuum of information, training, and technical assistance.
- Assist CILs and SILCs to become strong community advocates/change agents by providing a continuum of information, training, and technical assistance.
- Assist CILs and SILCs to develop strong, consumer-responsive services by providing a continuum of information, training, and technical assistance.

How To Free Our People Real Life Solutions

Learning Objectives

Participants will learn:

- To demonstrate an understanding of the laws and regulations that support transition.
- To identify methods used to recognize consumers for transition.
- To identify supports needed for successful transition.
- To identify methods for overcoming barriers to transition.
- To develop a plan of action for use in the center or community.

I. THE OLMSTEAD DECISION

History and Overview

The Olmstead case was brought by two Georgia women whose disabilities included mental retardation and mental illness. At the time the suit was filed, both plaintiffs lived in state-run institutions, despite the fact their treatment professionals had determined that they could be appropriately served in a community setting. The plaintiffs asserted that continued institutionalization was a violation of their right under the ADA to live in the most integrated setting appropriate.

The Supreme Court ruled that "Unjustified isolation...is properly regarded as discrimination based on disability". It observed that (a) "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life," and (b) "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.

Under the Court's decision, States are required to provide community based services for persons with disabilities who would otherwise be entitled to institutional services when: (a) the State's treatment professionals reasonably determine that such placement is appropriate; (b) the affected persons do not oppose such treatment; and (c) the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others who are receiving State-supported disability services. The Court cautioned however, that nothing in the ADA condones termination of institutional settings for the persons unable to handle or benefit from community settings. Moreover, the States responsibility, once it provides community-based treatment to qualified persons with disabilities, is not unlimited.

Under the ADA, States are obliged to "make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature if the service, program or activity." The Supreme Court indicated that the test as to whether a modification entails "fundamental alteration" of a program takes into account three factors: the cost of providing services to the individual in the most integrated setting appropriate; the resources available to the State; and how the provision of services affects the ability of the State to meet the needs of others with disabilities.

Source: Understanding Medicaid Home and Community Services: A Primer, Introduction, U.S. Department of Health and Human Services, October 2000

A. Implementing Olmstead

Olmstead v. LC

- 527 U.S. 581, 119 S. Ct. 2176, 144 L. Ed. 2d 540 (1999).

Title II of the ADA

- ". . .No qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."
- 42 U.S.C. § 12132.

Integration Regulation

- "A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."
- 28 C.F.R. § 35.130(d).

History of Integration Mandate

- The Rehabilitation Act of 1973, 29 U.S.C. § 794, was not consistently construed to contain an integration mandate. The cases were mixed at best.
- § 504's language is very close to Title II of ADA
- *Traynor v. Turnage*, 485 U.S. 535 (1985)
- Upheld VA regulation excluding "primary alcoholics" from a benefit that extended to persons disabled by alcoholism related to mental disability.

Southeastern Community College v. Davis, 442 U.S. 397 (1979)

- Rehab Act does not impose affirmative action requirements on recipients of federal funds.

Alexander v. Choate, 469 U.S. 287 (1985)

- Rehab Act does not encroach upon the State's decisions about the types of disability services they provide under the Medicaid Act.

Helen L. v. DiDario, 46 F.3d 325 (3rd Cir. 1995)

- First case to find that the ADA requires a public entity to provide programs, services, and activities in the most integrated setting appropriate to the needs of the individual with a disability.
- ADA Title II case.
- Discrimination to require person to receive services in a nursing home instead of attendant care program

B. Olmstead Holdings

- Unjustified isolation is discrimination under the ADA.
- Undue institutionalization is discrimination under the ADA.

Institutionalization is Discrimination: Why?

- It perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.
- It severely diminishes the everyday life of individuals; family relations, social contacts, work options, economic independence, educational advancement, culture.

Discrimination under the ADA

- Georgia argued that LC and EW were not discriminated against 'by reason of their disabilities.'
- Georgia said discrimination necessarily requires uneven treatment of similarly situated individuals
- Three Justices, Rehnquist, Scalia and Thomas agreed.
- Supreme Court said 'Congress had a more comprehensive view of the concept of discrimination advanced in the ADA.'
- "Congress explicitly identified unjustified segregation of persons with disabilities as a form of discrimination."
- In the ADA, Congress for the first time referred expressly to 'segregation' of persons with disabilities as a 'form of discrimination,' and to discrimination that persists in the area of 'institutionalization.'

C. Limits of Olmstead

- Only "qualified individuals" are protected.
- Must meet the essential eligibility requirements for receipt of services or the participation in programs or activities provided by a public entity.
- States may rely on the reasonable assessments of its own professionals in determining whether an individual meets the essential eligibility requirements.
- Community based services cannot be imposed on people who do not want them.
- The ADA does not require States to phase out institutions.
- ADA does not allow bumping of people higher up on the waiting list by people lower down who commenced civil actions.

Fundamental Alteration Defense, Factors:

- Cost of providing community services to individuals

- Resources available to the state
- State's need to maintain a range of facilities
- State's need to distribute limited resources in an evenhanded way

Counter to Fundamental Alteration Defense

- The best defense is that the person in the institution should be able to take their Medicaid long-term care funding with them out of the institution into the community. Texas has done this with their Rider 37, a budget proviso. Kansas has done this by verbal agreement at this point. State budget officers and Departments of Public Welfare have agreed this is feasible and at least budget neutral. It would not be a fundamental alteration. Advocates should request a reasonable accommodation that their Medicaid long-term care money should follow them into the community in writing. This is a demand that the "Money should follow the person." We should be funding people, not institutions, nursing home, or any other providers.
- If your state has closed institutions, go back and calculate how much the institutions cost to run when open and how much they have saved by closing them.
- Money should be going to HCBS, not highways, tax cuts, or Governor's Mansion renovations.
- Compare the funding for the institutional alternative. Don't let government officials go unchallenged when they compare the cost of all community based programs against all of their fixed institutional costs. The only relevant inquiry is the systemic institutional costs for a single population against the costs for HCBS for that same population in the community. In the physical disability context, the relevant inquiry is into the nursing facility systemic costs versus the physical disability waiver. There are very few state run nursing homes. Most of them are private. Therefore there are no fixed overhead costs like there are for state hospitals for the MI and MR populations. The comparison should be direct.

D. State Olmstead Plan

- Defense to Olmstead suit.
- A comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated.

At Risk of Institutionalization

- The right to live in the community and not be segregated includes those who are at risk of going in to an institution. If a qualified individual with a disability is living in their own home, qualify for HCBS, are on the waiting list, and are at imminent risk of entering an institution, they have a civil right to the most integrated setting.
- *Makin v. Hawaii*, 114 F. Supp. 2d 1017 (D. Hawaii 1999)

State's Obligation

- Not cost-neutral
- Olmstead requires states to find the money.
- Institutionalization is discrimination, therefore the state must reallocate resources to fund community placements.

Limits to States' Obligation

- "The State's responsibility, once it provides community-based treatment to qualified persons with disabilities, is not boundless."
- *Olmstead v. L.C.*, 527 U.S. 581, 603 (1999).
- "Sensibly construed, the fundamental-alteration [defense] would 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 disabilities
- *Olmstead*, 527 U.S. at 604.
- The fundamental alteration defense requires court to examine the resources available to the states, including not only the cost of providing HCBS to litigants, but also the range of services the State provides others with disabilities, and the State's obligation to mete out those services equitably.

Olmstead and Budgets

- How much has the state saved on closed institutions? In Olmstead it was zero.
- Go back to 1990. Has the state cut taxes when it knew or should have known it had a legal obligation to provide HCBS?

- Look at the consensus caseloads (Mandatory Medicaid Caseloads). Are non-mandatory services included and funded at the expense of HCBS? Is the State funding non-mandatory state funded only programs?
- Does the state have an Olmstead Plan?

Populations Affected

- Nursing home residents
- Long-stay patients in state hospitals
- Individuals who cycle in and out of hospitals due to lack of community services
- People in jail because of a lack of services
- People in the most integrated setting who are at risk of going back in.

Creating the Plan

- Planning process should move quickly.
- Planning process should involve advocates and consumers.
- Plan should expand HCBS
- Plan must be comprehensive
- Plan must be funded
- Plan must identify individuals who are needlessly institutionalized
- Plan's effectiveness must be monitored.
- The plan must ensure quality care in the community.
- HCBS placements must move at a reasonable pace.
- 90 day waiting lists.

E. Olmstead Cases

Cramer v. Chiles, 33 F. Supp. 2d 1342 (S.D. Fla. 1999)

- Beneficiaries have a private right of action to enforce Medicaid provisions requiring procedural due process
- State plan violated statutory freedom of choice requirement.
- Institutionalization of individuals with developmental disabilities, against their will, where less confining programs will satisfy their needs, violates the ADA's integration mandate
- Underfunding HCBS waiver programs compels institutionalization, thus negating meaningful choice.

Makin v. Hawaii, 114 F. Supp. 2d 1017 (D. Hawaii 1999).

- Court denied summary judgment to Hawaii because trial needed to determine if state's administration of HCBS services violated ADA's integration mandate.
- The court held that the ADA's Title II integration requirement covers people who are at risk of institutionalization but still living in the community, not just people who are currently in an institution.

Lewis v. New Mexico Dept. of Health, 94 F. Supp. 2d 1217 (D. N.M. 2000).

- Court denied New Mexico summary judgment because ADA and Section 1983 allowed suits against state on claims of disability discrimination and integration mandate.

***Rodriguez v. City of New York,* 197 F.3d 611 (2d Cir. 1999).**

- Plaintiffs requested a new service, safety monitoring, be provided as part of the community based plan. The court held that the City was not required to provide a new service. New services are not required by Medicaid or the ADA.

F. People with Olmstead Rights

- Consumer is clearly qualified individual with a disability.
- Clear, substantial disability.
- Clearly qualified for HCBS.
- State assessment shows consumer is qualified for HCBS.
- Consumer wants HCBS.
- Placement can be reasonably accommodated taking into account the resources available to the state and the needs of others with disabilities.

G. Olmstead Resources

- Under Court Order, www.bazelon.org/lcruling.html
- Template of Key Elements, www.protectionandadvocacy.com/temploct12.htm
- The Americans with Disabilities Act and Community Integration: Understanding the Concept of "Fundamental Alteration," Sara Rosenbaum et al, Center for Health Care Strategies, Inc., May 2002.
- Defining "Reasonable Pace" in the Post-Olmstead Environment, Sara Rosenbaum et al., Center for Health Care Strategies, April 2002.
- Community Integration of Individuals with Disabilities: An Update on Olmstead Implementation, Jennifer Mathis, Journal of Poverty Law and Policy, Nov-Dec 2001.
- Olmstead and Supportive Housing: A Vision for the Future, Ann O'Hara and Stephen Day, CHCS, Dec. 2001.
- Forward to Fundamental Alteration, Jeff Smith, 24 Harvard Journal of Law and Public Policy 695, Summer 2001.
- A Right to Personal Assistance Services: Most Integrated Setting Appropriate Requirements and the Independent Living Model of Long Term Care, Andrew Batavia, 27 Am. J. L. & Med 17, 2001.
- Addressing Long Waits for HCBS Through Medicaid and the ADA, Jane Perkins, 45 St. Louis L.J. 117, Winter 2001.
- Implementing Olmstead: Defining "Effectively Working" Plans for "Reasonably Paced" Wait Lists for Medicaid HCBS, Melody Kubo, 23 Hawaii L. Rev. 731, Summer 2001.
- The States' Response to the Olmstead Decision: A Work in Progress, Wendy Fox-Grange, NCSL, 2002.
- Dear Medicaid Director Letters, CMS.

II. CONSTITUTIONAL AND CIVIL RIGHTS OF PEOPLE WITH DISABILITIES

Constitutional Rights

Constitutional Rights apply to "State Action" including state laws. As advocates we must be aware of the constitutional rights of people with disabilities. We must use these powerful constitutional rights and assert them. We must help people with disabilities learn their constitutional rights, peer counsel them on assertion strategies, and put those in to practice. For example, the *Cruzan* case stands for the proposition that people have a right to die. But the positive aspect of Cruzan is that it is based on the fundamental common law right of informed consent. The court said, "no right is held more sacred, or is more carefully guarded, by the common law, that the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law." *Cruzan*, 497 U.S. 261 at 269. This principal invokes its corollary, that the doctrine of informed consent must include the right not to consent, including the right to refuse medical treatment. In Cruzan, the Supreme Court found a substantive constitutional right to refuse medical treatment. "The Fourteenth Amendment provides that no State shall deprive any person of life, liberty, or property, without due process of law. The principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions." *Cruzan*, 497 U.S. at 278.

People with disabilities can use these constitutional rights and apply them to their own lives in nursing facilities or other institutions. People with disabilities do not leave their constitutional rights at the nursing facility door. They carry them with them like a sword and shield. Most people who enter a nursing facility become angry and frustrated at the lack of freedom, respect, and dignity. When we assert our rights we are labeled "depressed," "adjustment disordered," or "some bullshit, not otherwise specified." As advocates we can peer counsel consumers in NFs that they have a constitutional right to refuse consent to anything. They may also assert their constitutional and statutory right to refuse psychotropic drugs. At the same time, we should include in our counseling that an NF may then refer us to Adult Protective Services or for a guardianship. These rights include the right to choose one's physician, nurse, or other health care practitioner, where to receive medical treatment, and what kind or amount of treatment or services to receive.

An important aspect of advocacy for constitutional and statutory rights is to counsel the person with a disability to document everything. At least a person should keep a diary. At best, letters to the administrator, documenting significant events, conversations, and violations of constitutional and statutory rights should be written. Repeated violations should be referred to legal counsel for follow up.

Federal Bill of Rights

1st Amendment: Free speech, freedom of religion, right to peaceably assemble, right to petition government.

4th Amendment: right to be secure in person, house, papers, and effects against unreasonable search and seizure.

5th Amendment: right not to self-incriminate oneself and federal due process.

7th Amendment: right to a jury trial.

8th Amendment: right against cruel and unusual punishment.

14th Amendment: due process and equal protection from state action. Liberty.

15th & 19th Amendment: right to vote.

State Constitutional Rights

Advocates should be familiar with their state constitution. Many state constitutions start with a bill of rights. Often, these state rights are broader than the federal constitutional rights. Each state supreme court has the power to interpret their own state's bill of rights as expansively or narrowly as it deems legal and proper.

Constitutional Rights - Case Law

14th Amendment: People who are involuntarily institutionalized have a liberty interest in reasonably safe conditions of confinement, freedom from unreasonable bodily restraints, and such minimally adequate training as reasonably might be required by these interests.
Youngberg v. Romeo, 457 U.S. 307 (1982).

14th Amendment: involuntarily civilly committed person with a disability has a liberty interest to live in their own home and not be confined in an institution if they are not dangerous and can safely live in their own home.
Mere public intolerance or animosity cannot constitutionally justify deprivation of a person's physical liberty.
O'Connor v. Donaldson, 422 U.S. 563 (1975)

14th Amendment: Right to Marry
Loving v. Virginia, 388 U.S. 1 (1967)
Zablocki v. Redhail, 434 U.S. 374 (1978)

14th Amendment fundamental right to marriage and procreation.
Skinner v. Oklahoma, 316 U.S. 535 (1942)
Loving v. Virginia, 388 U.S. 1 (1967)

14th and 9th Amendment right to Privacy and to control of one's body. A woman has a fundamental constitutional right to choose not to bear children, to implement that choice by us of contraceptive devices or medication, and, subject to reasonable restrictions, to terminate a pregnancy.
Griswold v. Connecticut, 381 U.S. 479 (1965)
Roe v. Wade, 410 U.S. 113 (1973)

14th Amendment liberty interest includes the right of a competent person to refuse unwanted medical treatment.
Cruzan v. Missouri, 497 U.S. 261 (1990).

14th Amendment right to due process, notice, and a fair hearing.
Goldberg v. Kelly, 397 U.S. 254 (1970).
Parham v. J.R., 442 U.S. 584 (1979).
Blum v. Yaretsky, 457 U.S. 991 (1982).

The Right to Travel
A state statute imposing a durational residence requirement on a person before they were eligible to receive TANF violated the constitutional right to travel. The right to travel and be treated equally in the new state is a privilege and immunity of both a state citizen and a United States Citizen protected by the privileges and immunities clause of the Fourteenth Amendment. The right to travel has three components: 1) the right to enter and leave a state; 2) the right to be treated as a welcome visitor; and 3) the right to be treated equally as other citizens of the state. The right is so important that it is assertable against private interference as well as governmental action. *Saenz v. Roe*, 526 U.S. 489 (1999).

Right of Family Association
People have a fundamental constitutional right to a family association. This constitutional right includes the right to make decisions as to care, custody, and control of their children. *Prince v. Massachusetts*, 321 U.S. 158 (1944); *Troxel v. Granville*, 530 U.S. 57 (2000); and Brokaw v. Mercer County, 235 F3d 1000 (7th Cir. 2000) (The Due Process Clause includes a substantive component that provides heightened protection against government interference with certain fundamental rights and liberty interests. These decisions recognize that the right of a man and woman to marry, and to bear and raise their children is the most fundamental of all rights—the foundation of not just this country, but of all civilization.)

Right to access to courts *Bounds v. Smith*, 430 U.S. 817 (1977)

Right to protest
There is a basic constitutional right embedded in the First and Fourteenth Amendments to freedom of speech and assembly, and freedom to petition the government for a redress of grievances. The Supreme Court has repeatedly stated that these rights are not confined to verbal expression. They embrace appropriate types of action which certainly include the right in a peaceable and orderly manner to protest by silent and reproachful presence, in a place where the protestant has every right to be, the unconstitutional segregation of public facilities.
Brown v. Louisiana, 383 U.S. 131, 141, 142 (1966) (Lunch counter sit-in case.)

Right to Vote
Harper v. Virginia State Board of Elections, 383 U.S. 663 (1966) (invalidating a state's poll tax); Katzenback v. Morgan, 384 U.S. 641 (1966) (invalidating a state's literacy test); and *Baker v. Carr*, 369 U.S. 186 (1962) (One person, one vote).

The Constitutional liberty interest includes the right to be free in the enjoyment of all of one's faculties; to be free to use them in all lawful ways; to live and work where one will; to earn any livelihood or avocation.
Allgeyer v. Louisiana, 165 U.S. 589 (1897).
Grosjean v. Am. Press, 297 U.S. 233 (1936)
Conservatorship of Mildred G, 707 P.2d 760 (1985).

Liberty means more than freedom from servitude, and the constitutional guarantee is an assurance that the citizen shall be protected in the right to use his or her powers of mind and body in any lawful calling.
Smith v. Texas, 233 U.S. 630, 636 (1914).

Liberty is not confined to mere freedom from bodily restraint. Liberty under law extends to the full range of conduct which the individual is free to pursue, and it cannot be restricted except for a proper governmental objective.
Bolling v. Sharpe, 347 U.S. 497, 499-500, (1954).

Every citizen has an interest in and the right to freedom of travel, association, and speech; in essence, an interest in and right to all the incidents of freedom "implicit in the concept of ordered liberty."
Palko v. Connecticut, 302 U.S. 319, 325 (1937).

A state law that made the "status" of narcotic addiction a criminal offense violated the 8th Amendment's prohibition against cruel and unusual punishment.
Robinson v. California, 370 U.S. 660 (1962).

An individual has a liberty interest in avoiding the unwanted administration of antipsychotic drugs under the Due Process Clause of the Fourteenth Amendment.
Washington v. Harper, 494 U.S. 210, 221-22 (1990)
Jurasek v. Utah State Hospital, 158 F.3d 506, 510 (10th Cir. 1998).

Person who is subject to involuntary civil commitment has a constitutional right to: Notice, due process, fair hearing, presumption of competency, burden of proof on state, right to counsel, right not to self-incriminate self, access to reports, witnesses, and doctors, and the right to preliminary hearing before being detained more than 48 hours. *Lessard v. Schmidt*, 349 F. Supp. 1078 E.D. Wis. 1972)

People involuntarily committed through non-criminal procedures to institutions for the mentally retarded have a constitutional right to receive such individual habilitation as will give each of them a realistic opportunity to lead a more useful and meaningful life and return to society.
Wyatt v. Stickney, 344 F. Supp. 387, 390 (M.D. Ala. 1972)

Adequate and effective treatment is constitutionally required because, absent treatment, the hospital is transformed into a penitentiary where one could be held indefinitely for no convicted offense.
Wyatt v. Stickney, 344 F. Supp. at 390.

The purpose of involuntary hospitalization for treatment purposes is treatment and not mere custodial care or punishment.
Wyatt v. Stickney, 344 F. Supp. at 390.
Affirmed by *Wyatt v. Aderholt*, 503 F.2d 1305 (5th Cir. 1974).

A guardianship proceeding to determine competency should invoke the full panoply of procedural due process rights comparable to those present in involuntary civil commitment because no less loss of liberty and freedom is at stake.
Guardianship of Hedin v. Gonzales, 528 N.W. 2d 567, 574 (IA 1995)

4th Amendment right to protection from unreasonable searches and seizures. A state caseworkers home visit on an AFDC recipient was not unreasonable because it was made pursuant to state law, was not permitted outside working hours, and forcible entry and snooping were prohibited. *Wyman v. James*, 400 U.S. 309 (1971). A person has a 4th Amendment right not to be seized from his or her house by police and placed in protective custody or have one's children placed in protective custody without due process of law and upon probable cause that life or limb is in immediate jeopardy. *Brokaw v. Mercer County*, 235 F.3d 1000 (7th Cir. 2000); but see *Pino v. Higgs*, 75 F.3d 1461 (10th Cir. 1996) (No 4th Amendment violation where seizure was reasonable and based on probable cause.)

Right to Live in The Community
Unnecessary institutionalization is discrimination. A person who lives in an NF, who is qualified for HCBS, has a civil right to live in the most integrated setting appropriate to their needs, usually their own home.
Olmstead v. L.C., 527 U.S. 581, 587, 607 (1999).

Rights of Persons in a Nursing Facility:

A resident has a right to a dignified existence, self-determination, and communication with and access to persons and services inside and outside the facility. A facility must protect and promote the rights of each resident, including each of the following rights: 42 C.F.R. § 483.10

The resident has the right to exercise his or her rights as a resident of the facility and as a citizen or resident of the United States.

The resident has the right to be free of interference, coercion, discrimination, and reprisal from the facility for exercising his or her rights.
42 C.F.R. § 483.10(a)(1),(2).

In the case of a resident adjudged incompetent under the laws of a State by a court of competent jurisdiction, the rights of the resident are exercised by the person appointed under State law to act on the resident's behalf.
42 C.F.R. § 483.10(a)(3).

In the case of a resident who has not been adjudged incompetent by the State court, any legal-surrogate designated in accordance with State law may exercise the resident's rights to the extent provided by State law. (Durable Power of Attorney)
42 C.F.R. § 483.10(a)(4).

Notice of Rights:

The facility must inform the resident both orally and in writing in a language that the resident understands of his or her rights and all rules and regulations governing resident conduct and responsibilities during the stay in the facility.
42 C.F.R. § 483.10(b)(1).

The resident has a right upon an oral or written request, to access all records pertaining to himself or herself including current clinical records within 24 hours (excluding holidays and weekends); and copies at community standard cost within 2 days.
42 C.F.R. § 483.10(b)(2).

The resident has the right to be fully informed in language that he or she can understand of his or her total health status, including but not limited to, his or her medical condition.
42 C.F.R. § 483.10(b)(3).

The resident has the right to refuse treatment, to refuse to participate in experimental research, and to formulate an advance directive as specified in paragraph (8) of this section;
42 C.F.R. § 483.10(b)(4).

The facility must inform each resident who is entitled to Medicaid benefits, in writing, at the time of admission to the nursing facility or when the resident becomes eligible for Medicaid of what Medicaid covers and what the NF may charge the resident for in excess of Medicaid.
42 C.F.R. § 483.10(b)(5).

The facility must furnish a written description of legal rights which includes:
A description of the manner of protecting personal funds;
A description of the requirements and procedures for establishing eligibility for Medicaid;
A posting of names, addresses, and telephone numbers of all pertinent state client advocacy groups.

42 C.F.R. § 483.10(b)(7).The facility must inform the resident in writing that they have a right to file a complaint with the appropriate state agency concerning resident abuse, neglect, misappropriation of resident property in the facility, and non-compliance with advance directives.
42 C.F.R. § 483.10(b)(7).

The facility must inform each resident of the name, specialty, and way of contacting the physician responsible for his or her care.
42 C.F.R. § 483.10(b)(9).

Notification of changes:
The NF must inform the resident of its decision to transfer or discharge the resident from the facility; a change in the room or roommate assignment; or a change in resident rights.
42 C.F.R. § 483.10(b)(11).

Protection of Resident Funds:

The resident has the right to manage his or her financial affairs, and the facility may not require residents to deposit their personal funds with the facility.
42 C.F.R. § 483.10(c)(1).

The facility must deposit any residents' personal funds in excess of $50 in an interest bearing account (or accounts) that is separate from any of the facility's operating accounts, and that credits all interest earned on resident's funds to that account.
42 C.F.R. § 483(c)(3)(i).

The facility must establish and maintain a system that assures a full and complete and separate accounting, according to generally accepted accounting principles, of each resident's personal funds entrusted to the facility on the resident's behalf.
The system must preclude any commingling of resident funds with facility funds or with the funds of any person other than another resident.
42 C.F.R. § 483.10(c)(4)(i-ii).

Notice of Certain Balances:
1. $200 less than the SSI resource limit for one person. ($2000)
2. That the resident may lose SSI and Medicaid eligibility if resources are above $2000.

The resident has the right to:
1. Choose a personal attending physician;
2. Be fully informed in advance about care and treatment and of any changes in care;
3. Participate in planning care and treatment or changes (Unless there is a court order of guardianship.)

42 C.F.R. § 483.10(d).

The resident has the right to personal privacy and confidentiality of his or her personal and clinical records. Personal privacy includes accommodations, medical treatment, written and telephone communications, personal care, visits, and meetings of family and resident groups, but this does not require the facility to provide a private room for each resident.
42 C.F.R. § 483.10(e)(1).

A resident has the right to voice grievance without discrimination or reprisal.
42 C.F.R. § 483.10(f).

The resident has the right to examine the results of the latest survey by the state agency responsible for surveys. The NF must place the survey results in a place that is readily accessible.

****The resident has the right to receive information from agencies acting as client advocates, and be afforded the opportunity to contact these agencies.
42 C.F.R. § 483.10(g).****

The resident has the right to work or not work.

The resident has the right to privacy in written communications, to send and receive mail unopened, and access to the means to create correspondence.
42 C.F.R. § 483.10 (h) and (i).

****A nursing facility must provide reasonable access <u>to any resident by any entity or individual</u> that provides health, social, legal, or other services to the resident, subject to the resident's right to deny or withdraw consent at any time.
42 C.F.R. § 483.10(j)(2).****

The resident has the right to have reasonable access to the use of a telephone where calls can be made without being overheard.
42 C.F.R. § 483.10(k).

The resident has the right to retain and use personal possessions, including some furnishings, and appropriate clothing, as space permits, unless to do so would infringe upon the rights or health and safety of other residents.
42 C.F.R. § 483.10(l).

Married couples have the right to share a room if they both want to.
A resident may refuse a transfer to another room within the institution if the purpose of the transfer is to locate the resident of a SNF to a NF wing, or a NF wing to a SNF wing.
42 C.F.R. 483.10(m) and (o).

A resident has certain rights pertaining to admission, transfer, and discharge. The resident has a right to not be transferred or discharged unless the NF can show necessity and give proper notice. A NF cannot charge, solicit, accept, or receive anything in addition to Medicaid for a person eligible for Medicaid.
42 C.F.R. 483.12

A resident has the right to be free from any physical or chemical restraints imposed for purposes of discipline or convenience, and not required to treat the resident's medical symptoms. A resident has the right to be free from verbal, sexual, physical, and mental abuse, corporal punishment, and involuntary seclusion.
42 C.F.R. §483.13(a) and (b).

A nursing facility must promote care for residents in a manner and in an environment that maintains or enhances each resident's dignity and respect in full recognition of his or her individuality.
42 C.F.R. § 483.15(a).

The resident has the right to choose activities, schedules, and health care consistent with his or her interests, assessments, and plans of care; to interact with members of the community both inside and outside the facility; and to make choices about aspects of his or her life in the facility that are significant to her.
42 C.F.R. § 483.15(b).

A resident has the right to reside and receive services in the facility with reasonable accommodation of individual needs and preferences, except when the health and safety of the individual or other residents would be endangered; and
to receive notice before the resident's room or roommate is changed.
42 C.F.R. § 483.15(e).

The facility must provide activities, social services and a safe, clean, comfortable, and homelike environment.
42 C.F.R. 483.15(f), (g), and (h).

A nursing facility must conduct initially and periodically a comprehensive, accurate, standardized, reproducible assessment of each resident's functional capacity.

A nursing facility must develop a comprehensive care plan for each resident that includes measurable objectives and timetables to meet the resident's medical, nursing, and mental needs.
42 C.F.R. § 483.20(b) and (k).

Each resident must receive and the facility must provide the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care.
The resident's ability to perform ADLs must not diminish unless it is unavoidable.
42 C.F.R. § 483.25.

A resident who has difficulty adjusting to the nursing facility must receive appropriate treatment.

A resident who has not used antipsychotic drugs should not be given these drugs unless therapy is necessary to treat a specific condition as diagnosed and documented in the clinical record. Drugs should be reduced unless not possible.
42 C.F.R. § 483.25(f) and (k).

NF Services

Every facility must provide nursing services, dietary services, physician services, rehab services, dental services, pharmacy services, infection control, adequate facilities, and administrative services to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident.
42 C.F.R. 483.30-.75.

PASARR & CARE Assessments

The Dept. on Aging, through the AAAs, is responsible to perform PASARR evaluations of all persons who have mental illness or mental retardation.
If a person has mental illness or mental retardation the state must provide or arrange for the provision of specialized services for the person while they reside in the NF.
42 C.F.R. § 483.116(b)(2).
PASARR & CARE

In general, a nursing facility is not an appropriate placement for a person with mental illness or mental retardation.

Placement of a person with MI or MR in a NF is only appropriate when the individual needs NF level of care and their individual needs for specialized treatment can be met.
42 C.F.R. § 483.126

III. OUTREACH AND IDENTIFICATION STRATEGIES

Outreach and identification for this project can be intimidating. Here are some simple steps you can take to begin the process.

1. Review your consumer lists. See if there are any people who live in nursing homes. Visit them and ask them if they want to get out.
2. Ask your consumers. Tell them we are working on this project. They probably know people who want to get out. Identify some of "the difficult people." These are the most likely to have agencies who try to put them in an institution and the ones who will fight back. They have friends who lost the fight.
3. Ask around. Neighbors. Friends. Your church group. We know a lot of people. Ask about people who have recently been sent to the nursing home and didn't want to go because they didn't know they has a choice. One email to our staff generated four people who were family members of staff.
4. If you know people who got out themselves, ask them to help. They have friends who they left behind and probably want their friends to have freedom too.

Once you are more comfortable with transitioning people, you can intensify your outreach activities.

1. Contact the local nursing home ombudsman program. These people are already in the nursing homes and they know people who want to get out.
2. Many people who go into nursing homes thing they are only going in for rehabilitation, but never get out. Perhaps you can track them down by asking a friendly nurse or resident doctor who works at the local hospital or clinic.
3. See if people have any attendants who work in nursing homes. Ask your attendants. They often have worked in the nursing homes and know people. They can be an excellent referral source.
4. Write a letter to the editor or editorial. People who read it will call you. Trust us.
5. Go to a local support group for people who have Multiple Sclerosis or have had a stroke. Tell them about the project. They probably know someone from that group who went into a nursing home. They probably are talking about how they fear being "put away." While you are there tell them about the Olmstead Decision. They will thank you.
6. Once you get in the nursing home door, look people in the eye as you go to visit the person you are there to see. If someone catches your eye, ask if they want to get out to go home. People may not believe you at first, so don't rule people out if they seen distrustful. After all, they see no way out.
7. Don't underestimate the network in nursing homes. Once word gets out. People will call you! Outreach becomes as simple as answering your phone.

IV. EXPLORING THE LIMITS OF COMMUNITY LIVING

John is a 47-year old man who was born with Osteogenesis Imperfecta (Brittle bone disease). Because of this disability, John's bones break very easily and he has sustained over 168 fractures in his lifetime. John spent much of his formative years in a State Developmental Center, where he endured appalling conditions, including physical and sexual abuse. Ultimately he moved out of this institution and received vocational training to secure employment. John has been married for over 18 years to a woman who has cerebral palsy. Both John and his wife use power wheelchairs and have significant physical disabilities. They own their own accessible home.

When John was 45, he went to the hospital complaining of a severe headache, blurred vision, weakness in his arms, and dizziness. He was told to take Tylenol and sent home. Three days later, John returned to the hospital and was ultimately diagnosed as having a brain stem stroke. The hospital did not immediately treat John for his stroke, and the delay in treatment caused further damage. The stroke has caused left sided paralysis, affected his ability to speak and swallow, and affected his vision.

John was given a trach to help him breath and a PEG tube because he is at risk for aspiration. The trach was ultimately removed and John can now breath on his own. John still has a PEG tube, but can eat some things by mouth. John is still on aspiration precautions and his lungs must be monitored to ensure that he does not get aspiration pneumonia. During the next year, John had two additional strokes.

John is on a variety of medications and requires physical assistance with taking them either through his PEG tube or injection into his abdomen. Most importantly, John's blood pressure medication is dispensed based on his blood pressure reading. The medical professionals maintain that he must have his blood pressure checked 8 times within a 24 hour period and then be given the medication based on these readings.

In addition, despite knowing that his bones break very easily, the nurses and aides did not take any special precautions in transferring John. Because of this, John sustained two fractures to his left leg, a fracture to his right leg, and a fracture to his left arm. John now has heavy plastic braces on both legs and his left arm. The weight of these braces is able to break his bones if not properly supported. Ultimately, the staff had to receive specialized training from the Physical Therapy/Occupational Therapy Department on proper transferring techniques so that additional fractures could be avoided. It is now mandated that two people assist John with all transfers.

Finally, John and his wife have too much income to qualify for Medicaid and their insurance will not pay for long term community services. Given John's multiple physical disabilities, the requirement for close monitoring of his lungs and blood pressure, the requirement of a 2-person assist for transfers, his need for 24 hour home care services, and a lack of a long term payer source, what can be done to help John return to the community?

Mary V. is a 67-year old woman who has a visual impairment and renal failure, secondary to diabetes mellitus, a seizure disorder and mild to moderate mental retardation. Mary is insulin-dependent and requires regular blood glucose monitoring. She receives dialysis three days per week. Mary is also on a variety of prescribed medications. Due to diabetic neuropathy and spinal stenosis, Mary has had an increasing number of falls over time. Mary lives alone and has no immediate family that can assist her.

Last year, Mary fell again while attempting to get out of bed to use the bathroom. Mary used her PERS and was taken to a hospital where they did surgery to repair her broken hip. While in the hospital, her home care services were terminated and the home care agency refused to reinstate her services saying that she was not safe to be at home. Referrals were made to all of the home care agencies in the area and she was denied by all of the remaining home care agencies because they could not provide the amount of hours that the hospital required that she have. The home care agencies all said they would re-evaluate Mary for services only if she was able to obtain 24-hour supervision.

The hospital became increasingly adamant that Mary must go into a nursing home. Additionally, her own doctor decided that she would be safer in a nursing home. The hospital then ordered Mary to have a psychological evaluation to try to prove that she was incapable of making her own decisions. The psychological evaluation showed that Mary was "incompetent" and the hospital then filed for guardianship so that they could force Mary to go into a nursing home.

It should be noted that prior to entering the hospital, Mary had an extensive history with one home health care agency. This agency reported that Mary was often difficult to deal with and became easily frustrated with her aides. The agency also reported that Mary interfered with her medication administration, although further investigation also revealed that Mary sometimes did not receive the appropriate amount of medications.

Given that Mary has been turned down for all forms of home health care and requires significant assistance, has no family members that are willing to assist her, and that the hospital has filed for guardianship to force her into a nursing home, what can be done to help her return to the community?

V. FIRST MEETING AND INITIAL PLANNING

The first meeting is a time for you and the consumer to introduce yourselves and get acquainted with one another. This is also an opportunity for you to get important background information that will be critical to the nursing facility transition process.

One of the things that you want to do during your first meeting is to explain your role as the Nursing Facility Transition Coordinator and discuss independent living philosophy. Both of these explanations are extremely important. You do not want the consumer to have any false expectations about your role. Furthermore, the consumer must be advised that he/she will be playing an active role in the nursing facility transition process. This is particularly important to stress when someone has been institutionalized for a long time because many times individuals who have been in a nursing home for a while have been discouraged from doing things by themselves.

During the initial planning stages, it is also extremely important to educate the consumer about the *Olmstead* decision and the rights under the Americans with Disabilities Act. Knowledge is power and, in this circumstance, it can mean the difference between confinement and freedom. It is important that the individual have a firm understanding of their rights so that when they are faced with adversity during the nursing facility transition process, they can firmly say "This is MY RIGHT and I know I do not have to stay locked up!"

To establish a relationship with the consumer, a suggestion is to speak to the consumer about what their interests are. What do they like to do? What will they like to do once they get out?

Have an open talk with the consumer about trust and honesty. Much of the nursing facility transition process involves a whole lot of both! Honesty is particularly important because valuable time can be lost if you do not know the whole truth. For example, if you ask the person about their experiences with home health agencies and they fail to mention that they kicked out aides from every agency, you are going to be at a real disadvantage when it comes times to advocate for home health services. This is not to say that kicking out aides is a bad thing, but it is something that you need to know.

In order to really begin the nursing facility transition process, you must obtain demographic and personal background information. Obtaining demographic information (i.e. age, disability type) will help you in determining what services the consumer might be eligible for. Background information (i.e. experiences with home health agencies, credit problems, etc.) will help to identify potential barriers. Finally, ask the consumer how they ended up in the nursing home. The answer to this question will provide insight into what the focus of your work will be. For example, if the person says, "I ended up here after my home care was terminated", you will need to find out why it was terminated and then know that you must work on getting home care re-instated. If the person says, "I ended up here because I didn't have anywhere else to go", you know you will need to work on getting housing.

The initial planning stages are also a time to determine what services and supports the person will need to return to the community. You will want to provide the person with a general overview of available services and supports and then help the person to decide which services and supports will best suit their needs and desires. To do this, you will need to ask many pointed questions. Make sure that you make the person aware of why you are asking these questions; it is not to be nosy, but you need to know the answers in order for you to help the person make informed choices about services and supports.

Questions that should arise during the initial planning stages include:

How long have you been here?

How did you end up here?

How is your nursing facility stay being paid for?
If the answer is Medicaid, make sure that it can be transferred into the community. This may involved asking the consumer questions about income and resources in order to assist them in transferring the Medicaid into the community.

Are you able to direct and manage your own care?
If the answer is yes, then the person may be interested in pursuing consumer-directed services. If the answer is no, find out if the person can appoint someone to manage their services for them. If the person has no one to manage their services, but would still like to pursue this option, assist the person in finding someone.

What types of things do you need assistance with?
At this stage, the person may be hesitant to tell you the entire truth. This is to be expected because many people who have been honest about their true needs have been forced into nursing homes!

Another related question is, what types of things do you WANT assistance with?
For example, some people who are in nursing homes do not use the toilet only because of a staff shortage at the nursing home. Maybe that person will want to use the toilet when they return home. In that case, the person will want help with toileting at home, even though they did not receive this help in the nursing home.

Were you receiving services while you were at home? Were you happy with your services and why were they terminated?

Do you have a home? Is it accessible?

What area do you want to look for an apartment in?

Are your family and friends supportive of you moving out?
Remember, you are working with the consumer, NOT their family or friends. This question is only important because nursing facility transition can be a very stressful time for the consumer and you want to determine if they have an informal support network. If they do not have an informal support network, you may want to explore helping them set one up.

What does your doctor say about you moving out?

Would you like to talk with someone who has been through the nursing facility transition process? Enough cannot possibly said about the value of peer counselors during this process. Nursing Facility Transition can be a very scary time, and peer counselors can share their experiences in order to help alleviate this fear.

*****A word about pressure sores*****
Although never a pleasant topic, ask the person if they have or had a problem with pressure sores. If they have developed pressure sores while in the nursing home (like many people do), find out what the protocol is for healing it. Will they need dressing changes at home? Will they need a customized wheelchair to alleviate pressure? Will they need a specialized mattress? If the person has had problems with pressure sores all of their life and, in fact, ended up in a nursing home because of a pressure sore, talk to them about ways to alleviate and prevent pressure sores.

VI. IDENTIFICATION OF BARRIERS

During the course of the initial planning stages, you will want to begin to identify potential barriers. For example, if you are talking with the consumer about the different home health options, find out what their experiences have been, if any, with home health care in the past. If the person tells you they were terminated, make sure you find out why and encourage the person to be completely honest with you. Things like non-compliance, refusal to let aides in, home health agencies refusing to reinstate services after hospitalizations, and history of falls, all signify potential barriers. However, with the proper advocacy, these barriers can be overcome!

Another example, when you are talking to the person about potential housing, it is advisable to find out where they lived before and why they no longer live there. Also discuss credit history and any criminal history. Although these barriers can be overcome with proper advocacy, it is important that you can identify these potential barriers before you apply for housing.

A final example of a potential barrier is a history with Adult Protective Services. Ask the person if there has been any history with Adult Protective Services. This does not necessarily mean that the person was actually a danger to themselves, but some States require that home health agencies refer people to Adult Protective Services when they terminate services. Medicaid may refuse to approve a person for home care because of a past history with APS. Again, this barrier can be overcome with proper advocacy, but you have to know this beforehand.

As you become more experienced with Nursing Facility Transition, it will be easier for you to identify potential barriers. One final word of advice...although nursing homes and departments of social services will sometimes exaggerate claims or become so entrenched in the medical model that they lose all common sense, you at least need to know what the nursing home is saying and discuss these allegations with the consumer. These allegations are potential barriers and must be addressed.

Potential Barriers

The following is a list of some potential barriers and advocacy strategies that can be used to overcome these barriers.

The consumer has unpaid utility bills and cannot get his/her utilities turned on until they are paid.

It is extremely important to bring up the subject of unpaid bills early in the nursing facility transition process. If do not find out this information until the consumer calls to get their utilities turned on, it could delay their discharge. If the consumer does have an unpaid utility bill, there a few different advocacy options that you could pursue. If the consumer is able to, they should pay off the unpaid bill immediately. This might involve asking family or friends for financial assistance. If he/she cannot pay the full amount of the unpaid bill, try to get a payment arrangement established that the consumer will be able to afford. If the consumer receives SSI, contact the local Department of Social Services to see if there is any financial assistance available to pay off the unpaid bill. Finally, you can try to use a medical doctor's statement stating that the utility (i.e. electric or phone) is medically necessary.

Consumer is denied housing because of negative credit rating or poor rental history.

Again, by the time you assist the consumer in applying for housing, you should already know if there is a potential for negative marks on his/her credit report. If the consumer has been denied housing because of a negative credit rating, he/she should request a copy of their consumer credit report to determine if it is accurate. If it is inaccurate, the consumer should contact the reporting agency to challenge any inaccuracies on the credit report. If it is accurate, the consumer should determine if he/she is able to pay any of their debts off in an attempt to clear up their credit. Another advocacy strategy is for the consumer to get a representative payee. By doing this, the consumer can show the rental agency that yes, they may not have paid all of their bills in the past, but their representative payee will now be handling their finances. A representative payee can also be used in circumstances where a consumer has a poor rental history. In addition, the consumer and yourself may want to personally advocate with the rental agent by discussing how things will be different and the consumer will be paying his/her bills on time. We have found this to be a really great advocacy strategy. In the long-term, if the consumer is successful in that particular apartment complex, it will be a lot easier for you to advocate with the rental agent on behalf of other consumers.

Consumer is denied housing because of a criminal history.

When you pose the question to the consumer about their criminal history, you should ask them, "Have you ever been CONVICTED of a crime?" If you just ask them if they have ever done anything to get arrested, you may get a "No" answer even if they were convicted of a crime. Next you will want to find out the nature of the crime that they were convicted of. Federal policy permits housing complexes to deny access to individuals whose tenancy could negatively affect the health, safety, and welfare of other tenants. Therefore, the nature of the crime is taken into consideration. Furthermore, particularly if the crime was drug-related, housing authorities can take into consideration successful rehabilitation in an approved program. If it is determined that the housing agency is following regulations and a denial of the application is justified, the consumer can look for other housing, such as housing available through private landlords that do not do criminal background checks.

Housing complex requires a security deposit

This is an issue that should be taken into consideration during the initial planning stages. The consumer should start saving as soon as possible for the security deposit and first month's rent. This is particularly difficult for individuals who receive SSI because they only get to keep $35/month while in the nursing home. If an individual is receiving SSI, you can check with the Department of Social Services to determine if a one time security deposit voucher is available. The consumer can also check with family or friends to see if they can pitch in some money. You can also find out if money is available through a Medicaid Waiver program. You and the consumer could ask the rental agent if the security deposit could be paid in installments with each month's rent. You need to be creative in this situation to come up with a solution. Someone from our agency was able to convince a nursing home to allow the consumer to keep more of her Social Security Disability money one month in order to pay the security deposit and first month's rent.

Consumer has a history of non-compliance with home care.

Non-compliance can mean many things--- from refusal to take vitamins to refusal follow pressure sore protocols. You need to determine why the consumer is being labeled as non-compliant and work on an advocacy plan. If the consumer truly was non-compliant and it affected their health or safety, you will also need to discuss with the consumer the importance of following a "plan of care" and provide Independent Living Skills Training and Peer Counseling when necessary. Another advocacy strategy is to develop a written agreement/plan that addresses the issues. A written agreement/plan is a good faith measure aimed at convincing the home care provider that the consumer will be compliant.

VII. HOUSING

Accessible, affordable housing is often difficult to locate. Even apartments with basic accessibility features, such as no-step entrances, can be difficult to find.

Where you look for housing and what kind of housing you look for will depend on the consumer's wants and needs. One of the first thing you will want to discuss with the consumer is where they would like to live. You will also want to be honest with the consumer about availability of housing and time frames for waiting lists.

To find accessible, affordable housing, one of the first places you should look is through the local housing authority. Other places to look include other subsidized apartment complexes, newspapers and any housing registries that are available in your state.

The first apartment that an individual moves into after a nursing home, will probably not be the apartment that they will remain in for the rest of their lives. Again, this will depend on the individual's desires, but we have found that most people opt to move into a place that isn't exactly their ideal apartment rather than wait for their ideal apartment to become available. Many people say "My freedom is more important to me than finding the ideal apartment" Whatever apartment the person moves into, it must at least have an accessible entrance and doorways that are wide enough to get a wheelchair through. Some of the people we have helped to transition out of nursing homes opted to move into apartments that do not have a roll-in shower rather than waiting for one that has a roll-in shower. They can still keep their name on the waiting list for an apartment with a roll-in shower and move into it when it becomes available.

Types of Housing

Own Home

During the planning process, you will need to discuss housing options with the consumer. One of the first questions you will ask is if the consumer has a home to return to? If the person says that they do have a home, you need to find out if it is accessible. If it is not accessible, you will need to work with the consumer to identify what funding is available to make it accessible. We aren't talking full roll-in showers here, but we are talking about basic accessibility requirements related to entrance and egress. Possible funding streams include community-based agencies that have home modification programs, Community Development Block Grant (CDBG) funding, Medicaid Waiver Programs, Vocational Rehabilitation, churches or civic groups, friends or family, savings, etc.

If it is an inaccessible apartment that the person will be returning to, the consumer should ask the landlord if they would be willing to do home modifications. You will also need to determine if it is the landlord's responsibility to pay for the home modifications. If not, they must at least allow the consumer to modify the dwelling to make it accessible. If that is the case, you will need to assist the consumer in identifying possible funding for home modifications.

If a person says that they do have a home to return to, you should try to verify that it is real. This is not to say that people lie about this, but we encountered a situation where a woman we were helping said she had a home to return to. She even said that some people went to the house to clean it up. Voc rehab had even paid for a ramp. After further investigation, we found out that the reason people went to the house to clean it up was because the house was foreclosed on! Her family had withheld this information from the woman because they said they didn't want to upset her.

Other types of housing
There are many types of housing. Where you and the consumer look for housing will depend on the consumer's desires regarding the type and location of housing. Of course, it will also depend on the individual's income and accessibility requirements. Based on this information, you should present all of the pertinent housing options to the consumer so that they can make an informed choice about where they want to live. Some of the housing options that are available include Public subsidized housing, other Section 8 programs, including Tenant based vouchers and home ownership, section 811 housing, private subsidized housing, enriched housing, supported housing, private housing, Adult Homes, and Assisted Living Facilities.

Most of the people that we have helped to transition from nursing homes have chosen to pursue public subsidized housing through the local housing authority or private subsidized housing that is available through many non-profit or for-profit agencies. Eligibility requirements are similar for both of these types of housing.

For any type of housing, the consumer will need transportation in order to view apartments and sign their lease. If your area has a paratransit system, talk to the consumer about applying for paratransit. Other ideas for transportation include community-based agencies that provide transportation (e.g. Independent Living Centers), family or friends with accessible vehicles, accessible taxis, and private pay transportation. We've actually been able to convince nursing homes to pay for transportation so that people can sign leases. Please note, that most nursing homes will not send aides with the consumer when they go to look at apartments. Therefore, if the consumer does not have a family member of friend going with them and they need someone to push their wheelchair, etc., you will need to meet them at the apartment complex to assist them.

At this point (if not sooner), the consumer will need to provide forms of identification such as a social security card and birth certificate. The consumer will also need proof of their income. All of this information will be needed when completing an application for public or private subsidized housing.

Before you even start to assist the consumer in completing the actual applications, you need to have a discussion with the consumer about any unpaid bills that they might have, any negative credit ratings, and any criminal history (see potential barrier section).

As you start to complete the housing applications with the consumer, you should encourage the consumer to apply for any housing that meets their expectations and standards, even if there are long waiting lists. It can never hurt to get a person's name on a waiting list and still look for other housing in the meantime. At this point, if not sooner, the consumer should either be saving for a security deposit and first month's rent or identifying someone that could assist with funding (see potential barrier section).

The first apartment that an individual moves into after a nursing home, will probably not be the apartment that they will remain in for the rest of their lives. Again, this will depend on the individual's desires, but we have found that most people opt to move into a place that isn't exactly their ideal apartment rather than wait for their ideal apartment to become available. Many people say "My freedom is more important to me than finding the ideal apartment" Whatever apartment the person moves into, it must at least have an accessible entrance and doorways that are wide enough to get a wheelchair through. Some of the people we have helped to transition out of nursing homes opted to move into apartments that do not have a roll-in shower rather than waiting for one that has a roll-in shower. They can still keep their name on the waiting list for an apartment with a roll-in shower and move into it when it becomes available.

****A final word of advice** Be creative when searching for accessible, affordable housing because you never know when you will find it!**

VIII. States' Use of Home Health, the PCS Benefit, and HCBS Waivers

Under Medicaid, states have three approaches for providing personal care, two of which may be offered at the discretion of the state. First, states must offer the Medicaid home health services benefit (including home health aides), which may provide unskilled personal care services. Second, states may choose to provide the PCS benefit, which offers unskilled personal care services as a part of the state's Medicaid benefit package. Third, HCBS waivers give states the option of providing personal care and other related services if they choose to do so.

All candidates for personal care and other long-term care services are given individualized assessments, frequently coupled with environmental evaluations that take into account the candidates' informal and community support. The objectives is to ensure that (1) services are focused primarily on those with the greatest need. (2) personal care is target to prevent institutionalization as a first priority, and (3) only those with no feasible alternative are admitted to nursing homes. How states approach assessments can vary, primarily in the degree of professional discretion afforded to the assessor. Thus, some states use an assessment instrument that produces a numeric score, which essentially determines the level of care that the state will provide. Other states rely exclusively on the professional judgment of the individual assigned to undertake the assessment.

States impose different limits on these services that are somewhat dependent on the states' use of home health, the PSC benefit, or HCBS waivers. Under home health and the PCS benefit, states may limit services through medical necessity or utilization controls, HCBS waivers provide a much wider array of means to limit services that includes targeting populations, limiting geographic availability (statewideness), and capping expenditures. In all cases, imposing limits on services can help states to control costs.

Home Health

States must offer home health services as a part of their Medicaid program to all beneficiaries who are entitled to nursing facility services. Under Medicaid, a physician must order home health services as part of a care plan that is reviewed periodically and includes part-time or intermittent nursing services; home health aide services; and medical supplies, equipment, and appliances suitable for use in the home. Home health aide services must be provided by a home health agency and can include the provision of personal care. States may also choose to provide physical, occupational, and speech pathology and audiology as optional services.

States can elect to limit the number of visits, the number of hours, or the dollar amount of certain services provided, under the Medicaid home health program. Table V.1 shoes the states' major limitations. Sixteen states specify no limitations and most states allow established limits to be exceeded with prior authorization.

Table V.1: Limits imposed Under the Medicaid Home Health Benefit

Alabama
104 visits per recipient per calendar year

Alaska
No limitation specified.

Arizona
No limitation specified

Arkansas
50 visits for any combination of home health nurse or aide services without prior authorization

California
More than one visit in 6 months is subject to prior authorization and to a physician-approved treatment plan requirement. A maximum total of 30 visits may be approved at any one time, valid for a period not exceeding 120 days.

Colorado
Covered visits is 2-1/2 hours, No more than five home health visits are covered per say. Simultaneous visits by two or more individuals count as one visit.

Connecticut
Prior authorization is required after the first two visits for intermittent nursing services when no home health agency exists in the area; for home health aide services in excess of 20 hours per week; and for physical, occupational, speech pathology, and audiology services.

Delaware
No limitation specified.

District of Columbia
36 visits per year unless prior authorization is obtained; services of a home health aide are limited to 4 hours per day except by prior authorization.

Florida
60 home health visits per year; 4 visits per day by a registered nurse; or 1 visit per day by a licensed practical nurse except by prior authorization.

Georgia
75 nursing or home health visits per recipient per calendar year.

Hawaii
One visit per day during the first 2 weeks; three visits during the next 5 weeks; one visit per week for the following 7 weeks, and one visit every 60 days thereafter; additional services require prior authorization.

Idaho
100 per recipient per calendar year; prior authorization is required for all medical equipment that costs more than $100 purchased by the department.

Illinois
Prior authorization is required except when services are provided by independently practicing physical, occupational, or speech therapists or by community health agencies.

Indiana
30 hours/sessions/visits in a 30-day period unless prior authorization is obtained.

Iowa
No limitation specified.

Kansas
Home health aide services are limited to one visit per day, and physical, occupational, speech therapy, and restorative aide service are limited to 6 months from the first date of service.

Kentucky
Prior authorization is required for durable medical equipment that costs $150 or more.

Louisiana
50 nursing and home health aide visits and 50 physical therapy services per year, except for recipients of Early and Periodic Screening, Diagnostic and Treatment program services.

Maine
No limitation specified.

Maryland
One visit of less than 4 hours per type of service per day, eight visits per month for physical or speech pathology, four visits per month for occupational therapy, and 12 home health aide services per month; services and medical supplies that cost more than $900 per month require prior authorization.

Massachusetts
Prior authorization is required for home health aide services exceeding 120 hours in a calendar month when services exceeded 120 hours in each of the 2 preceding months.

Michigan
No limitation specified.

Minnesota
Prior authorization is required, unless a professional nurse determines an immediate need for up to 40 visits per calendar year and for certain medical supplies and equipment.

Mississippi
Patients are limited to a combined total of 50 visits per fiscal year, medical equipment that costs less than $150 must be purchased, and a determination must be made whether to rent of purchase equipment costs more that $150.

Missouri
100 visits per patient per year

Montana
100 home health visits and 75 skilled nursing visits per recipient per fiscal year; home health aide services are not provided for an individual receiving personal care services.

Nebraska
40 hours per week and 8 hours per day.

Nevada
No limitation specified.

New Hampshire
Prior authorization is required to purchase durable medical equipment exceeding certain cost limits as well as portable and in-home oxygen equipment.

New Jersey
Personal care assistant services are limited to 25 hours per week.

New Mexico
No limitation specified.

New York
No limitation specified.

North Carolina
Prior authorization is required for durable medical equipment.

North Dakota
No limitation specified.

Ohio
No limitation specified.

Oklahoma
12 home health visits per year.

Oregon
No limitation specified.

Pennsylvania
15 visits per month after 28 days of unlimited visits, one fee per visit regardless of services provided, and 1 visit per month for prenatal care.

Rhoda Island
Prior authorization is required for more than eight visits per month and for all medical supplies, equipment, and appliances.

South Carolina
75 home health agency visits per fiscal year.

South Dakota
No limitation specified.

Tennessee
No limitation specified.

Texas
50 nurse and home health aide visits per recipient per year without prior authorization.

Utah
Housekeeping or homemaking services and occupational therapy are not covered.

Vermont
Routine services are covered for 4 months with a physician's certification.

Virginia
32 home health agency or registered nurse visits or home health aide services and 24 rehabilitation therapy services ordered annually without prior authorization.

Washington
Approval is required when the home health service duration or monthly payment will exceed the program's limits.

West Virginia
No limitation specified.

Wisconsin
30 visits by a registered aide, registered nurse, licensed practical nurse, or therapist without prior authorization; home health aide visits requiring more than 4 hours of continuous care required prior authorization.

Wyoming
No limitation specified.

**Source* _Medicare and Medicaid Guide_*, Commerce Clearing House, Inc.*

Personal Care Services Benefit

Twenty-seven states and the District of Columbia offer personal care under the PCS benefit, which is an optional benefit under the Medicaid program. Nine states provide personal care services to only the categorically needy, which include low-income children; pregnant women; aged, blind, or disabled people meeting Supplemental Security Income program requirements; and individuals who are eligible to receive federally assisted income maintenance payments. Such individuals must generally meet income and resource standards established for public assistance. The remaining 18 states and the District of Columbia provide personal care to both categorically needy and medically needy individuals. The latter group comprises those individuals whose income, resources, or both exceed the levels for the categorically needy, but who cannot afford to pay their medical bills. To control utilization of personal care services, states usually require prior authorization, establish concrete limits on the duration of services, or both. Table V.2 lists the control techniques used by each state. A few states have targeted eligibility for the PCS benefits by identifying a population or functional impairment for which they will provide assistance. For example, New Hampshire limits eligibility to individuals with chronic disabilities who use a wheelchair, and Florida limits personal care to children with disabilities.

Table V.2: Limits Imposed Under the Medicaid PCS Benefit

Alaska
Provide personal care services to only the categorically needy. One assessment and treatment plan per 12 months

Arizona
Provide personal care services to only the categorically needy. No limitation specified.

Arkansas
Provide most Medicaid services to both categorically needy and medically needy, but limit personal care services to categorically needy. Services cannot exceed 72 hours per month without prior approval.

California
Services must not exceed 283 hours per month.

District of Columbia
Services cannot exceed 4 hours per day or 1,040 hours in 12 months without prior authorization.

Idaho
Provide personal care services to only the categorically needy. 16 hours per week.

Kansas
Prior authorization is required for up to 24 hours per day.

Maine
Available to individuals with chronic or permanent disabilities who are able to self-direct a personal care attendant.

Maryland
Services are provided at one of four intensity levels of care subject to prior authorization.

Massachusetts
Prior authorization is required.

Michigan
No limitation specified

Minnesota
Prior authorization is required.

Missouri
Provide personal care services to only the categorically needy. Need assessment to be completed every 6 months.

Montana
40 hours per week unless prior authorization is obtained

Nebraska
40 hours per week unless prior authorization is obtained.

Nevada
Provide personal care services to only the categorically needy. Prior authorization is required.

New Hampshire
Recipients must be chronically wheelchair-bound.

New Jersey
25 hours per week or up to 40 hours per week with prior authorization.

New York
6 months for one of three levels of services with prior authorization unless exceptions are authorized for up to 12 months.

North Carolina
80 hours per month and covered only if no home health aide services are provided on the same day.

Oklahoma
Provide most Medicaid services to both categorically needy and medically need but limit personal care services to categorically needy. Departmental approval is required.

Oregon
Prior authorization is required.

South Dakota
Provide personal care services to only the categorically needy. 120 hours per calendar quarter.

Texas
Lesser of 50 hours per week or the rate of the average nursing facility; prior authorization is required and a plan of treatment must be reviewed.

Utah
60 hours per month and covered only if no home health aide services are provided on the same day.

Washington
Provide most Medicaid services to both categorically needy and medically needy, but limit personal care services to categorically needy. No limitation specified.

West Virginia
Limited on a per-unit, per-month basis; prior authorization is required for additional hours of care.

Wisconsin
Prior authorization is required for more than 250 hours per calendar year, housekeeping tasks are limited to one-third of the time spent in the recipient's home.

HCBS Waivers

Forty-three states and the District of Columbia provide personal care under an HCBS waiver; 24 states and the District of Columbia offer both the Medicaid PCS benefit and one or more HCBS waivers. While HCBS waivers offer broader opportunities to limit or target services, the availability of national data on them is limited. The APHSA database of HCBS waivers, however, does track waivers by target populations and number of clients services (see table V.3)

Table V.3: Clients Served by Medicaid HCBS Waivers with Personal Care, 1997

Waivers' target populations-Only HCBS waivers offering personal care or attendant care to adults were included in our state analysis of HCFA waivers and auxiliary services.

Alabama	
Mentally retarded or developmentally disabled people	3,290
Aged and disabled people	6,316
Disabled people	362
Arkansas	
Disabled adults who are 21 to 64	60
California	
Mentally retarded or developmentally disabled people who are technology-dependent	35,105
Aged and disabled people	8,314
People with HIV/AIDS	2,792
Colorado	
Aged and disabled people	5,843
People with HIV/AIDS	101
Chronically mentally ill people who are over 18	79
People with Traumatic brain injury	70
Developmentally disabled people who are 18 and older	Data not reported
Connecticut	
Disabled people who are 18 to 64 and need help with 2+ADLS	Data not reported
People with traumatic brain injury who are 18 to 64	Data not reported
Delaware	
People with HIV/AIDS-related conditions	174
District of Columbia	
Mentally retarded or developmentally disabled people who are 22 and older	75
People who are 65 and older	Data not reported

Florida

Aged and disabled people who are 18 and older	16,943
Mentally retarded or developmentally disabled people	10,302
Aged and disabled people who are 18 and older	1,380
People with AIDS	8,000
Mentally retarded or developmentally disabled people who are over 18	116
Elder people	Data not reported

Georgia

Aged and disabled people	16,500
Mentally retarded or developmentally disabled people	2,109
Disabled adults who are 24 to 64	121

Hawaii

Mentally retarded or developmentally disabled people	512
Aged and disabled people	338
People with AIDS/ARC. Aids-related complex	104

Iowa

People with HIV/AIDS	29
Mentally retarded people (including children)	4,530
People with traumatic brain injury who are 30 to 64	30
Mentally retarded or developmentally disabled people and mentally retarded children with disabilities	374
Elderly people	2,236

Idaho

Aged and disabled people 21 and older	1,429
Mentally retarded or developmentally disabled people 21 and older	415

Illinois

Disabled people	12,021
People with HIV/ARC/AIDS	984
Mentally retarded or developmentally disabled adults	5,224
People who have been disabled by an acquired traumatic brain injury	Data not reported

Indiana

Aged and disabled people	2,467
Mentally retarded people and those with related conditions	1,201

Kansas

Aged and disabled people	3,150
Physically disabled people who are 16 to 64	1,880
People with traumatic brain injury	160

Kentucky	
Aged and disabled people	11,500
Adults and children with traumatic brain injury	Data not reported
Louisiana	
Mentally retarded developmentally disabled people	2,095
People with loss of sensory motor function	103
Aged and disabled people	222
Maryland	
Mentally retarded or developmentally disabled people	3,600
Main	
Elder people	554
Physically disabled people	204
Disabled people who are 18 to 60	13
People with traumatic brain injury	Data not reported
Michigan	
Aged and elderly people	2,804
Minnesota	
Elderly people	6,582
Mentally retarded people and those with related conditions	5,657
Disabled people under 65	2,751
People with acquired traumatic brain injury	290
Missouri	
Mentally retarded or developmentally disabled people	5,860
People with HIV/AIDS	140
Disabled people and developmentally disabled people who are 21 to 64	Data not reported
Mississippi	
Disabled people who are 21 to 64	100
Mentally retarded or developmentally disabled people	325
Montana	
Aged and disabled people	1,158
Mentally retarded or developmentally disabled people	652
North Carolina	
Mentally retarded or developmentally disabled people	3,201

North Dakota

Mentally retarded or developmentally disabled peopled	1,792
Aged and disabled people	366
People with traumatic brain injury who are 18 to 64	9

New Hampshire

Mentally retarded or developmentally disabled people	1,303
People with acquired traumatic brain injury who are 22 and older	27

New Jersey

Mental retarded or developmentally disabled people	5,242
People 18 to 65 who incurred traumatic brain injury after age 16	153

New Mexico

People with AIDS/ARC	60
Aged and disabled people	1,200
Mentally retarded or developmentally disabled people	1,500

Nevada

Frail elderly people 65 and older	898
Elderly people in group care	72

Ohio

Aged and disabled people	17,000
Aged and disabled people under 60	3,904
Mentally retarded or developmentally disabled people	2,512
Mentally retarded or developmentally disabled people 18 and over	Data not recorded

Oregon

Aged and disabled people	19,471

Pennsylvania

Physically disabled people	Data not recorded
Elderly people	675

Rhode Island

Elderly people 65 and over	600
Physically disabled people	80

South Carolina

Aged and disabled people	7,658
People with HIV/AIDS	637
Mentally retarded peopled and those with related conditions	2,288
People with traumatic brain injury and spinal cord injury	161
Adults who are technology-dependent (ventilator-dependent)	27

IX. General Guidelines for Nursing Facility Transition

Overview
The following provides a general guide for nursing facility transition. It is broken down by subject area and tasks should be viewed as being done simultaneously, as opposed to being done in order. Nursing facility transition is an ever-changing process and much of the work is based on an individual's needs, choices, and preferences. The guide does not specify which activities should be completed by the consumer, advocate, or other interested parties. During the nursing facility transition process, the consumer, yourself, and other interested parties should share responsibilities for the activities.

All of these are general considerations in the nursing facility transition process. The most important thing to remember is that you need to be thorough and make sure that all community services and supports are in place prior to discharge. Don't overlook the simple things! (i.e. how will the person get groceries?) This guide should be used in conjunction with the "Tips for Nursing Facility Transition" and the "General Checklist for Basic Necessities."

Referral
When you receive a referral, schedule an appointment to meet with the person at the nursing home. Make sure you obtain the individual's name, address, and phone number in case this appointment must be rescheduled. If you are familiar with the nursing home, encourage the person to include their Social Worker in the meeting. The Social Worker can be very helpful with many of the activities that need to be completed and can also act as a liaison between the consumer and medical professionals. Also, make sure the person knows that they can include any family or friends in any of the meetings.

I. General Planning Information

A. Education
The initial meeting provides both the advocate and the consumer with a chance to discuss goals, services, and rights. This is a chance for you to explain your role as a Nursing Facility Transition Coordinator, explain Independent Living Philosophy as it pertains to consumer control and consumer choice, and explain the *Olmstead* decision and an individual's rights under the ADA.

B. Demographic Information and Background
When you initially begin working with the consumer, make sure you obtain their demographic information, including their age and type of disability. This is very important because some community services are age or disability type specific. This information should be obtained once the person has decided that they want to pursue

nursing facility discharge. Also ask how they ended up in the nursing home. The answer to this question will provide insight into what the focus of your discharge planning will be.

C. Social Worker

If the Social Worker is not at the initial meeting, ask the individual if he/she has advised the Social Worker that they want to leave the nursing home. If you have had positive experiences with the Social Worker, encourage the individual to let the Social Worker know that he/she wants to leave and ask the individual to invite the Social Worker to a meeting. If the individual tells you that the Social Worker is opposed to them being discharged, wait until you and the consumer have developed a list of needed supports before speaking to the Social Worker. Our experience indicates that the Social Worker can play a very valuable role in the discharge process by both assisting with discharge plans and acting as a liaison with medical staff at the nursing home.

D. Establish Ground Rules

Advise the individual that you both must be honest with each other at all times during this process. The nursing facility transition process is really based on trust, and dishonesty can cause difficulties which can impede the entire process. Emphasize to the individual that your role is to help them get out of the nursing home, and you are not there to judge them.

II. General Community Based Services and Supports

A. Payer Source

Ask the person about a payer source. If it is Medicaid, make sure that it can be transferred from the nursing home into the community. Discuss ways to get community based Medicaid (i.e. spend downs, Supplemental Needs Trusts). If necessary, assist the individual in contacting an attorney to establish a Supplemental Needs Trust.

B. General community based services and supports

Discuss all of the community based services and supports with the consumer. Make sure you explain to the consumer all of the options (i.e. home health care vs. personal care assistance vs. consumer directed personal assistance). The consumer should then choose whatever community based services and supports they will need.

C. List of community based services and supports

You and the individual should develop a list (from your previous discussion of community based services and supports) of the community based services and supports that will be necessary. If the Social Worker is involved at this point, include him/her in this activity. If the Social Worker is not involved at this point, ask the consumer to schedule a meeting with you, the consumer, and the Social Worker to discuss this list.

D. To do lists.
Create to do lists to delegate responsibilities between yourself, the consumer, and the Social Worker (if involved).

E. Potential Barriers
Discuss any potential barriers to community living (i.e. outstanding bills, credit problems, criminal history, previous problems with home care agencies).

III. Actual Community Based Services and Supports

A. Housing

1. Finding Housing

   You first want to find out if the consumer has accessible housing to return to. If the consumer does not have accessible housing, you will want to work with the consumer to obtain accessible, affordable housing. The following are some of the activities that must be done prior to discharge:
   - Review type of housing, location, and other preferences
   - Locate housing
   - Assist in clearing up credit if necessary
   - Get on waiting lists
   - Save money for security deposit
   - Sign lease and get keys
   - Put in change of address
   - Discuss how the consumer will physically be paying rent and assist the person in setting this up if needed (i.e. representative payee, friend, attendant, etc.)

2. Utilities
   - Make arrangements to pay any unpaid utility bills or advocate to get them waived
   - Set up appointments for phone, electric, and gas to be turned on
   - Buy a telephone if needed

3. Household items
   - Make a list of items needed
   - Contact churches, friends, or civic groups for donations if needed
   - Arrange to have belongings moved

4. Home modifications

   If the person has existing housing that needs modifications, assist the person in applying for funding for modifications and/or finding someone to do the modifications.

B. Personal Finance

1. Change of Address
   Assist the individual in completing a change of address form for all income sources and resources. (i.e. Social Security Administration, pensions, banks)

2. Income source
   If the individual has no income, assist the individual in applying for SSDI or SSI. If the individual has SSI, assist the individual in notifying SSA so that their SSI will go up after discharge (this may not be able to be done until the person is actually discharged)

3. Budgeting
   If the person chooses, assist them in setting up a monthly budget

4. Cash on Hand
   Encourage the individual to budget for some cash on hand for the day of discharge. This is for any unforeseen expenses

C. Public Benefits

1. Community Medicaid
   Make sure that, prior to the discharge, the person will be able to transfer their Medicaid into the community. If the person will need to set up a Supplemental Needs Trust, assist the person in contacting a lawyer to establish this. If the person has a spend down, assist the person in figuring out how they will meet their monthly spend down.

2. Food Stamps
   If qualified, assist the person in applying for food stamps, including setting up an appointment.

D. Transportation

1. Medicaid transportation
   If the person is eligible for Medicaid, assist them in applying for Medicaid transportation. If the person is not eligible for Medicaid, discuss how the person will be getting to medical appointments and assist them in setting up arrangements.

2. Non-medical transportation
   Assist the person in applying for transit or para-transit services. If para-transit, educate the person on how to go about setting up rides.

E. Personal Care Assistance

Discuss with the person what type of personal care assistance is needed and the options that are available. Issues that should be addressed should include assistance with feeding, meal preparation, bladder care, bowel care, toileting, transferring, and dressing. Other issues such as grocery shopping, housekeeping, and laundry should also be addressed.

Make sure that a referral is made to the appropriate home care agency and advocate for adequate coverage. Make sure that approval is secured and that the actual hours of coverage are adequate.

For Consumer Directed Personal Assistance services, make sure that the consumer has recruited and hired attendants and back-up attendants and that they are approved to start working. If the consumer is responsible for training the attendants, arrange this with the nursing home. Assist the person with setting up schedules and lists of responsibilities.

F. Therapy

Discuss with the consumer any physical, occupational, or speech therapy that will be needed. Make sure that referrals and appointments are set up for these therapies

G. Medicaid Waiver Services

Make referrals as appropriate and make sure that services are approved prior to discharge.

H. Durable Medicaid Equipment/Assistive Technology

Determine what equipment/technology will be needed and obtain approvals as appropriate. Ensure that funding is available for this equipment. Make arrangements for delivery of equipment and assistance in learning how to use the equipment.

I. Supplies/Medications

Make a list of what supplies will be needed upon discharge. Make sure that prescriptions have been made and determine how the person will obtain these supplies/medications upon discharge. Determine if the nursing home will give the person at least a week's supply of supplies upon discharge.

J. Doctors

Help the person to obtain a primary care doctor in the community. Assist with setting up the first appointment after discharge, as well as transportation to the appointment. Assist the consumer in setting up other doctor's appointments (i.e. specialists, dental, eye, mental health, etc.)

K. Recreational Activities

If the person wants assistance in planning activities, assist with this task.

L. Peer Support

If interested, have the person meet with a peer counselor who has gone through the transition process.

M. List of contact people
If the consumer does not have an address book, assist them with making a list of contact people (i.e. yourself, doctor, family, friends, attendants) that they can put in an accessible place.

N. Employment and Education
Discuss this with the consumer. Explore possible paid or volunteer opportunities. Make Vocational Rehabilitation Referral.

O. Food
Make sure that the person has enough groceries on hand for at least one week.

IV. Discharge Meeting

Approximately one week prior to discharge, schedule a discharge meeting with all interested parties. This meeting should establish the actual discharge date and provide the opportunity to review the community based services and supports that have been obtained. Assign responsibilities for obtaining the services and supports that are not yet in place. Also, determine how the person will be getting home on the day of discharge.

V. Day of Discharge

You should meet the consumer at the facility to review the discharge instructions. You should then meet the consumer at his/her home to make sure that they get settled in.

VI. Follow-up

Follow-up after discharge will really depend on the consumer's desires. Sometimes a consumer will want you to meet with them on a weekly basis to assist them in getting adjusted to community living.

X. Timeline of Activities For Transition

A. Planning Activities

Two to Three Months Prior to the Move

1. Determine scope of planning.
2. Decide PCP methods.
3. Initiate PCP.
4. Identify possible barriers, e.g. outstanding bills, substance abuse problems, etc.

One Month Prior to the Move

1. Review PCP
2. Create to-do lists for the consumer and Coordinator.
3. Start contact person/phone list.

One Week Prior to the Move

1. Review PCP & update to-do list
2. Review move schedule
3. Develop emergency contact list, copy to key people

One to Two Days Prior to the Move

1. Make shopping list for food and personal items. Determine who will do the shopping.
2. Review move schedule and update to-do list.

Day of the Move

1. Meet at facility to review discharge instructions with the consumer.
2. Update to-do list

First Week After the Move

1. Review PCP and outcomes.
2. Revise plans as appropriate.

First Month After the Move

1. Review & revise PCP
2. Confirm duties with other providers
3. Determine follow-up schedule (e.g. 2 visits/month)

B. Health

Two to Three Months Prior to the Move
1. Create list of supplies and medical equipment needs
2. Complete OT evaluation and order equipment &/or seek funding.

One Month Prior to the Move
1. Set up community doctor appointment for 1-3 days post discharge.
2. Determine source and procedure for obtaining med. supplies. Find out how soon order can be placed.

One Week Prior to the Move
1. Assure timely delivery of supplies and equipment
2. If hospital bed is required, set up delivery date.
3. Change address with established doctors and Medicaid/insurance company.

One to Two Days Prior to the Move
1. Confirm delivery of supplies, etc.
2. Select pharmacy
3. Obtain & fill prescriptions.

Day of the Move
1. Obtain discharge instructions.
2. Obtain from facility medications and supplies
3. Review emergency contact list & procedures

First Week After the Move
1. Make appointments for medical follow-up care (dental, optical, etc.)

C. Housing

Two to Three Months Prior to the Move
1. Review type of housing, location and other preferences.
2. Locate housing.
3. Get on waiting lists.
4. List needs (furniture, supplies, etc.).
5. Begin looking for resources.

One Month Prior to the Move
1. Solicit donations for needed household items and furniture.
2. Involve consumer and other support people in securing items.
3. Complete change of address with post office.

One Week Prior to the Move

1. Involve consumer in setting up utilities and phone service
2. Notify SSA, FIA, Medicaid worker, bank, etc of address change.
3. Move belongings, if possible.
4. Review and prioritize what is still needed.

One to Two Days Prior to the Move

1. Confirm utility and phone hook-ups.
2. Buy phone, if needed. Ensure phone service is working.

Day of the Move

1. Assist consumer in setting up home. Involve as many support people as possible.

First Week After the Move

1. Work with consumer and landlord to resolve any housing problems.

First Month After the Move

1. Follow-up to ensure rent and utilities payments.

D. Transportation

Two to Three Months Prior to the Move

1. Apply for public transportation ID
2. Explore options for transportation training.
3. Use public transportation

One Month Prior to the Move

1. Make arrangements for transportation from NH to home.
2. Check on status of ID card.

One to Two Days Prior to the Move

1. Confirm discharge transportation

First Week After the Move

1. Follow-up with transportation training. If not available, make other arrangements, e.g. peer trainer.

First Month After the Move

1. Follow-up on transportation issues.

E. Daily Living

Two to Three Months Prior to the Move

1. Determine which tasks will require assistance.
2. Determine if consumer is maximally independent. If not, Plan for training & therapies.

One Month Prior to the Move

1. Assist consumer in determining hours of assistance required. Select care providers.
2. Contact FIA and schedule evaluation for Home Help services.
3. If any unmet equipment needs, seek funding from FIA PDS fund.

One Week Prior to the Move

1. Determine PA Schedule. Make list of PA tasks with consumer.
2. Finalize arrangements with FIA and providers.
3. Food stamp application

One to Two Days Prior to the Move

1. Confirm initial visits and schedule with PAs
2. Obtain keys for PAs
3. Obtain food and personal items adequate for several days. (Check food banks.)

Day of the Move

1. Review emergency procedures and back up plans with consumer.

First Week After the Move

1. Assist consumer in problem-solving situations.

First Month After the Move

1. Review caregiver needs; plan for changes as appropriate.

F. Personal Finance

Two to Three Months Prior to the Move

1. Get SSA report to determine income post discharge.
2. Assess other income
3. Identify personal debts
4. Develop personal budget.

One Month Prior to the Move

1. Resolve personal debts.
2. Determine money that will be required for the move and seek community resources.

One Week Prior to the Move

1. Notify SSA, MA, MC, FIA of address change
2. Review budget.
3. Set up bank account near community home.

One to Two Days Prior to the Move

1. Set up automatic deposit for SSI/SSDI checks. (1-800-772-1213).

Day of the Move

1. If possible, have some cash available for unforeseen expenses.

First Week After the Move

1. Review & adjust budget.

First Month After the Move

1. Assist consumer in paying first month's bills.
2. Review & adjust budget as needed (e.g. monthly for 3-6 months).

G. Social/Recreation

Two to Three Months Prior to the Move

1. Begin community activities. Seek to build community relationships (e.g. places of worship, clubs, friends).
2. Consider CIL peer support.

One Month Prior to the Move

1. Continue community activities. Expand to other places.

One Week Prior to the Move

1. Continue activities, peer support.

Day of the Move

1. Assist consumer in meeting neighbors and community support persons.

First Week After the Move

1. Continue to support community relationships and activities.

First Month After the Move

1. Continue and expand community relationships.

H. Employment

Two to Three Months Prior to the Move

Introduce as a possible planning issue.

First Month After the Move

1. Investigate work and volunteer options
2. Make Vocational Rehabilitation referral.

XI. Developing a Safety Plan

A. Fictitious Example of Safety Plan, "John"

CONCERN	RESOLUTION
Safety in case of fire	Staff will verify that working smoke detectors and fire extinguishers are located in John's home; attendants will be trained on how to evacuate John in case of an emergency; John and his wife have already received training on fire safety and evacuation procedures; fire department has been notified that an individual with a mobility impairment resides in the house
Unsteady balance	John's wheelchair will be equipped with a harness, seatbelt and side supports on upper half for extra stability. John will have a two-person transfer by trained staff
Safety in the kitchen	Attendants and his wife will cook meals and clean kitchen
Risk of aspiration and food allergies	John will be given the time to eat safely; wife does not buy food that John is allergic to; attendants to be briefed on John's allergies; attendants and wife understand aspiration precautions; John can identify which foods he is allergic to; CHN will listen to John's lungs and monitor for signs of aspiration or aspiration pneumonia;
John cannot be left alone	John will receive 24-hour supervision/assistance by trained staff, friends or family members
Back-up plan for 24 hour supports	John's wife is able to supervise and assist with John's care; John is very likeable which promotes attendants' commitment to working with him; attendants will be required to remain with John until someone else is available to assist him; attendants can assist John in securing a replacement; trained staff from CDR is available to go to John's in an emergency; for an after-hours emergency, friends trained in his care who live within 3 minutes from John's home will assist; John has an emergency contact list
Numerous medications	Generic meds will not be used to avoid meds that look alike; a CHN will prepare a weekly medi-set; John, his wife, attendants, and other staff have been trained on proper medication administration

Dosage of blood pressure medication dependent on blood pressure reading	Attendants and staff to be trained on using the blood pressure monitor and will check John's blood pressure; training on proper dosage will be developed with doctor's input; John's wife, attendants, and staff will be provided with specific training on proper medication dosage; John's wife has a cell phone and can assist in answering medication questions if needed; CHN will review record of blood pressure readings and check vital signs
Medication allergies	John's wife, attendants, and staff will be informed as to what medications John is allergic to; doctor will not write prescriptions for any meds that John is allergic to; wife, attendants, and staff will be instructed to call John's doctor in case of any reactions to medications
Bones break easily	John will have a 2-person transfer for his personal safety; John and his wife are very familiar with proper transferring procedures and can direct attendants and staff; attendants and staff will be given specific training on proper transfers; attendants and staff will be instructed to assist him slowly and ask yes/no questions to verify that they are assisting him correctly
Risk of skin breakdown	Attendants will be given specific training on transferring and positioning John; attendants will be trained to assist John in monitoring his skin; John will have an air mattress for his bed; John will have a "RoHo" cushion on his wheelchair to reduce pressure on his skin; CHN will provide additional oversight with monitoring John's skin for breakdown

STATE OF NEW YORK
DEPARTMENT OF HEALTH

Office of Continuing Care 161 Delaware Avenue Delmar, NY 12054

Antonio Santi, M.D., M.P.H.
Commissioner

Dennis P. Wall
Executive Deputy

Fictitious Plan of Protective Oversight

Name: David Cool

Phone #: 458-5555 (HOME)

Address: 30 North Ocean St.
Rochester, NY 14600

CIN #: AD444444

Date Submitted: October 2002

[X] Original Plan for Protective Oversight
[ ] Revision of Plan for Protective Oversight
[ ] No change since last submission

Information about Anyone Listed in this Plan for Oversight

Name: David Cool Relationship: consumer **Phone (home)** 458-5555

Name: Darla Cool **Relationship:** wife **Phone(home)** 458-5555 **(work)** 546-4444
Cell (585) 230-2222 **Pager** (585) 939-0000

Name: Jane Abraham **Relationship:** Service Coordinator **(work)** 546-4444
Service Coordination Emergency Pager (585) 939-0000

I. Finances

a. **Can waiver participant mange his/her own finances?** [ ] Yes [X] No

b. **If the waiver participant needs assistance with his/her finances, who will provide the assistance?**

1. **ATM:** Darla Cool
2. **Banking:** Darla Cool
3. **Bill Paying:** Darla Cool

4. **Budgeting:** Darla Cool

5. **Checking:** Darla Cool

c. **Does the waiver participant request a Representative Payee? [ ]Yes [X] No If so, who will act in this capacity?**

II. Fire and Safety

a. **Can the waiver participant use the various means of egress in his/her home?**
[ ] Yes [X] No

b. **If not, have other arrangements been made to assure that the waiver participant can be as safe as possible in case of a fire?**
[X] Yes [ ] No [ ] Not applicable

Please list all of these extra precautions:
David and Darla have both been disabled throughout their lives. Because they could not quickly egress their home they have learned how to address fire safety issues long before David's stroke. They both realize that they cannot evacuate as quickly as an able-bodied person, so they have taken every precaution for their safety. They have smoke detectors and a fire extinguisher. David's attendants will be trained on how to evacuate David in the event of a serious emergency. The Emergency Transfer and Evacuation Plan is attached to this document.

c. **Does the waiver participant have a tendency to be unsteady in his/her balance?**
[X] Yes [ ] No

If yes, what measures have been taken to decrease the probability and/or sequlae of his/her falling within the home?
David will spend most of his time in a Quickie T45 wheelchair, equipped with a harness, seat belt, and side supports on the upper half, for extra stability. He will have a two-person transfer by trained staff.

d. **Is the waiver participant safe within the kitchen? [ ] Yes [X] No**
If not, what activities may be unsafe for the waiver participant
David will not be able to cook meals or clean up the kitchen afterwards. Attendants

and Darla will be cooking his meals and cleaning the kitchen. ILST will help set up a training plan, so HCSS can help David with ideal meal planning and eating safely. A copy of his Aspiration Precautions has been attached to this document.

What actions have been taken to increase the likelihood that the waiver participant will be as safe as possible in the kitchen?
Attendants, HCSS, and Darla will be cooking David's meals and cleaning up the kitchen. David does have several food allergies, such as peaches, pears, nectarines, apricots, and peas. Avoiding these foods will not be difficult. Darla doesn't buy these foods or keep them in the house. Attendants will be fully briefed on David's allergies. David also will play a significant role in this area. While in the hospital, David has refused to eat foods that he is allergic to.

III. Emergency Plan for Usually Unstaffed Time

Although the waiver participant's need for supervision has been assessed and dealt with more fully in other sections of the Service Plan, there may be emergencies during the time when there is no immediate unpaid or paid support.

a. Is the waiver participant receiving 24-hour supervision? [X] Yes [ ] No
This is provided by: [ ] Paid staff only
[X] A combination of natural and paid staff
[ ] Natural supports only

b. If there is the need for 24-hour supervision, is a back-up plan for supports clearly defined and included in the Service Plan? [X] Yes [ ] No

David's wife, Darla, is his primary caregiver and the backbone of this plan. In the hospital, Darla has been able to offer specific advice and information on effectively and safely assisting with David. David points out that Darla has helped the hospital avoid making additional mistakes that could have injured him further. Although Darla uses a motorized wheelchair and has some significant physical limitations, she is still able to supervise and assist with David's care. Even with only one attendant, (although it would be difficult) Darla could effectively clean David after a bowel movement. She is deeply committed to her husband and his safety.

Generally, CDO's experience that CDPAS participants have more consistent coverage than people enrolled in traditional home health care. The CDPAS program offers other features that address "back-up." The attendants who assist David will be fully trained and proficient with positioning and transfers. This small group of individuals will be scheduled with enough "regular hours" so they will have regular full-time employment and develop a commitment to working with

David. CDO is requesting an enhanced rate for CDPAS, which will allow the attendants to be paid a wage, will make a long-term commitment more likely. Attendants will be expected to remain with David until their replacement arrives. The attendant who is working with David can assist him in securing a replacement if needed.

David is a popular person with CDO consumers and staff, as he was very involved in the organization. CDO staff is highly motivated and willing to help David whenever he needs assistance. During business hours, there will be various trained staff available to go to David's home for assistance within minutes if necessary. In an after-hours "emergency" situation, there is HCSS staff available to assist David. Two HCSS staff trained in proper transfers and care, live within three minutes of David's home and have agreed to assist.

c. **If the waiver participant does have time when he/she will be alone, who will be contacted in case of an emergency? (Please list in order of who will be called. This list should be prominently displayed by the telephone in the waiver participant's home).**

It should be noted that David would **NEVER** be alone. Attendants will be instructed that they cannot leave David until their replacement arrives. The contacts listed below are available for staff in case of an emergency or questions.

Name	Telephone Number	Relationship
Darla Cool	(Work) 546-2222 (Cell) 230-0000 (Pager) 939-0222	Wife
Jane Abraham	(Work) 546-3333	Service Coordinator
Emergency Pager	(585) 452-4343	CDO
Bruce Springfield	(Work) 546-7788 (Home) 392-4454 (Cell) 370-3535	Natural Support

d. **Does the waiver participant have a Personal Emergency Response System?**
[] Yes [X] No
David does not have a PERS, but his wife Darla is currently looking into obtaining one for David's use. Because David has 24-hour attendant services, he will not be unattended. CDO is exploring a $30 device that will allow him to call for assistance within the house if the attendant is in another room because she is

cooking, doing laundry, or letting him sleep undisturbed. David is willing to use a PERS if it is determined that one is advisable.

e. **Are there any other systems/devices/supports that have been provided to the waiver participants for safety purposes?**
Darla and CDO staff are developing a detailed training manual for working with David which will assure that the attendants/HCSS staff who work with him have been effectively oriented and have a resource to refer to.

The commitment of David's family and friends has been demonstrated throughout his lengthy hospitalization. This network of support has shown it will do everything necessary to assist David in maintaining his safety and securing his freedom.

IV. Medication Administration

a. **Is the waiver participant presently taking prescribed medication?**
[X] Yes [ ] No

Attendants and staff will be provided with a medication list and the times that he needs to take them. Generic medication will not be used to avoid medications that look alike. The doctor will be asked to write, "Dispense as written" on the prescriptions. David will have a medi-set prepared by a Community Health Nurse. After a transition phase, this function will be transitioned to his wife.

David's blood pressure medication is dispensed based on his blood pressure reading. David will need to have his blood pressure checked often – eight times in a 24-hour period. Attendants and staff will be trained in using the blood pressure monitor and will be provided with specific instructions to follow. They will review the reading with David. Together they will determine the appropriate amount of medication, may contact Darla or the doctor, or call 911 depending on the reading. These materials will be prepared in conjunction with David's doctor.

David is allergic to codeine and morphine and should not take them under any circumstances.

b. **Is the waiver participant able to consistently take his/her medication independently? [ ] Yes [X] No**

David will need physical assistance with taking his medications. He is aware of his medications and knows when he needs to take them, he is just not able to physically taken them independently, at this point in time.

c. **If assistance is needed, what type of cueing is needed, including both visual and verbal cues?**
David will need to have physical assistance with taking the medication. However, he will not require verbal cueing or visual assistance.

d. **Does the waiver participant have assistance with pre-pouring of the medication?**
[X] Yes – Who provides this assistance: CHN/Darla Cool
[ ] No – If no, should this be considered?

e. **Who will the natural or paid staff contact in case there is concern about the waiver participant's reaction to medication or if the waiver participant is not taking his/her medication as directed?**

Name	Relationship	Phone
Darla Cool	Wife	(W) 546-2222(Cell) 230-0000 (Pager) 939-2323
Dr. Gordon Payne	Personal Physician	271-2899 (Cell) 764-3636

f. **Who will the natural or paid staff contact if the waiver participant's food intake decreases or increases noticeably?**

Name	Relationship	Phone
Darla Cool	Wife	(W) 546-2222 (Cell) 230-0000 (Pager) 939-2323
Dr. Gordon Payne	Personal Physician	271-2899 (Cell) 764-3636

Additional Comments:
**It should be noted that due to David having Osteogensis Imperfecta, or brittle bone disease, and that he has not regained strength in his limbs. David will need a two-person transfer for his personal safety. David and Darla are the best resources to manage all transfers and direct what can or cannot be done when moving/transferring David. David has lived with this disability his whole life and Darla has been married to David for 18 years. They are both familiar with transfer techniques and how to physically handle David without causing bone breakage. A CHN will be available to assist David and his wife with medical oversight and to answer questions as needed.

Signatures of Individuals Participating in the Plan for Protective Oversight

Waiver Participant ______________________ **Date** __________

Advocate/Representative ______________________ **Date** __________
(when applicable)

Service Coordinator ______________________ **Date** __________

Service Coordinator Supervisor ______________________ **Date** __________

Natural Support ______________________ **Date** __________

Natural Support ______________________ **Date** __________

Regional Resource Development Specialist

[ ] The information provided in this Plan for Protective Oversight documents that the Waiver Participant's health and welfare is being maintained and that he/she is not at risk for nursing home placement;

[ ] The information provided in this Plan for Protective Oversight raises serious concerns about the Waiver Participant's health and welfare. A Plan for Protective Oversight must be submitted to clarify concerns about the Waiver Participant's ability to remain in the community.

Signature: ______________________

Print Name: ______________________

Title: ______________________

Date: ______________________

This plan for Protective Oversight must be readily accessible to all staff and natural supports. This Plan must also be submitted to the Regional Resource Development Specialist with all Service Plans, and reviewed, at least every six months by the Service Coordinator. If there are incidents or concerns that arise which are directly related to the areas covered by the Plan for Protective Oversight, then that Plan should be reviewed immediately.

B. Fictitious Safety Plan, "Mary"

CONCERN	RESOLUTION
Risk of falling	Mary and staff will eliminate conditions in her apartment which can contribute to falls; staff will work with the Physical Therapist to identify adaptive equipment which could minimize risk of falls; Mary will not attempt to ambulate or transfer alone and will have one-on-one assistance will all ambulation and transferring; PERS necklace in case of emergency; female urinal will be kept near Mary's bed should she need to urinate while no one is present to help her
Recommendation of 24 hour care	Mary will utilize a variety of services and informal supports that will provide her with 24 hour supports/services including Consumer Directed Attendant Services managed by a Self Directing Other, Residential Habilitation, a recreation Drop In Center, dialysis, bingo, and her neighbors
Back-up services	Attendants and staff will be expected to remain until their replacement arrives; Attendants will check-in with Mary's neighbor when the arrive for their shift; Mary's service coordinator will be notified of any time that Mary is without an attendant or staff person and will arrange coverage
Management of medications	Generic medications will try to be avoided to avoid meds that look alike; All staff involved with Mary will have a listing of her meds and be updated of any changes; CHN will draw up medi-set and pre-draw injections; staff will monitor all of Mary's medications; CHN created a chart of her meds, gluing the actual pills to the chart and reviewed them with Mary; Mary will practice naming and identifying pills on the chart and comparing them to pills in her medi-set; Initially, staff will review medications with Mary every time she takes them; CHN agrees that after Mary has successfully indicated which medications she takes by time of day and selected the correct medications from among the pills for two weeks, strict oversight will be withdrawn; after Mary is able to manage her own meds, staff will check medi-set each day to determine she has taken the correct box of meds; while Mary is at her day program, staff will witness Mary taking her meds at the scheduled times and review the rest of the day's medications with Mary.

Diabetic monitoring	Mary has been giving herself injections for years and the hospital will retrain Mary to give her own injections; CHN will monitor on an ongoing basis; blood glucose will be monitored regularly and a log will be kept; CHN will review log and log will be shared with doctor at regularly scheduled visits; new blood glucose testing system will be obtained so Mary can test on a less sensitive part of body; health care team will develop protocols to respond to too high or too low blood glucose levels; staff will work with Mary to identify warning signs of high or low blood glucose levels and verify she knows how to respond; staff will accompany Mary to nutritionist appointments and review recommendations with Mary; staff will help Mary share this information with her other service providers; staff will help Mary to try new foods that are on her diet; staff will take Mary shopping for groceries and support her with making better food choices; staff will offer Mary emotional support.
Personal Hygiene	Mary will obtain enough service hours so that the attendants can adequately assist her with managing her personal hygiene; Mary will have a hand-held shower head to make it easier to thoroughly wash her body; Mary, her Self-Directing Other, and staff will prepare an activity list for attendants.
Difficulty in controlling emotions/Risk of losing attendants	Close monitoring of blood glucose levels should address issues of low blood sugar; Staff will work with Mary to identify people she can call when she is upset; staff will work with Mary to better understand grievance procedures regarding her attendants so that issues can be resolved effectively; staff will work with Mary on managing and minimizing her frustration level; people that Mary trusts and listens to very closely will be used to explain the plans to Mary.
Safety in case of fire	Mary's apartment is equipped with firewalls, sprinklers in every room, and has two smoke alarms; the fire department has been informed of Mary's status; Mary has an alarm immediately outside her apartment which rings loudly throughout her complex; alarm system directly notifies the fire department and unlocks her front door; Mary has a PERS; if with an attendant, the attendant will assist Mary with transferring to her wheelchair and evacuating the apartment; Mary has two exits in her apartment

Background

Mary Jones is a 67-year-old woman who has a visual impairment and renal failure secondary to diabetes mellitus, obesity, a seizure disorder, and moderate mental retardation. Mary's gait has become increasingly unsteady because of diabetic neuropathy and spinal stenosis. She has had an increasing number of falls over time, some with injury.

On October 15, 2002 Mary fell at approximately 6:25 AM while attempting to get out of bed to go to the bathroom. Although she is on a fluid restricted diet, Mary typically needs to use the bathroom when she awakens in the morning. Without an aide available to assist her, she tried to walk to the bathroom without assistance rather than urinate in her bed. Mary used her Personal Emergency Response System (PERS) to get emergency assistance and was taken to Strong Memorial Hospital where she underwent surgery which "pinned" her broken hip. Mary remained at Strong Memorial Hospital while she waited for attendant services to be set up for her. On February 4, 2003 she was transferred to the Alternative Level of Care (ALC) unit at Highland Hospital.

Due to spinal stenosis and diabetic neuropathy, it is anticipated her skill in ambulation and transfers will decline over time. Additionally, the frequency of her seizure disorder has increased since she started dialysis, even while she has been in the hospital. Due to these conditions, Ms. Jones requires assistance with walking and is at risk of falls and injury.

General Overview

CDR staff have prepared this Plan of Protective Oversight to assist in the development of a safe discharge plan for Mary to return to her own apartment. Mary's medical team has stated that she needs assistance 24-hours a day. A coordinated system of supportive services has been developed to meet her needs and allow her to live in her own apartment.

The plan addresses the following issues:
1. Coordinated Supports
2. Monitoring and Backup Plan
3. Safety and Mobility
4. Medications
5. Diabetic Monitoring and Diet
6. Personal Care
7. Communication
8. Finances
9. Fire Safety Plan
10. Other Emergencies

Coordinated Supports

Mary will have assistance 24-hours a day with an extensive back-up system in place. Under this plan, Mary is either at a specific medical or social service provider site or covered by paid CDR staff and attendants. Several layers of formal and informal supports are in place to provide back up as well. Mary will not be alone at any time. To assure that staff will be told they can not leave her alone if the next shift does not arrive. Attendants and CDR staff will be clear that leaving Mary without coverage will be grounds for immediate termination as either a CDR staff person or CDPAS attendant.

The supports Mary receives will include attendant services Consumer Directed Personal Assistance Services-CDPAS), Residential Habilitation and Day Habilitation services from the Center for Disability Rights, and dialysis from Strong Memorial Hospital. These services will be arranged and monitored by her OMRDD Medicaid Service Coordinator, provided by the Center for Disability Rights.

The schedule for assistance she receives will be based on the following model day schedules listed below.

Monday, Wednesday, and Friday

Mary typically wakes at 6:00 AM. On these days, the attendant will get Mary ready for her day. Mary will receive assistance with her blood glucose testing/monitoring, preparing and eating breakfast, and taking her morning medications. The attendant will provide Mary with assistance to her Liftline ride.

Mary will arrive at the Center at 9:00 AM and she will remain there until 2:30 PM. CDR Day Hab staff will provide her with assistance into the building. While at the Center she will have staff supports and receive assistance with her blood glucose testing/monitoring, afternoon meal, medications, and medical oversight. She will receive Day Hab and Recreation Services there. She will leave the Center and the Medicab driver will assist her to his vehicle and transport her to dialysis at Strong Memorial Hospital.

After dialysis, the Medicab driver will assist Mary to the vehicle and transport her home where her evening attendant will meet her. The attendant will assist her in preparing and eating her evening meal. Mary will get ready for bed and the attendant will remain with her to assist during the night.

Tuesday and Thursday

Mary typically wakes at 6:00 AM. On these days, the attendant will get Mary ready for her day. Mary will receive assistance with her blood glucose testing/monitoring, preparing and eating breakfast, and taking her morning medications. The attendant will provide Mary with assistance to her Liftline ride.

Mary will arrive at the Center at 9:00 AM and she will remain there until 8:00 PM. She will have staff supports all during this time. While at the Center she will have staff supports and receive assistance with her blood glucose testing/monitoring, afternoon and evening meals, medications, and medical oversight. She will leave the Center and receive assistance to the Liftline vehicle which transports her home. At home she is met by the evening attendant who assists her to her apartment, helps her prepare a healthy snack, and gets her ready for bed.

Weekends

Even on weekends, Mary typically wakes at 6:00 AM. On these days, the attendant will get Mary ready for her day. Mary will receive assistance with her blood glucose testing/monitoring, preparing and eating breakfast, and taking her morning medications. At 9:00 AM, Mary's CDR Residential Habilitation staff arrive. Mary's Res Hab staff work with her until 12:00 noon when attendant arrives at noon. Res Hab staff will assist her with blood glucose testing/monitoring, preparing and eating her afternoon meal, medications, and medical oversight. Attendant service resume at 12:00 noon and the attendant will assist Mary with her with blood glucose testing/monitoring, preparing and eating her evening meal, and taking her remaining medications.

	Sun	Mon	Tues	Wed	Thurs	Fri	Sat
Midnight	Attendant Services	Attendant Services	Attendant Services	Attendant Services	Attendant Services	Attendant Services	Attendant Services
1:00 AM							
2:00 AM							
3:00 AM							
4:00 AM							
5:00 AM							
6:00 AM							
7:00 AM							
8:00 AM							
9:00 AM	CDR Res Hab	CDR Day Hab Program	CDR Day Hab Program	CDR Day Hab Program	CDR Day Hab Program	CDR Day Hab Program	CDR Res Hab
10:00 AM							
11:00 AM							
12:00 PM	Attendant Services						Attendant Services
1:00 PM							
2:00 PM							
3:00 PM		Strong Dialysis		Strong Dialysis		Strong Dialysis	
4:00 PM							
5:00 PM							
6:00 PM		Attendant Services		Attendant Services		Attendant Services	
7:00 PM							
8:00 PM			Attendant Services		Attendant Services		
9:00 PM							
10:00 PM							
11:00 PM							

Monitoring and backup plan

This plan monitor's Mary's coverage and assures adequate backup to prevent her from being left alone. Monitoring Mary for changes in mental status are also included here. Because a change in mental status may have a variety of causes, monitoring her mental status is included here rather than in other specific parts of this oversight plan.

Monitoring Coverage

Mary's neighbor Joe Santacesaria will monitor the attendants and track the times that the attendants arrive to sign in and sign out when they leave. **In the event that Joe is not home, a clipboard will be posted outside of his apartment with instructions to call the SDO and also the on-call Service Coordinator and let them know they have arrived**. This will help verify that the attendants are arriving on time and covering their full shift. If an attendant tries to sign out before the next shift arrives, the attendant will be instructed that she can not leave and will be reminded that leaving Mary alone is grounds for immediate termination. Should an attendant attempt to leave or leave before the end of their shift, or there are any anticipated coverage problems, Joe will contact the emergency pager and notify CDR Case Managers, Community Support Coordinators, and the SDO, allowing CDR and the SDO to intercede immediately if there is a problem. It is expected that Mary will also make this notification, but Joe will always do this to assure that notification is made.

CDR Case Managers, Community Support Coordinators, and the SDO will also make weekly "spot-checks" of the attendants and Res Hab staff to assure that they are on site and working with Mary. Unannounced calls and visits to Mary's apartment will reduce the risk of attendants and staff leaving Mary unattended during their shifts.

Prior to Mary leaving Day Hab on Tuesday and Thursday evenings, CDR staff will verify that the attendant has arrived to assist Mary. The attendant may meet her at the Center or "call-in" from a neighbor's house to indicate she is there. If the attendant is not available to assist Mary, Day Hab staff will go to her home and assist her until a staff person or attendant arrives.

Backup

Mary's neighbor will know immediately if there is a problem with attendants because they sign in and out at his apartment. If an attendant does not come in to sign in on a sheet, Joe will immediately verify that Mary has coverage and then make the required notifications. If Mary has been left alone, Joe will remain with Mary until backup coverage arrives. Joe will immediately contact the SDO, Adele Carlson, the emergency case management pager, and the Community Support emergency pager.

Attendant leaves or is "no-show"

In addition to informal support from Mary's neighbor, Adele Carlson will immediately go to the apartment. She will try to secure a backup attendant and providing coverage until another attendant is in place.

CDR Case Managers and Community Support Coordinators and their staff will also be "on-call" to assist in this instance as well. Several CDR staff live in Mary's neighborhood and can be called by our on-call staff to provide backup assistance as well.

Changes in mental status or medical condition

Mary typically speaks to Adele each day and will be seen by trained CDR staff everyday of the week. In addition to this monitoring, any change in mental status or medical condition will be immediately reported to the emergency case management pager and the SDO. Staff and attendants will be instructed to make this notification if Mary seems unexpectedly sleepy, tired, lethargic, irritable, confused or unresponsive. Additionally staff and attendants will make this notification if she has any changes in her speech or vision, suddenly awakens at night, is experiencing new numbness or dexterity problems, begins sweating for no apparent reason, a headache, or has a seizure. CDR case management staff and the SDO will work with the attendant or staff person to identify the appropriate course of action. If Mary becomes unconscious or have chest pains, the attendant or staff person will first contact 911 and then contact the emergency case management pager and the SDO.

Safety and Mobility

The greatest risk to Mary's safety at home is the risk of fall. Over the past two years the incidence of falls has steadily increased. To address this risk CDR staff have developed the following plan:

1. Eliminate conditions in Mary's apartment which can contribute to falls.
2. Identify adaptive equipment which could reduce the risk of falls.
3. Provide one-on-one assistance with all ambulation or transferring to reduce the risk of falling.

Eliminate conditions in Mary's apartment which can contribute to falls.

CDR staff reviewed Mary's apartment to identify conditions that might lead to potential falls. While Mary is awaiting a final discharge plan, CDR staff will work with Mary to reduce the clutter in her apartment. They will work to assure that Mary has clear and firm paths of travel. They will help her purchase storage units, which will allow her to keep many of her precious possessions without sacrificing safety. CDR staff have lowered Mary's bed to a height that will give her the most stable transfer from bed to wheelchair.

Identify adaptive equipment that could reduce the risk of falls

CDR will work with the Physical Therapist to identify a shower bench/chair for Mary's home bathtub that will assist in making her transfers safer. CDR staff will work with the Physical Therapist to identify other equipment that could be put in place to reduce the potential for falling, including grab bars.

One-on-one assistance with all ambulation or transferring to reduce the risk of falling. The most significant change will be that Mary will always use assistance when she walks anywhere. Mary has typically fallen when she was alone and needed to use the bathroom. In fact, she broke her hip while trying to get to the bathroom (at a time that she should have had attendant services through Visiting Nurse Service). While Mary was in Strong Memorial Hospital, the nursing staff worked with training Mary to use a female urinal so that she could go to the bathroom independently. CDR staff have also worked with her to reinforce that she can not independently get out of bed or she risks breaking her hip again and going into a nursing home.

While preparing for her discharge CDR staff will assist Mary in getting a phone for her bedroom and preparing lists of important telephone numbers written in large legible print by both phones. In the rare event she was unable to use the phone, she has a PERS necklace that she wears at all times. Mary will be able to call for assistance from her SDO, in the event that she is unable to use the telephone. Mary has shown that she can use the PERS to summon help in an emergency. This will be an additional safety measure, because Mary will be scheduled to have coverage 24-hours per day. CDR case managers and the SDO are identified as the emergency contact for the PERS system as well.

Medications

Mary has been able to manage her medications for 30 years with some basic support. She has been able to recognize her medications by appearance (color, shape, and size) and give a general description of the medication's purpose, although she is not always able to give the exact name of every medication. Mary is able to use a "mediset" and can take her medications at the appropriate times. Given the extended stay in the hospital, she will probably need some support in relearning and enhancing these skills because her medications have changed while she has been in the hospital. To assure that Mary is able to manage her own medications, this plan describes:

1. The procedures for providing oversight to Mary's medications while she learns the new medication regime.
2. The methodology for teaching her the information and skills she needs to be fully self-medicating.
3. The assessment for determining when the strict monitoring can be reduced to general oversight.
4. The protocols for making changes in the medications.

Medication oversight plan

All of Mary's medications will be prescribed "Dispensed As Written." When this is unavailable, Mary's Service Coordinator will work with the pharmacist to find generic medications that will be recognizable by appearance. The Community Health Nurse

(CHN) will set-up the mediset as directed by the Primary Care Physician. The CHN will also pre-draw Mary's insulin and Lovenox. Upon Mary's transition back to the community, CDR staff will monitor all of Mary's medications. They will verify that she has selected the correct box from her mediset and taken the correct medications.

Medication training

Mary's CHN from Visiting Nurse Service had created a chart of her medications, gluing the actual pills to a chart so that they could be reviewed with Mary and helping her easily identify the pills by size, color and shape. CDR will update this chart for Mary when she is discharged. During the initial transition, CDR staff who are monitoring her medications will review the chart with Mary. Mary will repeat the names of the medications and the frequency she takes the pills. Mary will again repeat the names of the pills and identify them as she takes each of the pills. She will be asked to compare what she is taking to her chart. Each day at Day Hab, Mary will also review the chart of her medications and practice naming and identifying them.

To facilitate her return to the community, medication training can begin while Mary is in the ALC unit. Hospital staff can review Mary's medications with her every time she takes them.

Assessment for Independence

The Community Support Coordinator will assess Mary to determine when strict oversight of her medications can be withdrawn. Mary will be given her mediset, asked to indicate what medications she takes by time of day (i.e. morning pills, lunchtime pills, and evening pills) and asked to select the correct medications from among the pills in her mediset. When Mary has successfully done this for two weeks, strict oversight will be withdrawn.

Ongoing medication monitoring

After it has been determined that Mary is able to manage her own medications with support from the attendant, she will still have her mediset filled by the CHN and her morning medications will be monitored by the attendant. CDR staff, however, will not oversee every dose. Mary will bring her mediset to her Day Habilitation program during the week. While at the program, Day Hab staff will check the mediset to make sure Mary has taken the correct box of medicines that morning. Day Hab staff will witness Mary taking her medicines at the scheduled times while she is at program and will also review the rest of the day's medications with Mary to make sure she knows what to take and when.

Changes in medications

At any time when Mary's medications change, she will again return to strict monitoring until she is again assessed as independent.

Medication List

Taken by mouth:

Nephrovite (multi-vit)	1 tab every AM (8AM)
Norvasc	5 mg every AM (8 AM)
Dilantin	200 mg twice every day (8 AM & 9PM)
Senna	2 tabs twice a day (8 AM & 9 PM)
Phenobarbital	150 mg twice a day (8 AM & 9 PM)
Zantac	150 mg twice a day (8 AM & 9 PM)
Calcium Acetate	1334 mg (2-667 mg tabs) with meals everyday (8 AM, 12 Noon, 5PM)
Doxaziusin Mefylate	10 mg at bed time (9 PM)

By injection:

Lovenox	30 mg every morning (8 AM)
Insulin NPH Regular 7/30	15 units, every morning after a blood glucose level check

Person(s)to be notified of concerns regarding medications

MD
Strong Memorial Internal Medicine
(585) 222-5555

Service Coordinator (CDR)
(585) 222-4444
After-hours contact (585) 222-6666

Service Coordination Supervisor (CDR)
(585) 222-7777

Community Health Nurse (TBA)

Diabetic Monitoring and Diet

Mary is an insulin dependent diabetic, and is on a diabetic, low-fat, 1200cc fluid restricted diet to maintain proper blood glucose levels. Mary's PCP will be consulted for advice related to testing equipment, its schedules, and goals. Mary has been giving herself injections for years. The hospital can retrain Mary to give her own injections and CHN will monitor her on an ongoing basis. Mary's blood glucose will be monitored regularly. Prior to her most recent hospitalization, Mary regularly tested her blood glucose once daily. CDR recognizes that as we work to achieve tighter blood sugar control, Mary is at greater risk for hypoglycemia. CDR is initially recommending that she test her blood glucose levels every morning prior to insulin injection and then check it at noon and before bed. CDR will work with Mary's medical team to determine if this frequency is sufficient. Should more frequent testing be recommended, CDR will implement that schedule.

With assistance of the hospital and her service coordinator, Mary is looking into new testing equipment, such as the One Touch Ultra Blood Glucose Monitoring System which would allow Mary to test on a less sensitive part of her body, like her arm. Mary's blood glucose levels need to remain within a normal range, a log of results will be maintained. Each day a CDR staff person (either through Day Habilitation or Residential Habilitation) will review the monitor and chart the electronic memory variables into a logbook. Staff and attendants will also log her activity levels and food intake. This log will be reviewed by the CHN when she fills Mary's syringes and shared with the doctor at regularly scheduled visits.

CDR will work with Mary's Primary Care Physician to determine an approach which could provide tighter control of Mary's diabetes. The health care team will also develop specific protocols to respond to either high or low blood sugar levels, including emergency procedures for low blood sugar and protocols for contacting a health care professional.

Early hypoglycemia can be recognized. Mary's attendants and staff will be trained to identify the signs and symptoms of hypoglycemia. By checking her blood sugar when any of these early signs occur, CDR staff will be able to help Mary learn to identify these herself. It is not expected that Mary will ever fully manage her condition, however by helping her become aware of the issues surrounding her care, she will become better equipped to assist in her diabetes management. Of course, in the event that Mary has any change in mental status including diabetes-related changes, staff would take the appropriate action.

Mary sees a nutritionist, who helps her review her food choices. CDR will work with Mary's nutritionist to develop an appropriate meal plan using the American Diabetes Association's Meal Planning Exchange System. Service Coordination staff will accompany Mary on regular nutrition appointments to make sure that dietary information is presented to Mary in way that she clearly understands. The service coordinator will then share this information with her other service providers, including the SDO, attendants, and CDR staff. Day Hab program staff who will help Mary try new foods that are on her diet to develop a wider variety of better foods that she likes to eat. Res Hab staff will use the meal planning information from the nutritionist to prepare a weekly meal plan, work with Mary to develop a shopping list, take Mary shopping for groceries, and support her with making better choices that fit her meal plan. Res Hab and Day Hab program staff will offer Mary emotional support, on days when Mary is frustrated and tempted to go off her diet.

Seizures

Mary has absentee seizures. During these seizure she will look as if she is "zoning out"; she may turn her head to one side and stair up at the ceiling as if thinking about something. This type of seizure can last a couple of seconds up to a minute, they are fast, but during this time Mary will lose time and possibly lose track of the conversation. Because she does not have uncontrolled movements and thrashing commonly associated with seizures, Mary's seizure activity can often be overlooked as one might think she was just trying to ignore the situation.

Mary often can tell that a seizure is coming on. She will say that she "needs to sit down". When Mary says she feels the need to sit-down, attendants and staff will immediately assist her is sitting in a safe place until she feels confident to move. Staff and attendants will treat Mary's seizures as a change in mental status and make the necessary contacts. CDR case managers will track these episodes and report them to Mary's Primary Care Physician.

Personal Care

Mary will have attendants to assist her on a daily basis with her Activities of Daily Living. These attendants will be provided by either a Certified Home Health Agency or the Consumer Directed Personal Assistance Program with Adele Carlson hiring and directing Mary's attendants with additional paid OMRDD assistive supports.

Hygiene is an important part of Mary's safe discharge. Good personal hygiene will help reduce the risk of infection and generally will improve Mary's self-image and mood. Prior to her fall Mary had difficulty with Visiting Nurse Service covering the assigned shifts and did not have the assistance she needed with personal care tasks. Often her attendants would arrive about 20 minutes before she had leave for her morning transportation.

If Mary is provided three hours of attendant service in the morning, she will have adequate time to manage her personal hygiene. The attendants will help her in the shower. Mary will have a hand-held shower to make it easier for her and the attendants to thoroughly wash all of Mary's body. Mary is able to wash her hands, face, upper front torso, and to brush her teeth on her own. She does require total assistance with cleaning her genital area, back legs, and feet, due to mobility limitations and the potential for falls. Mary's attendants will clean Mary after urinating/defecating because Mary cannot reach these areas. CDR Day Hab or Res Hab staff will assist her with these tasks at the times she is with those staff.

Mary, her Res Hab staff, and Self-Directing Other (if applicable) will prepare an activity list which closely follows the routine Mary followed at home. This will greatly reduce Mary's frustration level and assure that her needs are met.

Communication

Several factors, such as Mary's illness and diabetic condition influence and may limit Mary's ability to manage frustration, anger, and verbal responses. CDR will work to rule out physical issues first.

According to her medical providers, Mary's record indicates that she has objected to care and/or caregivers before and during hospitalization. If the judge decides that Mary lacks capacity, she will not be able to independently refuse needed care. Adele Carlson has a long history of successfully working with Mary to accept services. CDR has found that including Adele (as Mary's Health Care Proxy) has resolved these difficulties.

Mary also can have a quick temper if she feels she is being ignored. CDR has identified people that Mary can call when she is upset so she can calm down and continue to work with the attendants that she has. Res Hab staff will work with Mary to better understand how to resolve potential problems with her attendants. This will assist Mary with controlling her emotions and developing skills to vent her anger and situational anxiety constructively. Mary's service coordinator and Res Hab staff will assist and advocate for Mary to resolve her frustrations in the best manner to meet her ongoing needs.

Staff will recognize that good communication is critical to Mary's success with her attendants and consequently her success in living in the community. Mary expresses valid points, but may do so in an inappropriate manner, which can be frustrating to untrained staff. Mary may correctly point out that someone has not done what she has asked them to do, but in her frustration may swear at them or make others derogatory comments. Res Hab staff will work with Mary on managing and minimizing her frustration level.

CDR has also identified several people whom Mary trusts and listens to very closely. These people have demonstrated an ability to present information to Mary in ways that she can understand and still feel respected and in control. The people include Adele Carlson, Norita Darling, Bruce Darling, Debbie Bonomo, Julie Marello and Chris Hilderbrant. These staff and natural supports will be used to explain the plans to Mary. They have met with Mary and explained to her the more difficult to accept aspects of this plan, such as the need to use a female urinal while in bed if in the unlikely event that there is no one present to help Mary transfer from bed to use the bathroom.

Finances

Due to the court proceedings, Mary may be assigned a guardian, who may or may not be ultimately be responsible for her finances, depending on which areas of Mary's life are subject to guardianship. CDR staff will work with Mary and the appointed guardian to make sure Mary is in compliance with accounting requirements or wishes that the guardian may have.

It is important to point out Mary has successfully managed her own finances for years with support. She is very good with paying recurring expenses and is always current with her rent and her other bills. She utilizes Res Hab to help her review her checkbook once a month and check or help with math. Mary does an excellent job of saving money. She is very frugal, and at times needs to be reminded that it is acceptable to

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Mary receives Res Hab and her worker will continue to review her checkbook with her one time per month and check her balances against the bank statement with her. Mary's Res Hab staff also review Mary's bills with her and help her set a monthly budget. Mary's Res Hab workers also help Mary identify food and other items that she needs for her home and take her out to purchase these items. Res Hab workers report to their supervisors, who in turn, keep Mary's case manager informed. If there are any concerns about Mary's ability to manage her finances, they will be reviewed weekly with her, until the concerns are addressed.

Fire Safety Plan

Mary's home is operated by the Rochester Housing Authority; the apartment is equipped with firewalls, to prevent any spread of fire from neighboring apartments. There are two smoke alarms, which will alert her, and her attendants, to the presence of smoke, and sprinklers in every room of her apartment, which will extinguish internal fires.

The Fire Department Engine Stations #3 and #5, located at 1051 Emerson Street and 4050 Lyell Avenue, have been informed of Mary's status. They are aware of her special needs and considerations in case of a fire in the building.

In the event of fire, the alarm system also sounds an alarm immediately outside the apartment, which rings loudly throughout the apartment complex. (This alarm is also sounded if Mary pulls one of her alarm switches. The alarm system also directly notifies the fire department and unlocks her front door.

Mary has a Personal Emergency Response Service (PERS) button, that when pressed, goes to a call center, where an operator will talk directly to Mary, and notifies 9-1-1 and then CDR's on-call case manager, of the emergency situation.

In case of fire while an attendant is with Mary, the attendant can assist Mary to transfer into her manual wheelchair and then evacuate the apartment through the most convenient exit, of which there are two, one in front and one in back. The backdoor exit from Mary's apartment leaves directly from her bedroom to the outside. The front door exits from space shared between her living room and dining room.

In the unlikely event that Mary is not accompanied by an attendant, and a fire occurs, the firewalls, Personal Emergency Response System (PERS) and sprinklers will keep her safe while the fire department responds. Fire department personal are aware of Mary's situation and will assist Mary transfer to her wheelchair and evacuate her apartment.

In the event that there is a fire in her apartment, and the emergency response team determines Mary needs medical attention, she will be transported to the hospital, for evaluation and treatment. The service coordinator will meet Mary at the hospital.

Other Emergencies

In case of any emergency situation, Mary will use her PERS in order to notify 9-1-1 and her service coordinator of the situation. Mary's service coordinator will contact Mary to discover the nature of the emergency. If the service coordinator is unable to contact Mary, they will immediately go to Mary's apartment to investigate the situation.

Natural Supports involved in this plan of protective oversight

Friend /Health Care proxy
(585) 222-6666

Friend /Alternate Health Care Proxy
(585) 222-7777 home
(585) 222-9999 x118 work

Neighbor and Friend
(585) 222-5555

OMRDD Paid Support involved in this plan of protective oversight

Service Coordinator (CDR)
(585) 222-9999 x131
After-hours contact (585) 222-9989

Service Coordination Supervisor
(585) 222-9999 x119
After-hours contact (585) 222-9988

Dir of Community Support (CDR)
(585) 222-9999 x110
After-hours contact (585) 222-7722

Coordinator of Community Support
(585) 222-3333
After-hours contact (585) 2222-1111

Director of Recreation Services (CDR)
(585) 222-3333

Medical Providers

Primary Care MD
Memorial Hospital Internal Medicine
(585) 222-7574

Community Health Nurse (TBA)

XII. COGNITIVE IMPAIRMENT, GUARDIANSHIP, DURABLE POWER OF ATTORNEY & ADULT PROTECTIVE SERVICES

Cognitive Impairment

The issue of guardianship, power of attorney, surrogate decision-maker, or adult protective services should not come up unless the consumer is a person with a significant cognitive impairment. Physical disability alone should never be grounds for guardianship. A person with a disability may need a guardianship if they have a significant cognitive impairment, lack appropriate alternatives to guardianship, and lack of appropriate social services that the person is unable to provide for essential services to meet their health, safety and welfare.

Centers for independent living should have a protocol in place for obtaining the informed consent from consumers. If a person with a disability has significant cognitive impairment and a CIL fails to obtain and document informed consent and capacity to make and give informed consent, subsequent events could unfold to open the CIL up to liability or an APS charge. CILs should do training with a psychologist on a very basic screening tool, like the Mini Mental Status Exam, to help determine and document, basic cognitive ability. Basic cognitive ability is the ability to understand their living situation, form intent, and communicate that intent.

Centers for Independent Living may be exposed to risk of liability if it helped a consumer with significant cognitive impairment, moved them out of a nursing facility, and the person was injured or died because of the significant cognitive impairment or a failure to exercise good judgment. For example, a person with significant cognitive impairment tells an ILC they want out of a NF and into their own home. The ILC helps the consumer move, they leave their house, cross a busy street, and get hit by a car and are seriously injured. Another example is a consumer with serious decubitus ulcers requests to move out of an NF and into their own home. The ILC helps the consumer move out without getting the medical records or asking about serious health problems. Five days later the consumer gets a very serious infection in the bone and gets taken to the ER. The ER sees the infection and the ulcers and reports to APS. Five days later, even with hospital intensive care, the consumer dies from the infection. Hostile third parties or government agencies will be looking for someone to blame and those radical ILC people should have known this person was not safe in the community. We know this is not true, but we should seek out and find the line where a person is and is not legally responsible for and capable of being responsible for their own health, safety, and welfare. If we do not think there is a line, a lawyer and a judge are going to tell us there is a line and exactly where it is. One thing a CIL executive director never wants to hear a judge say, "I hope you have good liability insurance."

Guardianship

Guardianship is a statutory procedure in state court to determine if a person is impaired to the extent that they are not able to provide for the essentials necessary to meet needs of health, safety, and welfare, and without which, serious illness or injury is likely. Since guardianship is a state court function, all fifty states have their own guardianship laws, and all are different. In a guardianship proceeding, the person with a disability is called the proposed ward. Once a guardianship is ordered by the court, the person is called a ward.

Your state's guardianship statute should have substantial procedures in place. The best ones make it hard to get a guardianship in the first place, give a person with disabilities substantial due process rights, and make it easy to revoke a guardianship or restore the individual to legal capacity. A person should be given notice, appointed counsel, opportunity to face accusers, doctors, psychologists and intensively cross-examine them. They should be presumed fully capable until proven otherwise by clear and convincing evidence. They should be able to hire experts and put on a vigorous defense. It is a good idea for every CIL to have their own lawyer or at least have access to one who understands IL and knows disability law.

If a consumer has a guardian, all is not lost. Good guardianship laws require petitioners to allege and prove that they have exhausted attempts for less restrictive alternatives like powers of attorney, living wills, and joint tenancies. Ask if this has been done. Talk to the consumer and their guardian. Ask to see their Letters of Guardianship. This is the court order that sets out the powers of the guardian. Many guardianship statutes expressly require certain actions by a guardian, like ensuring they live in the least restrictive setting, exercising authority only to the extent necessary, encouraging participation, encouraging the ward to act on their own behalf, and encouraging an independent living plan toward full restoration. Good guardianship laws also prohibit a guardian from placing a ward in an institution or nursing facility, requires a court order for more restrictive placement, prohibit the guardian from denying marriage, prohibit experimental surgery, prohibit denial or withdrawal of essential nutrition or health care, and prohibits sterilization. It would be very beneficial to become familiar with the duties and prohibitions of guardians in your state.

If a consumer has a guardian, assume it is limited until proven otherwise. Get the Letters of Guardianship and then try to work with the guardian. If the guardian is the problem, anyone can usually file a petition to change a guardian, revoke the guardian's powers, change or restrict the guardian's powers, or restore the ward to full legal rights.

Conservatorship

A conservatorship is usually different than a guardianship. A guardianship is over the freedom of the person with a disability. A conservatorship pertains to the property of the person. A person with a disability can have a guardian but not a conservatory or can have a conservator and no guardian. The focus of any guardianship or conservatorship should not be over a person's disability, but over their ability to think, reason, understand, and especially function over time. A person should be entitled to the dignity of risk. A person should be entitled to the respect to make his or her own mistakes and learn from them. A person should be entitled to give money to a fraud TV evangelist. That does not prove lack of capacity. Not paying bills, or arranging to have them paid with the resulting loss of electricity and heat in one's home could be a problem factor.

Again, assume a limited conservatorship until proven otherwise. Ask to see the letters of conservatorship. File petitions, or help the consumer file petitions to limit, restrict, revoke, or terminate conservatorships where appropriate.

Power of Attorney

A power of attorney is a document that represents an agency relationship. An agency relationship is where one person, a principal, obtains an agreement from another person, called the agent, to represent them to do a certain act or all acts. A person who engages another to be their agent is the principal. A principal engages an agent that is called an attorney-in-fact. The attorney-in-fact does not have to be, and usually is not, an attorney. A person with a disability must have the capacity to enter into a power of attorney. The capacity required by law is usually pretty low. A person should have a basic understanding that they want to appoint another person to help them with certain acts, like health care decisions or financial decisions, and what the risks and benefits of having them act are. Power of Attorney is the name of the agreement that should be reduced to writing. All states have statutes that regulate the creation, substance, and execution of powers of attorney. A power of attorney can be limited or general. A limited power of attorney engages an attorney-in-fact for one or only a few specific duties, like health care decisions only. A general power of attorney engages another to do any and all acts that the principal could do. General powers of attorney are dangerous and should be avoided unless they are absolutely necessary and the agent is absolutely trustworthy or bonded. A power of attorney may be durable or non-durable. A durable power of attorney survives the incapacity of the principal. A non-durable power of attorney expires upon the disability/incapacity of the principal. All powers of attorney, except for very few exceptions, expire upon the death of the principal. Finally, a power of attorney may be springing or immediate. A power of attorney that springs into effect is one that springs into effect only upon the occurrence of a contingency, like incapacity. A power of attorney that is immediate is one that goes in to effect immediately upon execution.

A power of attorney is not a mandatory obligation like a guardianship. A person who holds a power of attorney does not have to act, unless they have agreed to be so bound, and this is very rare. A person who has executed a power of attorney often has not given up the right to make their own decisions or take their own actions. A person may always revoke a power of attorney. If someone tells you that they are the attorney-in-fact under a power of attorney given by your consumer, always ask them for a copy of the DPOA for your file. Read it. Assume it is limited and only springs into effect until you read differently.

Adult Protective Services Issues

Most, if not all states, have adult protective services statutes. These statutes require certain classes of health care, social service, and educators to report abuse, neglect, and exploitation of persons. Often, there is immunity for all reports of APS. This may lead to vindictive, ideological, and strategic APS filings. An ILC employee who is charged with abuse, neglect or exploitation has full due process rights and should exercise them. ILCs should be very familiar with their state's APS statutes. Sometimes there is a philosophical chasm between APS and ILCs. Some APS departments place an absolute value on safety and security. If a person with a disability is not absolutely safe and secure then someone is guilty of abuse, neglect or exploitation. APS may be at odds with your states Medicaid Agency. Usually, a state Medicaid Agency wants to keep costs down as little as possible. They will only approve the minimal hours and services for a person's HCBS plan of care. But APS departments may intervene and demand more hours, or too many hours, or deny placement on the plan of care because it is not safe. These conflicts can be very frustrating and place the consumer and the ILC in a catch 22. We must advocate for our consumers and try to work with both departments to make sure that it does not happen. No place is absolutely safe. People die, are beaten, abused, neglected, have things stolen, and get bed sores in nursing homes every day. They are not safe. They are at least no safer than most people's homes with adequate supports and services. Advocate for the dignity of risk. Advocate about the CIL's duty under federal law, the Rehabilitation Act, to ensure independent living and self-direction. Advocate for the consumer's civil right to live in their own home, the most integrated setting.

APPENDIX A

GLOSSARY OF COMMON TERMS AND ABREVIATIONS

AAA	Area Agency on Aging
ADL	Activities of Daily Living
ALF	Assisted Living Facility
APS	Adult Protective Services
CHHA	Certified Home Health Agency
COLA	Cost of Living Adjustment
DME	Durable Medical Equipment
HCBS	Home and Community Based Services
HMO	Health Maintenance Organization
IADL	Instrumental Activities of Daily Living
MDS	Minimum Data Set
PAS	Personal Assistance Services
PERS	Personal Emergency Response System
POA	Power of Attorney
RAI	Resident Assessment Instrument
RAP	Resident Assessment Protocol
RUG	Resource Utilization Group
SNF	Skilled Nursing Facility
SNT	Supplemental Needs Trust
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income

Definitions

Activities of Daily Living (ADL)
Any of the core activities that must be performed in the course of daily living. These activities include transferring, bathing, eating, dressing, toileting, and continence care.

Acute Care
Immediate, emergency or scheduled medical/surgical care, required for a worsening medical condition, generally provided in a hospital of in an outpatient setting (clinics, doctor's office).

Adult Care Facility
A family-type home for adults, a shelter for adults, a residence for adults or an adult home, which provides temporary or long-term residential care and services to adults who, though not requiring continual medical or nursing care, are, by reason of physical, mental, or other limitations associated with age, physical or mental disabilities or other factors, unable or substantially unable to live independently.

Adult Day Care
Provision during the day, on a regular basis, at a site outside of the home, of health, medical, psychological, social, nutritional, educational, and other services that a person with a disability needs in order to remain in the community.

Adult Home
An adult care facility established and operated for the purpose of providing long-term residential care, room, board, housekeeping, personal care and supervision to five or more adults, unrelated to the operator.

Adult Protective Services (APS)
A government or community-based service agency that investigates cases of suspected abuse, self-abuse, neglect, or endangerment to adults with disabilities or seniors.

Advanced Directives
Includes health care proxy and living wills that guide health care decision making if a person is unable to make or express decisions on his or her own behalf regarding their health care.

Area Agency on Aging (AAA)
The local planning and service units designated by the Department of Aging to administer a program of comprehensive community services for seniors. AAA's can be a part of county government or a private non-profit agency.

Assisted Living Facility (ALF)
These facilities are defined on a state-by-state basis. Generally, and ALF is a group residential setting not licensed as a nursing home where assistance with daily living, personal care, and routine nursing services are provided or arranged.

Assistive Equipment
Tools that are designed to promote an increase in functional capacity. Assistive Equipment includes hands-free phones, communication devices, and reachers.

Bed Hold
Reservation of a bed in a nursing facility during times of temporary absence from the facility. Some state Medicaid programs pay for bed holds.

Certified Home Health Agency (CHHA)
A public, voluntary, or private proprietary agency, certified by the federal government and the State to provide nursing and aide services, medical supplies, physical therapy, speech therapy, occupational therapy, social work services and/or nutritional services.

Chore Services
Infrequent tasks related to home maintenance such as repairs and yard work. Under Title XX, personal care activities and other domestic services such as shopping and housecleaning are included in this definition as well.

Cost of Living Adjustment (COLA)
Legislation enacted in 1973 allow for automatic cost of living adjustments to Social Security Disability (SSD) benefits and Supplemental Security Income (SSI) benefits. The purpose of the COLA is to prevent inflation from eroding SSD and SSI benefits.

Consumer Directed Personal Assistance Services (CDPAS)
Allows Medicaid eligible individuals with disabilities to have greater control over their home care services. In the CDPAS model, individuals with disabilities (1) recruit, hire, and train their attendants, (2) define their attendants' duties and work schedules, (3) supervise attendants regarding how specific tasks will be performed, (4) manage payroll functions, and (5) discipline and discharge their attendants.

Durable Medical Equipment (DME)
Equipment that is designed to last for several years such as hospital beds, wheelchairs, and oxygen tanks as opposed to consumable medical supplies such as diapers and dressings.

Guardian (or Conservator)
A court-appointed person designated to act on behalf of someone who has been declared legally incompetent.

Home and Community Based Services (HCBS)
Services provided in an individual's home or other community setting (e.g. work, school, recreation) which enable to person to function in those settings.

Home Health Aide
Person who, under the supervision of a home health or social service agency, assists seniors and individuals with disabilities with household and personal maintenance, hygiene tasks and paramedical tasks. Home health aides are usually trained by the Home Health Agency or by outside training programs.

Homemaker Services
Services such as shopping, housekeeping, meal preparation, transportation assistance, money management, and home repairs.

Health Maintenance Organization (HMO)
A type of managed care plan in which the primary care physician coordinates all of the member's medical care.

Instrumental Activities of Daily Living (IADL)
Activities related to daily living that include preparing meals, managing money, shopping for groceries or personal items, and housework.

Medicaid
Joint federal-state program, created in 1965 by Title XIX of the Social Security Act to pay for health services for individuals with very low income. Medicaid is administered by the State under broad federal guidelines. Program eligibility, services offered and varies widely from state to state. The Medicaid program has become the insurer of last resort for about 70% of nursing home residents.

Medicaid Spend down
In some states, individuals with disabilities or seniors are able to "spend down" their excess resources or income in order to become eligible for Medicaid.

Medicaid Waiver
States may request "waivers" of certain federal requirements in order to develop Medicaid-financed programs that offer community based alternatives to nursing facility placement. By definition, Medicaid Waiver programs must be at least cost-neutral in that, on a per capita basis, the cost of providing home and community based services cannot exceed the cost of providing care for the identical population in a nursing facility. States have the flexibility to select the mix of waiver services that best meets the needs of the population they wish to serve. Medicaid Waivers may be provided statewide or only to specific geographic subdivisions. Furthermore, states may target 1915 (c) waiver programs by specific types of disabilities.

Medicare
Federal health insurance program created in 1965 by Title XVIII of the Social Security Act. It provides health insurance benefits primarily to persons over age 65 and younger individuals with disabilities who are eligible for Social Security Disability benefits. Medicare has two parts, Part A (Hospital Insurance) and Part B (Supplementary Medical Insurance). Long term nursing home stays and full-time, constant home health services are not covered by Medicare.

Minimum Data Set (MDS)
A federally mandated minimum core of defined and categorized patient assessment questions that is part of the Resident Assessment Instrument (RAI). The MDS, as part of the RAI, must be completed within a certain time frame from the date of admission into the nursing facility and must be reviewed on a scheduled basis or whenever there is a significant change in the resident's condition. In the MDS, the resident's needs are scored in a variety of areas, and the results of those scores trigger treatment protocols which should be addressed in the resident's care plan.

Nursing Home (also called Nursing Facility)
A state licensed healthcare facility that is staffed with nurses around-the-clock and a physician on call, and has approved procedures for maintaining medical records and administering medications.

Ombudsperson (Long Term Care)
Under the federal Older Americans Act, every state is required to have an Ombudsperson Program to help address complaints in the long term care system. An Ombudsperson is an advocate for residents of nursing homes and can assist residents in resolving quality of care complaints.

Personal Assistance Services (PAS)
Assistance with ADLs and IADLs. Personal Assistance Services may be provided by persons without professional skills or training.

Power of Attorney (POA)
A written legal document that is used to delegate legal authority to another. The person that appoints the Power of Attorney is referred to as the "principal" and the person that they appoint is referred to as the "agent". The authority granted under a POA can be very broad or very limited in nature. Generally, the POA is used to make decisions or sign documents related to legal, property, or financial affairs.

Program of All-inclusive Care for the Elderly (PACE)
Programs which combine Medicaid and Medicare benefits into a single managed care program for eligible individuals aged 55 and over who reside in a PACE service area. PACE programs are designed for qualified individuals who are certified as needing a nursing home level of care, but can live safely in the community with services and supports.

Personal Emergency Response System (PERS)
An electronic device which helps individuals with disabilities and seniors to summon help in an emergency. A PERS has three components: (1) a small radio transmitter (a help button that can be carried or worn), (2) a console connected to the user's telephone, and (3) an emergency response center that monitors calls and alert emergency service provider's to the person's home if needed.

Resident Assessment Instrument (RAI)
Congress mandated in 1987 that all certified Medicare and Medicaid long term care facilities conduct periodic assessments on each of their residents. In response, the Health Care Financing Administration, now knows as the Centers for Medicaid and Medicare Services (CMS), created a uniform patient assessment instrument which contains the MDS and the Resident Assessment Protocols (RAP).

Resident Assessment Protocol (RAP)
When the information obtained in the MDS evaluation shows a problem, it triggers the Resident Assessment Protocol (RAP). The RAP is a guide for further, more detailed assessment of potential problems and risk areas.

Resource Utilization Group (RUG)
A classification system for nursing facility residents. Based on information collected by the RAI/MDS, residents are classified into different Resource Utilization Groups (RUG) which affect Medicare reimbursement.

Skilled Nursing Facility (SNF)
A nursing home that is qualified to provide around-the-clock nursing care to residents who need skilled care, extensive medical care and supervision, and/or therapy and rehabilitation.

Social Security Disability Income (SSD or SSDI)
A federal income maintenance program for individuals who become disabled after they have worked a minimum period of time. Payment amounts are determined by the duration and level of a recipient's prior earnings.

Sub-acute care
A care level below acute care, but more intense than long-term care. Sub-acute care services are generally provided for a limited period of time, as part of rehabilitation or recovery from an acute care problem.

Supplemental Needs Trust (SNT)
Trusts which are created for qualified individuals with disabilities who are receiving government assistance (e.g. SSI, Medicaid) without disqualifying or otherwise making such persons ineligible for such government benefits. The trust is created to supplement government benefits, rather than diminishing such benefits.

Supplemental Security Income (SSI)
A federal income maintenance program for low-income seniors and individuals with disabilities that do not qualify for SSD due to insufficient work history. To qualify, individuals must meet strict income and resource tests.

Appendix B

General Checklist for Basic Necessities

Housing
___Lease signed (Date:______________)
___Keys (Date:______________)
___Security Deposit paid (Date:______________)
___First month's rent paid (Date:______________)

For existing home owners
____Housing is accessible
    If no, dates that other modifications will be made:
        ____________Ramps
        ____________Door widening
        ____________Other

Utilities
___Utilities turned on
    Date that utilities will be turned on: _____
___Phone working (check this prior to discharge)

Cleaning supplies
___Sponges/Dish cloths
___Dish soap
___Laundry detergent
___Broom
___Dust pan
___Bleach, etc.
___Paper Towels

Toiletries
___Soap
___Shampoo
___Toothpaste or denture cleaner
___Deodorant
___Toothbrush or denture holder

Other Household items
___Dishes (at least two)
___Utensils (at least two of each)
___Pots/Pans (at least one of each)
___Cup or glass (at least two)
___Containers for leftovers
___Garbage can
___Garbage bags
___Can opener

___Light bulb
___Towels (at least 2-3)
___Sheets (at least one set)
___Blanket (at least one)
___Pillow (at least one)
___Clock
___Toilet Paper
___Blinds or curtains
___Phone

Furniture
__Bed (if hospital-type bed, make sure you have approval for it and a delivery date)
___Chair
___Lamps (if no light fixture in apartment)
___Sofa (if available)
___Table

Date that furniture will be delivered? ________

Change of address
Date that change of address was put in? ______

Income Source
___SSDI
___SSI
___Other

___SSI notified that individual is moving into the community (Date that benefit rate will go up: _______)

Medicaid
___Verification that community Medicaid has been approved
___Verification of spend-down amount
___Copy of Medicaid card

Food Stamps
___Application for Food stamps
___Food stamp appointment made (Date of food stamp appointment: ______)

Transportation
___Medicaid transportation set up
___Transportation to medical appointments has been arranged (if non-Medicaid)
___Para-transit approved

Personal Care Assistance
___Home Care approved
    Name of home care agency: _________
    Number of hours approved: __________
For Consumer Directed Personal Assistance
___Attendants and back-up attendants hired
    Number hired:______
___Attendants trained
___Attendant Schedule established
___Attendant responsibility list made

Medicaid Waiver Services
____Services approved
    Type of Medicaid Waiver:______

Durable Medical Equipment/Assistive Technology
___Lifts (i.e. Hoyer) approved and delivery date set
___Bed approved and delivery date set
___Specialized mattress approved and delivery date set
___Wheelchair approved and delivery date set
    Loaner obtained if needed: ___
    Training on wheelchair use and battery use:____
    Cushions if needed: _____
___Shower chair/bench
___Grab bars
___PERS
___Other DME or Assistive Technology items (if needed)
    ___Adaptive utensils/cups
    ___Communication devices

Supplies/Medications
___Prescriptions written and sent to pharmacy
___Pick-up or delivery from pharmacy arranged
    Date that meds or supplies will be picked up or delivered: _____
___Other Supplies
    ___Gloves
    ___Adult diapers
    ___Medi-sets
    ___Catheter supplies
    ___Bowel regiment supplies

Doctors
___Community Doctor Obtained
    Name and phone number of Community Doctor: ____________________
___First appointment made

Date of first appointment:_______________

___Other doctor appointments
  _____Eye doctor
  _____Dentist
  _____Specialists
  _____Mental Health

Recreational activities

____Assistance in planning activities

Contact people

___List of contact people made
  _____Placed in new home

Groceries

___Groceries for one week

Apartment Review Form

Street Address and Apt Number ______________________________________

City ____________________________ State _________ Zip____________

Terms and Conditions

Date Available	/ /		
Deposit	$_______		
Rent Amount	$_______		
Rent due (Date)	$__________________		
Late Payment charges	$_______		
Length of lease	________________________________		
Penalty for breaking lease	________________________________		
Pets allowed***	Yes	N/A	No
Pet deposit***	$_______		
Additional pet charges***	$_______ per _______		
Physical changes allowed***	Yes		No
Subletting allowed	Yes		No

Utilities

Water included in rent?	Yes	No, monthly cost $_______
Heat included in rent?	Yes	No, monthly cost $_______
Type of Heat:	☐ Electric ☐ Gas ☐ Oil	
Garbage included in rent?	Yes	No, monthly cost $_______
Other: _______________	Yes	No, monthly cost $_______

General

Ramp or no-step entrance	Yes	N/A	No
Exterior doors open easily	Yes	N/A	No
Elevator in building	Yes	N/A	No
Interior doors passable in wheelchair	Yes	N/A	No
Widened hallway	Yes	N/A	No
Blinds/Curtains with reachable cords	Yes	N/A	No
Cable TV Connection	Yes	N/A	No
Ample closet space	Yes	N/A	No
Adjustable rods in closet	Yes	N/A	No
Paint/Wall in Acceptable Condition	Good	OK	Bad
Adequate Storage Space	Yes	N/A	No
Accessible Storage Space	Yes	N/A	No
View	Good	OK	Bad
Water Pressure	Good	OK	Bad

Bathroom

Widened Doorway	Yes	N/A	No
Lever door handle	Yes	N/A	No

Low Threshold	Yes	N/A	No
5 foot turning radius	Yes	N/A	No
Sink lowered to useable height	Yes	N/A	No
Open front vanity (no cabinets under sink)	Yes	N/A	No
Roll in shower	Yes	N/A	No
Grab bars in tub or shower	Yes	N/A	No
Hand held shower head	Yes	N/A	No
Raised toilet	Yes	N/A	No
Grab bars by toilet	Yes	N/A	No
Reachable light switch	Yes	N/A	No
Reachable electrical outlets	Yes	N/A	No
Lowered towel bars	Yes	N/A	No
Emergency pull cord	Yes	N/A	No
Overall usability of bathroom	Good	OK	Bad

Bedroom

Widened Doorway	Yes	N/A	No
Low Threshold	Yes	N/A	No
Lever door handle	Yes	N/A	No
Reachable light switch	Yes	N/A	No
Reachable electrical outlets	Yes	N/A	No
Ample electrical outlets	Yes	N/A	No
Ample closet space	Yes	N/A	No
Adjustable closet rods	Yes	N/A	No
Hardwood floor	Yes	N/A	No
Carpet	Yes	N/A	No
Phone Jack	Yes	N/A	No

Kitchen

Condition of Refrigerator	Good	OK	Bad
Dishwasher	Yes	N/A	No
Condition of Gas/Electric stove	Good	OK	Bad
Stove with knobs on front	Yes	N/A	No
Garbage Disposal	Yes	N/A	No
5-foot turning radius	Yes	N/A	No
Adjustable/lowered counters	Yes	N/A	No
Loop cabinet handles/drawer pulls	Yes	N/A	No
Adjustable cabinets	Yes	N/A	No
Lowered sink	Yes	N/A	No
Reachable light switch	Yes	N/A	No
Reachable electrical outlets	Yes	N/A	No
Ample electrical outlets	Yes	N/A	No
Phone Jack	Yes	N/A	No
Overall usability of Kitchen	Good	OK	Bad

Living Room

Reachable light switch	Yes	N/A	No
Reachable electrical outlets	Yes	N/A	No
Ample electrical outlets	Yes	N/A	No
Hardwood Floor	Yes	N/A	No
Carpet	Yes	N/A	No
Phone Jack	Yes	N/A	No

Laundry Facilities

Location	[ ] In apartment		[ ] on site
Front loading washer and dryer	Yes	N/A	No

Community

Noise level	Good	OK	Bad
Parking	Good	OK	Bad
Accessible garage or carport	Yes	N/A	No
Mailbox reachable from wheelchair	Yes	N/A	No
Snowplowing and shoveling service	Yes	N/A	No

Safety

Accessible emergency exits	Yes	N/A	No
Fire extinguishers	Yes	N/A	No
Emergency pull cords	Yes	N/A	No
Functioning windows	Yes	N/A	No
Windows at usable height	Yes	N/A	No
Lead hazards	Yes	N/A	No
Locks on all doors	Yes	N/A	No
Secure building	Yes	N/A	No
Intercom	Yes	N/A	No
Screens for windows	Yes	N/A	No
Outside lighting	Yes	N/A	No
Audible/Visible smoke detectors	Yes	N/A	No

Neighborhood

Public transportation proximity __________ block(s)
Distance from school/work __________ mile(s)
Proximity of grocery store __________ mile(s)
Proximity of bank __________ mile(s)
Proximity of post office __________ mile(s)

***Landlords must comply with all fair housing laws including the Fair Housing Amendments Act of 1988, Section 504, and the Americans with Disabilities Act in regards to support or service animals and reasonable modifications.

Grocery Items to Stock Kitchen in the New Apartment

Baking powder
Baking soda
Beans, dried
Bouillon
Bread
Butter or Margarine
Cereal
Cheese
Cocoa
Coffee
Cooking spray
Cornstarch
Drink mixes
Eggs
Flour
Herbs
Honey
Ketchup
Mayonnaise
Milk (__fat free; __1 %; __ 2%)
Mustard
Napkins
Oil (Vegetable or Olive)
Pasta
Pepper
Pet food
Plastic bags and wraps
Rice
Salt
Sauces (liquid and powdered)
Shortening
Soup
Spices
Sugar, brown
Sugar, granulated
Sugar, powdered
Syrup
Tea
Vanilla
Vinegar

Household Items You May Need for Your New Apartment

Bags for trash
Bathroom cleaner
Bleach
Broom
Brushes, (scrub, tile, etc.)
Bucket
Cloths for cleaning (rags)
Dish wash soap or detergent
Dust cloths
Facial tissue
Floor cleaner
Glass cleaner
Kitchen cleaners, disinfectants
Light bulbs
Mop
Powdered cleanser
Silver and metal polish
Sponges
Toilet plunger
Toilet tissue
Vacuum cleaner
Wastebaskets

Note: This list is designed to help identify what items are useful. ALL of these items are NOT required for transition.

Items to review for Grocery List

- Apples
- Applesauce
- Bacon
- Bagels
- Bakery goods
- Baking powder
- Baking soda
- Bananas
- Beans
- Beef, hamburger
- Beef, roast
- Beef, steak
- Beets
- Biscuit mix
- Biscuits/rolls
- Bouillon cubes
- Bread (_White/_Wheat)
- Bread crumbs
- Bread, French
- Broccoli
- Butter
- Cabbage
- Cake/brownie mix
- Carrots
- Celery
- Cereal
- Cheese, block
- Cheese, cottage
- Cheese, parmesan
- Cheese, sliced
- Cheese, spread
- Cherries
- Chicken
- Chili
- Chili beans
- Chinese food
- Chips, potato
- Chips, tortilla
- Chocolate chips
- Chocolate, baking
- Cocoa
- Cocoa mix
- Coffee
- Cookies
- Cooking spray
- Corn
- Corn meal
- Corn syrup
- Cornstarch
- Crackers
- Cream cheese
- Cream, non-dairy
- Cream, whipping
- Croutons
- Cucumber
- Dessert
- Dips
- Drink mix
- Eggs
- Evaporated milk
- Fish
- Flour
- French fries, frozen
- Fruit, canned
- Fruit, fresh
- Fruit, frozen
- Garlic
- Gelatin
- Graham crackers
- Granola bars
- Grapefruit
- Gravy
- Green pepper
- Ham
- Honey
- Hot dogs
- Ice cream
- Jam/Jelly
- Juice, bottled
- Juice, frozen
- Ketchup
- Lemon juice
- Lemons
- Lettuce
- Limes
- Lunch meat

Macaroni
Mandarin oranges
Margarine
Marshmallows
Mayonnaise
Meat, canned
Meat, fresh
Sauce, Sloppy Joe
Milk (type _____)
Molasses
Muffins
Mushrooms
Mustard
Noodle, mix
Noodles / Pasta
Nuts
Oatmeal
Oil
Olives
Onion
Onion rings, frozen
Oranges
Pancake mix
Peaches
Peanut butter
Pears
Peas
Pepper
Pickles
Pie crust
Pie filling
Pineapple
Pizza, dough
Pizza, frozen
Pizza, sauce
Plums
Popcorn
Pork
Pork and beans
Pot pies
Potatoes
Poultry
Pretzels
Pudding
Raisins
Ravioli
Relish
Rice
Rice, mix
Salad dressings
Salt
Sauce, Barbecue
Sauce, Chili
Sauce, Enchilada
Sauce, Hot
Sauce, Pasta
Sauce, Picante
Sauce, Soy
Sauce, Steak
Sauce, Tartar
Sauce, Worcestershire
Sauerkraut
Sausage
Seasoning packets
Shortening
Soda pop
Soup, canned
Soup, dry
Sour cream
Spaghetti
Spices
Stew
Stuffing
Sugar, brown
Sugar, powdered
Sugar, white
Syrup
Tea
Tomato paste
Tomato sauce
Tomatoes, canned
Tomatoes, fresh
Tortillas
Tuna
Turkey
Vanilla
Vegetables frozen
Vegetables, canned

Vinegar
Waffles, frozen
Water, Bottled
Yams
Yeast
Yogurt

Appendix C

Planning Work Sheet for Health

Priorities and support needs

- medical supplies
- adaptive equipment
- Medicaid card
- preventative health care
- pain management
- exercise
- evaluations (O.T., hearing, etc.)
- pharmacy
- community doctor
- therapy
- dentist
- specialist
- specialist
- other
- other

Resources

- own equipment
- other
- other
- other
- other

Plan

For each item, define

1. What needs to be done?
2. When it needs to be done.
3. Who will do it both on the short term and for the long term.

- Arrange for personal assistance.
- Arrange for transportation.
- Other....

Planning Work Sheet for Housing

Goal____

Priorities and support needs

- access to home
- utilities
- appliances
- access to rooms
- telephone
- furniture
- bathroom modifications
- change of address
- equipment
- kitchen modifications
- keys for care providers
- location
- subsidized housing
- pet accommodations
- independent housing
- shared housing

Resources

- Physical Disability. Services
- Donated funds
- Own furniture
- Donated furniture

Plan

For each item, answer the questions

- What needs to be done?
- When?
- Who will do it? (Short-term & On-going).

- Change of address with FIA, MA, SSI, Post Office, other
- Utilities
- Phone

Notes

Housing Resources

For each, list Source (name of agency) Contact Person, and Phone Number.

- Police
- Fire
- FIA
- Physical Disability Services
- Utilities
- CIL
- Housing resource
- Kiwanis
- Landlord

Planning Work Sheet for Daily Living

Goal____

Priorities and support needs

- personal assistance services
- housework
- IL skill training
- equipment
- personal items
- assistance with mobility
- taking medication
- meal preparation
- shopping
- pet care
- clothing
- food
- emergency procedures
- emergency contact list
- privacy needs
- other...

Daily Living Resources

For each item, list

- the Source (agency)
  Contact Person
- Phone Number and other contact information.
- FIA
- Kiwanis
- CIL IL Specialist
- Others...

Planning Work Sheet for Financial Matters

Goal____

Priorities and support needs

- determine SS income
- bank account
- Medicaid eligibility
- direct deposit
- food stamps
- any current debts or bills

Resources

- SSI
- employment income
- pensions
- personal savings
- family support

Plan

For each item, answer the following questions

- What needs to be done?
- When?
- Who will do it? Both Short-term & On-going
- Get from SSA "personal earning and benefits estimate" income information.
- Develop a budget.
- Apply for food stamps .

Notes

Financial Resources

For each item, list the source (agency) Contact Person and Telephone or other contact information.

- SSI
- FIA
- Food Stamps
- Legal aid

Planning Work Sheet for Self-Determination

Goal____

Priorities and support needs

- Assistance with
    - memory
    - communication equipment
    - emotional support
    - organizing
    - health care advocate
    - support group
    - decision-making
    - legal advice
    - money management
    - living will
    - record keeping
    - other

Resources

(List Source, Contact Person, and Phone and other contact information.)

- Family
- Friends
- Church
- Social clubs.
- Other Plan

For each item, answer the following questions

- What needs to be done?
- When?
- Who will do it? Both Short-term & On-going

Self-Determination Resources

(List Source, Contact Person, and Phone and other contact information.)

- CIL peer support
- Support groups
- Legal aid
- Protection and Advocacy
- LTC Ombudsman
- Other
- Other
- Other

Planning Work Sheet for Social & Recreational Needs.

Goal____

Priorities and support needs

- visits from friends and family
- phone calls
- peer support
- religious affiliation
- meet neighbors
- private time
- future events to plan for
- holiday & birthday traditions
- ethnic, cultural traditions
- join community groups
- other
- other
- other

Resources

- family
- volunteer agencies
- friends
- volunteer opportunities
- place of worship
- CIL peer support
- other
- other
- other

Plan

For each item, answer the following questions

- What needs to be done?
- When?
- Who will do it? Both Short-term & On-going

Social and Recreation Resources

(List Source, Contact Person, and Phone and other contact information.)

- Family
- Friends
- Place of worship
- CIL peer support
- neighborhood group

Planning Work Sheet for Transportation

Goal____

Priorities and support needs

- personal transportation from Nursing Facility
- move belongings
- arrange specialized transportation.
- public transportation
- Schedules
- transportation training

Resources

- Dial-a -ride
- own vehicle
- family
- friends
- volunteers
- other
- other

Plan

List

- What needs to be done?
- When?
- Who will do it? Both Short-term & On-going

- Plan discharge transportation.
- Dial-a-ride application.
- Other
- Other
- Other

Planning Work Sheet for Employment

Goal____

Priorities and support needs

- assistive technology
- volunteer opportunities
- training
- education
- career planning
- assistance with job search
- assistance with accommodations
- assistance with resume writing
- other
- other

Resources

- friends
- MJC-RS
- family
- CIL
- place of worship
- organizations
- other
- other

Plan
List

- What needs to be done?
- When?
- Who will do it? Both Short-term &On-going

Employment Resources
(For each item list the Source, Contact Person , Telephone number and other contact information.

- CIL employment specialist
- MJC-RS
- UW Volunteer services
- Other
- Other
- Other

Appendix D

Nursing Home Transition Needs Survey

Developed for IndependenceFirst by Julie Alexander, Independent Living Coordinator and Advocate

Transition Services

1. Do you feel that you are able to direct and manage your own care?
   - A. Have you previously managed your own care?
   - B. When and how long?
2. Which agencies, if any, have you chosen to assist you in this transition into the community?
3. Have you selected a company for home care supplies if needed? Please provide name and phone number:

Housing Services

1. Have you obtained a housing list from an Independent Living Coordinator?
2. Have you placed your name on a waiting list for a housing complex in which you would like to reside?
3. Do you need accessible housing?
4. Do you have funds to pay for housing?
5. Are you being evicted from your current living situation? If so when?
6. What is your target date for moving?
7. What is the date of your lease?
8. Have you reviewed your lease?
9. What is the date housing was secured?
10. What date was the security deposit paid and rent paid?
11. What date is the moved scheduled for?
12. What is the date you pick up your keys?
13. If needed, are duplicate key(s) and/or key cards made and obtained?

Utility Services

1. Have you scheduled an appointment for your telephone service to be installed?

2. Have you scheduled an appointment for your electricity to be turned on?

3. Have you scheduled an appointment for your gas service to be installed?

4. If you want cable television, have you made an appointment for installation?

5. Have you requested that the Post Office change your address?

Funding Resources

1. Do you think that you will need Community Options Program (COP) funding or Title 19 assistance as you deal with independent living issues?
   A. If so, have you applied for these funds?
   B. Are you on a waiting list for COP or Title 19?
   C. When will you receive COP or Title 19?

2. If you have Title 19 funding, have you checked into whether or not this nursing home Title 19 can be transferred to independent living Title 19?
   A. Have you initiated such a transfer?
   B. What is the name and phone number of the Social Worker assisting you with this transfer?

3. Will you be eligible for Veteran's Services?

4. Have you checked into the process of the transfer of SSI/SSDI income from the nursing home to the community?
   A. Have you started the process of this transfer?

Personal Health Needs

1. Do you have your physician's approval for nursing home transition? Check any of the following activities you need assistance with:
   - Bathing in tub
   - Bathing in bed
   - Sponge bath

2. Do you need assistance with dressing? Check all that apply:
   - Lower extremities
   - Upper extremities
   - No assistance needed

3. Do you need assistance with toileting? Check all that apply:
   - With pads
   - Getting on and off the commode
   - No assistance needed

4. Do you need assistance with bowel care? Check all that apply:
   - Suppositories
   - Laxatives
   - Other
   - No assistance needed

5. Do you need assistance with Bladder Care? Check all that apply:
   - Catheter
   - Urinal
   - Other
   - No assistance needed

6. Do you need assistance eating? Check all that apply
   - Feeding
   - Set up
   - Cutting Food
   - Clean up
   - Meal preparation

7. Do you need assistance with housekeeping? Check all that apply:
   - Dusting
   - Moping
   - Vacuuming
   - General cleaning
   - Other
   - No assistance needed

8. Do you need assistance transferring from one place to another? Check all that apply:
   - Hoyer lift
   - Pivot lift
   - Need for worker to assist with equipment
   - Other
   - No assistance needed

9. Provide the names and phone numbers of supportive family members, friends or community advocates.

Personal Care Assistance Services

1. Do you need personal care assistance? If so, have you contacted:
   - PAS at IndependenceFirst
   - MA Program
   - Attendant Referral Program

2. Have you scheduled a needs assessment by these programs?
   - PAS at IndependenceFirst assessment
   - MA assessment
   - Attendant Referral Program assessment
   - COP worker assessment

3. What is the date assessments will be completed?

4. What is the target date for funding to be secured?

5. Have you recruited attendants and back up attendants?

6. Have you hired attendants?

7. Have you been orientated to the employer or employee manager role?

8. Have you made sure your attendant worker has received training and certification?
   A. What is the date of certification?

Assistive Technology/Devices Services

1. Do you need assistive technology or devices to assist you with your independent living needs?

2. Do you know what types of technology or devices you might like to use?

3. Would you like an assistive technology assessment?

4. If assistive technology/devices are required, have you ordered these pieces of equipment?

5. Have you worked out a plan of payment for this equipment?
   A. Do you need funding assistance to purchase this equipment?

6. Have you worked out delivery plan for the equipment?

7. Do you need assistance in learning how to use the technology/devices or equipment?

Medical Services

1. Will your doctor follow you into the community?
   A. If not, have you identified another doctor who is willing to accept you?
   B. Have you scheduled an appointment within two weeks of transition?

2. What is the name and phone number of the pharmacy you have selected?
   A. Does the pharmacy deliver?

3. Will your doctor write a prescription for a 30-day supply to meet your medication needs during transition?

Furnishings For Your New Home

1. Have you completed the attached transition checklist detailing what possessions you have and what possessions you will need to purchase before transition takes place?
   A. Do you have money to make such purchases?
   B. Are you aware of places which may donate furnishings?

2. Have you coordinated your move?
   A. Do you need assistance moving?
   B. Do you need assistance setting up?

Budgeting/Money Management Services

1. Have you established a monthly budget?
   A. Do you need assistance with this task?
   B. Have you written a "trial budget?"
   C. Do you need training in the areas of budgeting and money management?

2. Do you need to make arrangements for direct deposit of your income at a bank?

3. Have you established a bank account?
   - Checking
   - Savings

4. Do you need a payee?

5. Do you need to apply for additional forms of identification?

Transportation Services

1. Are you able to take care of your transportation needs?

2. Do you need specialized transportation?

3. Are you approved for Title 19 or User Side subsidy transportation?

4. Do you know how to schedule appointments to use specialized transportation?

Meal Planning Services

1. Do you need independent living skills training in this area?

2. Have you coordinated a plan so that you can purchase, cook and eat meals?

3. Who will do the initial shopping for groceries and supplies?

Social and Leisure Activities

1. Are you able to geographically orient yourself to your new neighborhood?

2. Do you need assistance in meeting your new landlord and neighbors?

3. Do you need assistance in planning daily or weekly social activities?

4. Do you want independent living training to assist you with any of these activities?

Appendix E

Understanding Medicaid Home and Community Services: A Primer

Overview of Medicaid Coverage of Home & Community Services

(Chapter 1)

Long-term care includes a broad range of health and health relative services, personal care, social, and supportive services, and individual supports. The chapter recounts the legislative, regulatory, and policy history of Medicaid coverage of longtime care services. Both institutional and home and community long-term care services are covered, with the latter described in greater detail. (Medicaid's coverage of primary and acute care is not included in the discussion.

Introduction

Medicaid is an entitlement program, which is designed to help states meet the costs of necessary health care for low-income and medically needy populations. States qualify to receive Federal matching funds to help finance these costs by filing a state Medicaid plan document with the Federal Health Care Financing Administration (HCFA). States have substantial flexibility to design their programs within certain broad Federal requirements related to eligibility, services, program administration, and provider compensation.

Program Evolution and current Spending Allocations

From its beginnings as a health care financing program primarily for welfare recipients, Medicaid has been amended and expanded in a patchwork fashion to cover a range of populations. Initially, Medicaid was the medical care extension of Federally funded programs providing cash assistance for the poor, with an emphasis on dependent children and their mothers, elderly persons, and persons with disabilities. Legislation in the 1980s extended Medicaid coverage to an expanded group of low income pregnant women and poor children, and to some low income Medicare beneficiaries who were not eligible for cash assistance.

When first enacted, Medicaid's main purpose was to cover primary acute health care services, such as doctor visits and hospital stays. Mandatory coverage for long-term care was limited to skilled nursing facility (SNF) services for people age 21 and older. States were given the option to cover home health services and private duty nursing services. In response to the high costs of nursing facility care, combined with criticism of Medicaid's institutional bias, states and the Federal government began to look for ways to provide long-term care services in less restrictive, more cost-effective ways. In 1970, home health services for those entitled to nursing home care became mandatory. Since 1970, Medicaid has evolved into a program that allows the states considerable flexibility to cover virtually all long-term care services that people with disabilities need to live independently in home and community settings.

The Federal Medicaid statute requires states to specify the amount, duration, and scope of each service they provide, which must be sufficient to reasonably achieve its purposes. States may not place limits on services or arbitrarily deny or reduce coverage of required services solely because of diagnosis, type of illness or condition. Generally, a state plan must be in effect throughout an entire state. (i.e., amount, duration, and scope of coverage must be the same statewide). There are certain exceptions to these rules. Two major ones: (a) states operating home and community based services (HBCS) waivers need not offer all services covered under the waiver to all beneficiaries in the state; and (b) targeted case management services offered as an optional benefit under the state plan are not subject to the statewideness rule.

In 1999, every state was providing home and community services under one or more of the available options, and Medicaid had become the nation's major public financing program for long-term care services for low-income persons of all ages with all types of physical and mental disabilities. Data since 1988 show how Medicaid long-term care service spending has been changing.

In 1988, Medicaid spending for all long-term services totaled $23 billion. Nearly 90 percent of those dollars paid for institutional services in nursing facilities and intermediate care facilities for persons with mental retardation (ICFs/MR); only 10 percent went for home and community services. Over the next eleven years, Medicaid spending for all long-term services grew by 9.8 percent per year, reaching $63.9 billion by 1999. Spending for institutional services increased more slowly (at 7.6percent per year). Spending for home and community services grew at the rate of 20 percent per year. From a low level of expenditures, home and community spending reached $17.9 billion in 1999.

HCBS waiver programs accounted for the majority of this growth. In 1999, HCB waiver service accounted for 16.6 percent of all Medicaid long term care services, compared with 9.4 percent in 1994 and only 4.4 percent in 1990. In 1996, expenditures for HCB waiver services surpassed spending for services provided under the home health benefit and the personal care option combined for the first time. In eleven years from 1988 to 1999, the portion of total Medicaid spending that went to all home and community services (waiver, personal care, targeted case management, and home health combined) grew from 10 to 28 percent. Following the Supreme Court's 1999 Olmstead decision, a state may decide to make increased use of the Medicaid program to increase both the amount and share of its resources going to home and community services.

Expansion of Home and community services relative to institutional services has been particularly pronounced for individuals with mental retardation and other developmental disabilities. In 1990, 144,000 such individuals were served in ICF's/MR, compared with 45,000 receiving HCB waiver services. By 1999, the number served in ICF's/MR has dropped to 118,000 while the number of participants in HCBS waiver programs had increased to almost 262,000.

It should be noted, however, that the share of Medicaid long-term care spending going to home and community services in most states is much lower than the national figure of 28 percent would lead one to expect. In 1997, for example, that share was less than 8 percent in half the states. In the same year, however, five states spent more than 20 percent of their Medicaid long-term care on resources on home and community services, with Oregon and New York heading the list (at 40 to 50 percent). The median annual per capita Medicaid expenditure on home and community services has also increased (rising from $310 to $522 between 1992 and 1997). This overall figure again masks considerable state variation-from $1180 per person age 65 or over in New York down to $29 in Mississippi.

Major Contours of the Medicaid Program's Home and Community Service Provisions
The remainder of this chapter presents a brief overview of the Medicaid law, regulations, and policy that give the states flexibility to create a comprehensive home and community service systems for persons of all ages with all types of physical and mental disabilities.

Home Health Services

There has been some misunderstanding about the coverage criterion for home health services because it is linked to the coverage criterion for nursing homes. States are mandated to cover nursing home care for categorically eligible persons age 21 and older. This mandate entitles persons age 21 and older to nursing facility care. States have the option to cover nursing home care for other Medicaid beneficiaries as well--e.g., persons under the age 21 would also be entitled to nursing home care. However, being entitled to nursing home care does not mean that one is eligible for nursing home care. In order to receive Medicaid covered nursing home care, entitled persons must also meet nursing home eligibility criteria (called level-of-care criteria).

Since 1970, home health services have been mandatory for persons entitled to nursing facility care. Confusion about eligibility for home health services has arisen because of the term entitled to nursing facility care has sometimes been erroneously interpreted to mean that people must be eligible for nursing facility care—i.e., that they must meet a state's nursing facility level-of –care criteria—in order to receive home health benefits. This erroneous interpretation has persisted not-withstanding its conflict with home health regulations prohibiting a state from conditioning eligibility for home health services on the need for discharge from institutional care. The Medicaid Assistance

Manual further clarifies that states may not limit home health services to individuals who require a skilled level of health care as defined by Medicare (i.e., needing skilled nursing or therapy services).

Federal regulations require that home health services include nursing, home health aides, medical supplies, medical equipment and appliances suitable for use in home. States have the option of providing additional therapeutic services under home health—including physical therapy, occupational therapy, and speech pathology and audiology services. States may establish reasonable standards for determining the extent of such coverage based on such criteria as medical necessity or utilization control. In doing so, as noted, a state must ensure that the amount, duration, and scope of coverage are reasonably sufficient to achieve the purpose of the service.

In 1998, following the ruling of the U.S. Court of Appeals for the second circuit in DeSario v. Thomas, HCFA sent a letter to state Medicaid Directors clarifying that states may develop a list of pre-approved items of medical equipment as a administrative convenience but must provide a reasonable and meaningful procedure for requesting items that do not appear on such a list. All home health services must be medically necessary and authorized on a physician's orders as part of a written plan of care.

Home health services are defined in Federal regulation as services provided at an individual's place of residence. In 1997, however, the Federal Court of Appeals for the Second Circuit ruled that home health nursing services may be provided outside the home, as long as they do not exceed the hours of nursing care that would have been provided in the home. The states covered by this ruling are New York, Connecticut, and Vermont.

EPSDT

The Federally Mandated EPSDT program for children from birth to 21 years entitles Medicaid eligible children to services found necessary to diagnose, treat, or ameliorate a defect, physical or mental illness, or condition identified by an EPSDT screen. The original 1967 legislation gave states the option to cover treatment services not covered under the state's Medicaid plan. In 1989, Congress strengthened the mandate by requiring states to cover all treatment services, regardless of whether or not those services are covered in the State's Medicaid plan.

As a result, the EPSDT component now covers the broadest possible array of Medicaid services, including personal care and other services provided in the home. For example, Wisconsin covers up to eight weeks of intensive in-home services for children with serious emotional disturbances, including parental skill training in behavior management techniques.

Optional Institutional Services

Options for covering institutional services assumed greater importance after 1981, when the waiver authority was created. This was because HCB waiver services can be provided only insofar as they provide an alternative to institutional care. *If a state is not covering a particular type of institutional service, it will not be able to offer that type of service in the community under an HCBS waiver program.*

The addition of services provided by ICFs and ICFs/MR as an optional benefit moved the Medicaid program into financing additional nursing home care. Adding optional institutional coverage of ICFs/MR made Federal matching funds available to help finance home and community services for persons with mental retardation (which had previously been supportable only with state funds), thus providing the institutional alternative for MR/DD waivers. Likewise, optional coverage of ICFs made Federal matching funds available for community coverage of a non-skilled level of care through aged/disabled waivers.

Optional Home and Community Services

When Medicaid was enacted, states were given the option of covering a wide range of services, several of which can be used in home and community settings. They include rehabilitation services, private duty nursing, physical and occupational therapy, and transportation services. In 2000, every stated provided at lease one optional service.

The rehabilitation option, in particular, offers states the means to provide a range of supportive services to people in home and community settings. Medicaid defines rehabilitation services as any medical or remedial services recommended by a physician for maximum reduction of physical or mental disability and restoration of a recipient to his or her best possible functional level. Rehabilitation services can be provided to people with either physical or mental disabilities.

The rehabilitation service option is a very flexible benefit, because services may be furnished either in the person's residence or elsewhere in the community. Many states cover psychosocial rehabilitation services, which—when combined with personal care and targeted case management services—can meet a wide range of services and support needs for persons who have a mental illness. In 1996, 31 states used the rehabilitation option for both categorically needy and medically needy populations; 13 additional states used it just for the categorically needy; and 9 states had Medicaid demonstration programs for rehabilitation services.

The rehabilitation option is not generally used to furnish long-term services and supports to individuals with disabilities other than mental illness. During the 1970s and 19080s, a few states secured HCFA approval to cover daytime services for persons with MR/DD under either the clinic is the rehabilitation option. However, HCFA ultimately ruled that the services being furnished were *habilitative* rather than rehabilitative and consequently could not be covered under either option.

The main basis for HCFA's ruling was the habilitative services could only be furnished to residents of ICFs/MR under the state Medicaid plan or through an HCBS waiver program for individuals otherwise eligible for ICF/MR services. A few states have maintained their state plan coverage of these services. Other states have terminated those coverages in favor of offering similar services through an HCBS waiver program.

Personal Care Services

Since the mid-1970s, states have had the option to offer personal care services under the Medicaid state plan. Making these services on of the longest standing Medicaid home and community benefits. This option was first established administratively under the Secretary's authority to add coverages over and above those spelled out in Section 1905 of the Social Security Act, if such services would further the Act's purposed. In 1993, Congress took the formal step of adding personal care to the list of services spelled out in the Medicaid statute.

When the option for states to offer personal care was created, it had a decidedly medical orientation. The services had to be prescribed by a physician, supervised by a registered nurse, and delivered in accordance with a care plan. Moreover, they could be provided only in the person's place of residence. Generally, the personal care services a state offered were tired mainly to assisting individuals in activities of daily living (ADLs)—bathing, dressing, eating, toileting, and transferring from a bed to a chair. Personal care workers could provide other forms of assistance (e.g., housekeeping and laundry) only on a limited basis and only if they were incidental to delivery of personal care services.

Starting in the late 1980s, some states sought to broaden the scope of personal care services and provide them outside the individual's home in order to enable beneficiaries to participate in community activities. In 1993, Congress not only formally incorporated personal care into Federal Medicaid law but also gave states explicit authorization to provide personal care outside the individual's home. Congress went even a step further in 1994, allowing states to: (1) use means other than nurse supervision to oversee provision of personal care services, and (2) establish means other than physician prescription, for authorizing such services. In November 1997, HCFA issued new regulations concerning optional Medicaid state plan personal care services to reflect these statutory changes.

In 2000, 27 states covered personal care services under their Medicaid state plans. However, Federal-state Medicaid outlays for these services, which totaled roughly $3.5 billion in FY1999, have grown at a relatively slow pace during the 1990s. This slow pace is at least in part because some states are electing to cover personal care services through more flexible and easy to target HCBS waiver programs instead of adding the coverage to their state plan or explaining the state plan coverage they already have in place.

In January 1999, HCFA released a State Medicaid Manual Transmittal that thoroughly revised and updated the Agency's guidelines concerning coverage of personal care services. The new Manual materials made it clear that personal care services may span provision of assistance not only with ADLs but also with Instrumental Activities of Daily Living (IADLS), such as personal hygiene, light housework, laundry, meal preparation, transportation, grocery shopping, using the telephone, medication management, and money management. HCFA also clarified that all relatives except "legally responsible relatives" (i.e., spouses and parents of minor children) could be paid for providing personal care services to beneficiaries.

The Manual further clarified that, for persons with cognitive impairments, personal care may include "cueing along with supervision to ensure the individual performs the task properly." And it explicitly recognized that provision of such services may be directed by the people receiving them. This consumer direction includes the individuals' supervision and training of their personal care attendants. (For the complete text see Appendix II.) Consumer direction of personal care services has been a feature of many personal assistance programs for many years (both under Medicaid and in programs funded only with state dollars). For example, consumer-direction was built into the Massachusetts Medicaid personal care program from its inception. The HCFA Manual clearly acknowledges and sanctions this model.

But neither the statutory provisions not the revised Federal regulations and HCFA State Medicaid Manual guidelines dictate that a state *must* change the scope of its pre-a993 personal care coverage, a state must file an amendment to its state plan. Taken together, therefore, these ground-breaking changes in Federal policy can help pave the way for a state to make its coverage of these services much broader than was the case in the past. But the states must act to bring about these changes in their own personal care programs.

Other State Plan and Optional Services

In addition to services listed under the "long-term services and supports" rubric, many other Medicaid benefits are relevant in meeting the needs of individuals with disabilities and chronic conditions. For example, states can provide powered wheelchairs and other mobility equipment through their coverage of medical equipment and supplies suitable for use in the home. State plans also cover many therapeutic services (e.g., occupational and physical therapy) that enable people with disabilities to achieve and maintain optimal functioning.

Establishment of HCBS Waiver Authority

In 1981, Congress authorized he waiver of certain Federal requirements to enable a state to provide home and community services (other than room and board) to individuals who would otherwise require SNF, ICF, or ICF/MR services reimbursable by Medicaid. The waiver programs are called 1915(c) waivers, named after the section of the Social Security Act that authorized them."

Under 1915(c) waiver authority, states can provide services not usually covered by the Medicaid program, as long as these services are required to keep a person from being institutionalized. Services covered under waiver programs include: case management, homemaker, home health aide, personal care, adult day health, habilitation, respite care, "such other services requested by the states as the Secretary may approve," and "day treatment or other partial hospitalization services, psychosocial rehabilitation services, and clinic services (whether or not furnished in a facility) for individuals with chronic mental illness."

All but the last were included when the statute was first enacted in 1981. Services for individuals with a chronic mental illness were added in the late 1980s. Neither the statute itself nor HCFA regulations further specify or define the scope of the listed services. However, the law that created the waiver program expressly permits the Secretary to approve services beyond those specifically spelled out in the law, as long as they are cost-effective. In the 19 years of the program's existence, HCFA has approved a wide variety of additional services.

In the early 1990s, HCFA first issued a standard HCBS waiver application format for states to submit requests to operate an HCBS waiver program. The standard format includes definitions of services states commonly cover in their HCBS waiver programs. The services listed in the standard format appear there because they: (a) arte included in the listing contained in the statue, or (b) are additional services frequently offered by states. The standard HCBS waiver application format now contains HCFA-suggested definitions of services states may cover under their HCS waiver programs, HCFA revised this standard format periodically, occasionally adding new services. (A complete listing of HCFA's service definitions is in Appendix 1.) The services a state may offer are by no means limited to those that spear in the standard format.

All states have HCBS waiver programs. In June 2000, there were 242 waiver programs approved by HCFA. States typically operate three or four, but some states offer more. Colorado, for example, operates ten. Federal-state spending for HCB waiver services totaled $10.6 billion in 1999. Roughly two-thirds of this underwrote HCB waiver services for people with developmental disabilities; the remaining third paid for HCB waiver services for other population groups.

Nationwide, the number of individuals participating in HCBS waiver programs increased from 240,000 in 1992 to an estimated 622,000 in 1998, reflecting an annual rate of increase of 17.2 percent. Individuals with developmental disabilities accounted for 39.7 percent of all waiver participants in 1998, about the same population as in 1992. Waiver programs for individuals with other disabilities (e.g., younger persons with non-developmental disabilities and/or persons over age 65 with disabilities) accounted for an estimated 57.1 percent of all participants in 1998. Highly targeted HCBS waiver programs (e.g., programs serving individuals with HIV/AIDS, persons with mental illness, persons who have had a brain injury or another brain disorder, and children with severe medical disabilities) accounted for the remaining 3.2 percent of program participants.

Average cost of HCB waiver services:
In 1998, the cost of HCB waiver services was about $14,950 per participant. However, there were marked differences in cost among HCBS waiver target populations. The average cost of HCB waiver services for people with developmental disabilities was $29,353 per participant. In contrast, HCBS waiver programs that serve seniors and/or younger persons with non-developmental disabilities incurred an average cost per participant of $5,362. The differences in HCBS waiver costs among target population groups stem from a wide variety of factors. Major factors that affect cost include: (a) differences in the intensity of the services particular target populations require; and (b) the extent to which other state plan services can meet the needs of the target populations (and thereby reduce the costs of the additional services that are furnished through HCBS waiver programs). Historically, the costs of supporting individuals with developmental disabilities through HCBS waiver programs have been well able cost of supporting other target populations, because a relatively high percentage of waiver participants with developmental disabilities have been receiving residential rather than in-home services.

The Katie Beckett Provision
The Kate Beckett provision is a statue—the Tax Equity and Fiscal Responsibility Act (TEFRA) 134—added to Medicaid in 1982. Katie Beckett is the name of the child whose parents petitioned the Federal government for her to receive Medicaid services at home instead of in a hospital, and whose plight led the Region Administration to urge Congress to enact the provision. TEFRA 134 gives states the option to cover non-institutionalized children with disabilities. Prior to enactment of this provision, if a child with disabilities lived at home, the parents' income and resources were automatically counted (deemed) as available for medical expenses. However, if the same child was institutionalized for 30 days or more, only the child's own income and resources were counted in the deeming calculation—substantially increasing the likelihood that a child could qualify for Medicaid. This sharp divergence in methods of counting income often forced families to institutionalize their children.

TEFRA 134 amended the Medicaid law to give states the option to waive the deeming of parental income and resources for children under 18 years old who were living at home but would otherwise be eligible for Medicaid-funded institutional care. Not counting parental income enables these children to received Medicaid services at home or in other community settings. Many states use this option, which requires states to determine that (1) the child requires the level of care provided in an institution; (2) it is appropriate to provide care outside the facility; and (3) the cost of care at home is no more than the cost of institutional care. In states that use this option, parents may choose either institutional or community care for their Medicaid eligible children.

Targeted Case Management

Until 1986, the only practical avenue available for a state to secure Medicaid funding for freestanding case management services (i.e., case management services not delivered as part of some other service or conducted in conjunction with the state's operation of its Medicaid program) was through an HCBS waiver program. Coverage of case management services in HCBS waiver programs was nearly universal at that time.

In 1986, Congress created the option for states to cover what were termed "targeted case management" services under their Medicaid plan. The expressed statutory purpose of targeted case management is to assist Medicaid recipients in "gaining access to needed medical, social, educational and other services." This option is unique among services afforded under the state plan, in that states are exempt from the comparability requirement to make such services available to all recipients. A state is permitted to amend this state plan to cover case management services for *specified groups of Medicaid recipients* (hence the term targeted). It may also offer these services on a less-than-statewide basis (again via state plan amendment instead of securing a waiver).

Given the expressed statutory purpose of the benefit—to assist individuals to obtain services from a wide variety of public and private programs—the scope of services a state may furnish through the targeted case management option is relatively broad. Covered activities include assistance in obtaining food stamps, energy assistance, emergency housing, or legal services. Covered activities also include service/support planning (including assessment) and monitoring delivery of the services and supports in order to ensure they are meeting a beneficiary's needs.

Financial Protections for Spouses Living in the Community

The Medicare Catastrophic Coverage Act of 1988 established special financial eligibility rules for institutionalized persons, to allow a spouse who remained in the community to retain more assets and income than had previously been allowed under Medicaid's financial eligibility rules. The figures for retainable resources are adjusted annually to reflect increases in the Consumer Price Index. The purpose of these rules is to prevent impoverishment of the spouse who is not institutionalized. States have the option to extend these rules to the spouses of beneficiaries receiving home and community services and also to follow the minimum maintenance allowance rules mandated for spouses of nursing home residents.

Program of All-Inclusive Care for the Elderly (PACE)

The Balanced Budget Act of 1997 (BBA) established the Program of All-inclusive care for the Elderly (PACE) model f care as a permanent provider entity within the Medicare/Medicaid programs. This provision enables states to provide PACE services to Medicaid beneficiaries as a state option, rather than as a demonstration as was formerly the case. The number of new PACE sites that can be established nationwide is limited to 80. the typical PACE program serves fewer than 300 individuals. PACE programs are funded by both the Medicare and Medicaid programs, and participants are generally eligible for both. PACE programs provide and manage all health, medical, and social services, and arrange other services as needed to provide preventive, rehabilitative, curative, and supportive care.

The PACE approach provides an alternative to institutional care for persons age 55 and over who require a nursing facility level of care. Services are provided in adult day health centers, homes, hospitals, and nursing homes. PACE providers receive payment only through the PACE capitation rate and are responsible for provisions of all items and services covered under both Medicare and Medicaid. The individuals enrolled in PACE receive benefits solely through the PACE program.

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This brief overview of Medicaid's statutory, regulatory, and policy provisions related to home and community services for people with disabilities provides a context for more detailed discussions in the chapters to come. Some of the institutional bias that remains in the program can be changed only by congressional amendments of Medicaid law (e.g., the requirement that a person must meet an institutional level-of-care standard to receive HCBS waiver services). But numerous provisions give state policymakers considerable freedom in designing their home and community service system to fit their state's particular needs. They have the option, in particular, to eliminate use of more restrictive financial criteria for HCBS waiver services than for institutional care. They also have considerable flexibility to create consumer-responsive systems that facilitate home and community living.

In the next several decades, as already noted, the U.S. population will age dramatically. Between 1987 and 1996, for example, the population of nursing home residents who were 85 and over rose from 49 to 56 percent for women, and from 29 to 33 percent for men. The severity of disability among the nursing home population has also been increasing. Almost 83 percent of nursing home residents in 1996 needed help with three or more ADLs, for example, compared with 72 percent of residents in 1987. Even is disability rates among older persons decline, more people will need long-term care services than at any other time in our nation's history.

Institutional care is costly. Given the projected demand for long-term care services, it u\is advisable for states to start planning now top create comprehensive long-term care systems that will enable people with disabilities—whatever their age or condition—to live in the community rather than rely on institutional residence and services. The Medicaid program can be the centerpiece of such a system—allowing states numerous options to provide home and community services that keep costs under control at the same time as they enable people with disabilities to retain their independence and their Dignity.

Source: Understanding Medicaid Home and Community Services: A Primer, Chapter 1, U.S. Department of Health and Human Services, October 2000

Understanding Medicaid Home and Community Services: A Primer

Transitioning People from Institutions to the Community

(Chapter 6)

The realization that many people with long-term care and support needs can thrive in integrated community settings has led to an increased commitment to transition people from ICFs/MR, nursing homes and other long-term institutions to the community. Since such persons have widely varying needs, the transition process presupposes that a wide range of community services and supports are in place or under development. Approaches and methods for developing the infrastructure needed to support community living are discussed in other chapters of the Primer. This chapter begins with a brief overview of how states have used Medicaid HCBS waiver programs to transition persons from ICFs/MR to the community. It then discusses (a) important factors states need to consider when planning transition programs in nursing homes and (b) options for using Medicaid dollars to help cover certain transitional costs.

Introduction

Many states have been active in creating alternatives to institutional care for persons with disabilities, in order to provide services and supports in the most integrated setting appropriate to an individual's needs. The recent Supreme Court decision (Olmstead v. L.C.) gives legal weight to this policy direction. State efforts top move persons out of nursing homes and other long-term care institutions into community settings can be an important part of a state's "comprehensive effectively working plan" for providing services to qualified persons in the most integrated setting, as described in HCFA guidance sent to states in January 2000.

Transitioning people with disabilities from institutions to the community began in a serious way with the recognition that many persons with mental retardation and other developmental disabilities were living in public institutions for whom institutional placement was not, in fact, appropriate. This recognition, starting in the 1970s, led to successful efforts by many states to sharply reduce the number of people living in large institutions (16 or more beds) by transitioning residents to a range of smaller, community settings, This dramatic wave of de-institutionalization set in motion the realignment of state developmental disabilities service systems from institutionally dominated to community-centered systems.

The first section of this chapter provides a brief overview of the transition experience from ICFs/MR, distilling the lessons learned from the experience that apply to transition programs more generally. The chapter then discussed major factors states need to consider when setting up transition programs, focusing primarily on the transition of nursing home residents.

Lessons from the Transitioning Experience with ICFs/MR
Medicaid funding for home and community services for persons with mental retardation and other developmental disabilities, particularly through HCBS waiver programs, has played a pivotal role in enabling a substantial majority of states to reduce (or in some case, end completely) long-term care service delivery in large state institutions. Between 1992 and 1999, states closed more than 80 large public institutions. Eight states and the District of Columbia no longer have any large state institutions in operation. The number of individuals served in non-state ICFs/MR in these and other states has also declined, as states have shifted to using HCBS waiver programs as a means to pay for home and community services for people with developmental disabilities.

When HCBS waiver programs became available, many states (e.g., Colorado, Oregon, Vermont, New Hampshire) ceased sponsoring additional ICF/MR development altogether. For example, while closing the Laconia state institution in 1984, New Hampshire switched entirely to providing HCB waiver services to both former residents and individuals with similar needs already in the community.

The decline in ICF/MR utilization began about the same time that the number of people with developmental disabilities participating in HCBS waiver programs began to grow very rapidly. Between 1990 and 1999, the number of individuals participating in HCBS waiver programs for people with developmental disabilities grew nearly six-fold. A major reason for increased use of HCBS waivers is the flexibility they afford states to offer services and supports that can accommodate individuals with a wide range of different needs in a targeted fashion without resorting to institutionalization (discussed further below).

The successful transitioning of people with developmental disabilities from institutions to the community demonstrates that HCBS services can be cost-effective substitutes for institutional services., However, the mere exchange of one source of funding for another is not the whole story. States that have been especially successful in closing large public facilities and reducing reliance or institutional and ICF/MR services overall have taken many other important steps to ensure that the needs of individuals with developmental disabilities could be met in the home and community. Many of these steps are equally applicable to beneficiaries with other disabilities being transitioned from nursing homes, state mental hospitals, and other institutions (as discussed further in the next section).

Development of community-based crisis and quick response capabilities. Maine established crisis response teams, resource coordinators, and emergency placement beds in small setting in each of its three regions as part of the initiative to close its

Pineland Center facility. Pineland Center had functioned as a "crisis-placement" facility. By providing resources in the community to respond to crises and working out permanent solutions for the individual, a prime rationale for operating Pineland was eliminated. Development of a similar capability was instrumental in Vermont's closing its Brandon facility in February 2000.

Being prepared to meet, in the community, the needs of individuals with multiple disabilities who need particularly intensive services. Individuals are often portrayed as "requiring" institutional services, when they can actually remain successfully in home and community settings as long as they have relatively intensive supports. The need for such intensive services may continue indefinitely for some of these individuals. For others, a decrease in service intensity over time has been noted. States have taken steps to provide the needed services in a community setting by permitting development of HCS waiver plans of care that allow costs above the average for institutions in that state. This allows states to decide on the plausibility of transitioning for a particular individual without forcing individuals *de facto* to seek institutional care simply because of a cost cap.

Provision of higher than average funding allocations for individuals transitioning to the community. States have found that the costs of community services for people being transitioned from institutional services can be higher that\n the costs of HCB waiver services furnished to persons who have not been institutionalized. This cost differential arises in part because many institutionalized persons have multiple functional limitations that require more intensive service provision to enable them to remain in the community. But the main reason for higher costs is that such individuals tend to require more paid service simply because they frequently lack adequate networks of informal and community supports (a lack that led to their institutionalization in the first place).

Although most states accommodate transitioning individuals from institutional settings through their existing HCBS waiver programs, a limited number operate distinct HCBS waiver programs for people transitioning from institutional settings. For example, Georgia created a special HCBS waiver program for individuals who transitioned to the community during the state's closure of its 320-bed, Atlanta-based Brook Run facility in 1997. Closure of this facility resulted in cost savings that enabled Georgia to provide HCB waiver services to 180 additional individuals over and above the person placed from institutional settings.

Development of family support programs. Family support services are crucial in avoiding unnecessary placements and are used by many states to reduce reliance on institutional services. For example, Michigan reduced the number of individuals it served in large public facilities from over 6000 in 1977 to fewer than 300 in 1998—in large part by launching and sustaining family support programs.

Development of strong, locally centered community service systems. In developmental disabilities services, creating a strong infrastructure at the community level has proven important in avoiding institutionalization and promoting quality service. Department of New Hampshire's locality-based, non-profit Area Agency system played a major role in facilitating closure of its Laconia facility. An important step in Michigan's transition activities was the state's strengthening of its network of local governmental Community Mental Health Service Programs. As part of its overall plan to close its Brandon facility, Vermont placed major emphasis on upgrading the skills of its community workforce and maintains a strong program of training community workers, In Kansas, the state developmental disabilities authority and the state's University Affiliated Program forged a partnership to improve the training and skills of the community work force—a step that was instrumental in enabling the state to transition many institutional residents to the community.

Making large-scale investments in quality assurance and quality improvement capabilities. Wyoming used such an investment to successfully place more than two-thirds of all the residents of its State Home and Training School in the community during the 1990s. The division of Developmental Disabilities out-stationed a cadre of field staff—initiating a comprehensive program of top-to-bottom reviews of community programs (including highlighting best practices), among other steps to improve worker training.

General Factors to Consider

Although states have much less experience transitioning people out of nursing homes than out of ICFs/MR, the earlier experiences transitioning persons with mental retardation and other developmental disabilities to the community provide valuable lessons for transitioning residents of nursing homes; and the same principles apply. The ability to achieve successful transitions from institutional to community-based living depends fundamentally on the ability to match the needs of the persons who have been living in nursing homes or other institutional environments with the availability of home and community services to meet those needs.

Persons leaving ICFs/MR have varying types and levels of need. Residents of nursing homes ort other types of institutions are an even more heterogeneous group. In the same nursing home, for example, the individuals to be transitioned may include a 75-year-old with cognitive impairment and multiple medical problems, a 45-year-old with quadriplegia, and a 25-year-old with a traumatic brain injury. They will have some needs in common. But they will also require services and supports tailored to their specific situations.

Whether a person currently resides in a nursing facility or an institutional facility the state is downsizing or closing, the steps in planning or arranging for community services are the same. In either case solid transitional planning is essential. However, additional challenges are involved when downsizing or closing an institutional facility, including maintaining the quality of facility services and worker morale, assisting workers to find other employment, addressing the "dual funding" problem (i.e., meeting the cost of maintaining facility operations while underwriting the costs of community placement), and ensuring that any special services provided in the facility will be available to individuals after they have left the institution.

Because each person has unique needs, the complexity and cost of an individual's actual transition process will vary. For this reason, it is crucial that transition programs be designed to operate with maximum flexibility. However, seven overarching steps need to be taken in setting up all transition programs, irrespective of the particular needs being addressed:

Identifying and addressing administrative and legal barriers

Identifying and educating residents with the desire and the potential for transition

Involving and collaborating with key players in the disability arena

Developing and implementing care management systems that supports transition

Identifying and addressing housing needs and payment sources

Providing innovative and flexible funding mechanisms

Establishing a quality assurance system that effectively balances risk and autonomy.

The remainder of this chapter discussed these activities as they relate to the transition of nursing home residents to the community. It is important to note that, although Medicaid can be used to help support many of these activities, states that have undertaken transition programs or facility closures emphasize that many costs associated with them are not covered by Medicaid. Such costs can include temporary rental assistance, furniture and clothing, and direct cash payments to individuals and families for one-time costs associated with the move.

Identify and Addressing Administrative and Legal Barriers

The first step a state must take when considering whether to start a transition program is to analyze state Medicaid regulations and administrative polices. This is to identify any institutional bias that might make it difficult or impossible for some people living in nursing homes to be served in the community. If a state does not use the 300 percent special income rule for its HCBS waiver program, for example. Some nursing home residents will not meet the financial eligibility criteria for waiver services, even though they can be appropriately served in the community. Similarly, if Medicaid's maintenance needs allowance is too low to permit the person to cover realistic room and board costs in the community, persons living in nursing home may be unable, simply for financial reasons, to transition to certain, residential care facilities.

Identifying and Educating Residents with Desire and Potential for Transition
Medicaid flexibility gives states the means to develop home and community programs able to serve individuals with widely varying needs. States, however, face a number of challenges when developing a successful nursing home transition program. They must first establish who the target population will be: Individuals under age 60? Those with a lower level of need (versus those needing a skilled level of care)? Those who have been in a nursing home for less than a year?

Once the target population has been selected, states must then develop referral, screening, and assessment procedures to identify individuals residing in nursing homes (or other institutions) who have the desire and the potential to be transitioned successfully to the community. Some states have used the nursing home minimum data set (MDS) or other screening and assessment tools as a baseline to identify potential candidates. The MDS is a core set of screening and assessment elements that forms the foundation of the comprehensive assessment for residents of long-term care facilities. By looking at factors captured in data sets—such as medical needs, functional status, and lengths of stay—transition programs can screen for potential candidates, who can then be further assessed for transition. The MDS data also include limited information on consumer preferences, which states might find useful to review in their initial screen as well.

Using MDS data in this manner, while a useful step, is by no means sufficient. Many individuals who are good candidates for a transition program may not show up in the initial screening. Therefore, programs should not rely solely on screening tools but should work with persons and groups who know the nursing home residents, as well as the services and supports that may be available to them. Such knowledge can make them invaluable sources of information to identify appropriate candidates for the program. Nursing home ombudsmen, independent living centers, protection and advocacy organizations, and other local groups and programs can also serve as important partners in the identification process itself. A number of states use centers for independent living to assist in the identification of individuals and with the transition process. The expertise and capabilities of such community organizations should be tapped early on to assure effective collaboration. Finally, individuals for whom a successful transition plan could not be arranged during the initial attempt should be recontacted on a regular basis to discuss new options for achieving the transition goal.

Involving and Collaborating with Key Players

To develop processes and procedures that will result in the successful relocation of nursing home residents who are appropriate for home and community settings, state need to take account of the interests of multiple constituents. Nursing facilities have business interests to protect; legislators have budgets and constituents to consider; communities and community providers have capacity constraints; families and other potential caregivers may have multiple competing responsibilities.

A Good way of taking these interests into account, and thus increasing a nursing home transition program's chance of success, is to develop partnerships with these key constituents. Partnerships can be with the consumer, the consumer's family and significant others advocacy groups, Centers for Independent Living, housing authorities, other state agencies, the state legislature, and nursing homes themselves. Some of these entities can also assist the state Medicaid program to identify the home and community service infrastructure necessary for a successful transition and help design service and support systems. It is important that the key constituent list include individuals or groups that are experienced in moving people out of nursing facilities and that they be involved at the earliest feasible point in the process.

Advocacy groups and consumers can be used to educate case managers about the consumer's needs and preferences. Nursing homes can be another valuable resource, and many welcome assistance with discharge planning. Nursing home social workers, for example, can work with residents and family members to identify necessary medical and other supports (therapists, physicians, mental health centers) and provide charts, MDS assessments, and plans of care. Nursing home staff can also help to identify candidates for transition.

Developing and Implementing Care Management Systems That Support Transition

Care management-also called case management and service coordination-is the process of using information from an assessment to develop a service plan. It involves working with a client (and family when appropriate) to identify the client's goals, preferences, and priorities, and to draw up a plan to provide the services necessary to support the client in the community. Case management also includes arranging for services, following up to ensure that services are in place, developing networks of individuals and organizations that can provide ongoing support, monitoring the client's situation on an ongoing basis, and adjusting the service package as needed.

Strong and flexible care management is central to the success of a transition program. Intensive care management systems can successfully relocate individuals into the community, often with long-term cost-savings, Medicaid allows states to pay for care management services related to transitioning an individual from an institution, as long as they do not duplicate regular discharge planning services paid for through another source. Medicaid-reimbursable care management services that help to ensure a successful transition include:

Discussing options with the resident

Arranging visits to potential settings

Providing consumer education and training prior to discharge

Arranging transportation on moving day

Making sure the new location is appropriately furnished

Implementing a plan of care so that services are available immediately when the beneficiary moves.

Three options are available for obtaining Medicaid reimbursement for care management service: case management as a waiver service, the targeted management option, and administrative claiming.

The targeted case management option is likely to offer the most flexibility because it can be targeted specifically to persons who are being transitioned to home and community settings. The Federal statute defines targeted case management as "services which assist an individual eligible under the plan in gaining access to needed medical, social, educational, and other services." This definition enables states to coordinate a broad range of activities and services outside the Medicaid program that are necessary for the optimal functioning of a Medicaid beneficiary. States desiring to provide these case management services under the targeted case management option may do so by amending their state plans accordingly. If a state does not plan to offer the service to all Medicaid recipients, the amendment must specify precisely the group or groups to be served.

HCFA recently enacted a policy change making it possible to obtain Medicaid funding for case management services provided during the 180 consecutive days of a Medicaid-eligible person's institutional stay, if provided for the purpose of community transition. When the case management services are provided under the targeted case management option, states may specify shorter time period or other conditions under which targeted case management may be provided.

Case management furnished as a service under an HCBS waiver may also be provided to institutionalized persons during the last 180 consecutive days prior to discharge. However, FFP is available only on the date the person leaves the institution and is enrolled in the waiver. In these cases, the cumulative total amount paid is claimed as a special single unit of transitional case management. See Appendix II for the complete text of the recent case management policy changes.

Identifying and Addressing Housing Needs and Payment Sources

Lack of accessible, appropriated, affordable, and safe housing can be a major barrier for transition programs. Waiting lists for support services often run up against even longer waiting lists for housing . In some cases, individuals may remain in nursing homes solely because there are no other housing alternatives. In such cases nursing homes could essentially become shelters for homeless people.

Housing needs differ, depending on individual needs. States have been working with their regional and local housing authorities with varying degrees of success to come up with the creative solutions to housing problems. Stronger partnership between health and housing authorities at both the state and Federal levels are often cited as the most important need in the search for comprehensive approaches to maintaining people in the community.

Many states have chosen to offer assisted living generally to persons age 65 and older. This term refers to a combination of housing and services in a residential environment that serves to maximize the autonomy and functioning of residents, many to whom require assistance to pursue their day-to-day activities. States do this by combining housing dollars from various sources (e.g., state, Federal, and private funds) with service dollars from Medicaid's HCBC waiver program or to a lesser extent, through the Medicaid state plan personal care option.

In FY 2000, the U.S. Department of Housing and Urban Development (HUD) was authorized to offer funding to develop and/or convert Section 202 housing stock to assist living facilities. HUD will provide subsidies to providers based on an approved state or local plan to furnish appropriate supportive services. Some analysts believe that conversion of Section 202 housing to assisted living has the potential to support a consumer focused model, by organizing services around the resident rather than a facility. Others argue the reverse-that these opportunities can limit individual autonomy by tying housing to services. These observers would rather see housing to services. These observers would rather see housing and service dollars following people to their settings of choice. In any case, pairing HUD and Medicaid dollars to provide assisted living does provide certain low-income-persons –particularly frail elderly persons-with an affordable alternative to nursing homes.

Assessments for accessibility

Environmental modifications are often crucial to a state's ability to serve an individual in the community. FFP may be available for the costs of assessing accessibility and the need for modifications in a person's home or vehicle in three ways.

First, FFP may be claimed at the administrative rate for assessments to determine whether the person's home or vehicle requires modifications to ensure the health and welfare of an HCBS waiver participant. (Assessment costs incurred to determine whether an individual's needs can be met under an HCBS waiver may qualify for FPP regardless of whether or not the person is eventually served under the waiver.)

Second, the cost of environmental assessment may be included in the cost of environmental modifications under an HCBS waiver. Third, the assessment may be performed by another service provider, such as a home health agency or occupational therapist. FPP is available at the service match rate when these providers perform assessment in addition to their other duties. (See Appendix II for the complete text of HCFA's guidance on FFP for assessing accessibility.)

Providing Innovative and Flexible Funding Mechanisms

One potential barrier to a successful transition program is inflexible funding streams. Even when home and community services are less expensive than nursing home care, it is often difficult for an individual to choose these services due to either one-time costs associated with transitioning or lack of coordinated funding. Typical one-time costs associated with moving into a community home include: first and last month's rent, security deposit, telephone deposit and installation fees, bed, linens and towels, and cooking utensils. Such costs will vary due to geographic differences in rents. One estimate puts them in the range of$1800

Transition programs need flexible funding arrangements that permit funding to shift from institutional care to home and community services by following individuals to the service setting of their choice. Oregon's regulations, for example, use state-only dollars to provide a special needs allowance for beneficiaries who are being diverted from entering or relocated from a nursing facility. Under this provision, payment for one-time needs can be authorized for household equipment and furniture, minor home repairs, rent or utility deposits, moving costs, property taxes, and transportation costs. Such special needs payments can be authorized only after all other sources of support (e.g., family, neighbors, friends, United Way, Salvation Arm) have been utilized.

Establishing a Quality Assurance System That Effectively Balances Risk and Autonomy

Community living presents a different set of risks from those associated with living in an institution. Transition programs need to have a quality assurance (QA) system that monitors and helps ensure service quality and client safety, particularly for the first few months in the community setting. At the same time, however, such a QA system must respect individuals' autonomy by acknowledging their choice to assume risk. The balance is delicate and can be hard to achieve. Programs that use a consumer-directed model allow individuals to assume more individual responsibility and accountability in a residential care setting than does an agency-directed model.

The assurances HCFA requires from states for approval of HCB waiver services include "necessary safeguards" to protect the "health and welfare" of persons receiving services in the community. Since HCBS waiver programs serve a diverse array of target populations, no one-size-fits-all application of these QA requirements can be prescribed. (Further discussion of quality assurance and improvements is outside the scope of this Primer.)

Obstacles to Look For

Although transitioning people out of institutions can save money over the long term, the process can incur major up-front costs that are not reimbursable by Medicaid. Given this, states may want to consider strategies that will divert people from entering institutions, particularly nursing homes, in the first place and ensure a quick return to the community if placement is unavoidable.

The ICFs/MR experience illustrates that the best transition program is one that makes sure that very few people will need to be transitioned. In the mental retardation and developmental disabilities field, this is known as the front door/back door connection. Little progress with transitioning can be made so long as the front door to the institution remains open; intervention before inappropriate placement (i.e. diversion) is easier than intervention after placement.

Many persons who can be served successfully in the community are admitted to nursing homes from hospitals. In some cases, this may be because hospital social work staff, under pressure to discharge people quickly, may not be aware of or have time to explore community options. As part of their approaches to expanding community placement strategies, Colorado an Texas have developed procedures specifically to divert appropriate individuals from nursing home placement after a hospital stay.

Colorado's program serves as an example. Colorado developed its diversion program to address state-specific barriers to community placement. These included: (a) long delays in processing Medicaid eligibility prior to discharge planners and consumers; (c) inadequate personal resources to stay in the community. To respond to the first of these obstacles, Colorado instituted a hospital-based care management program that dispatches a special case manager to pilot site hospital (both inpatient and outpatient settings) solely for the purpose of ensuring an expedited Medicaid eligibility determination process. The program is now in the process of developing a screening instrument to identify persons at risk of nursing facility placement, for use by hospital discharge planners and case managers.

Nursing Home Transition Grants Program

To assist states in providing transition options to Medicaid beneficiaries residing in nursing homes, HHS—through the combined efforts of HCFA and ASPE—has sponsored a grant program entitled the "Nursing Home transition Program." Its purpose is to assist current nursing home residents who choose to do so to move to home and community settings, remain these safely, and maximize their participation in community life, in 1998, grants averaging $175,00 were made to four states: Colorado, Michigan, Rhode Island, and Texas. In 1999, grants averaging $500,000 were made to four additional states: New Jersey, New Hampshire, Vermont, and Wisconsin. Each of the grantee states has implemented transition programs unique to their long-term care systems. HHS plans to continue making grants under this program for one additional year and perhaps longer. The 199 Supreme Court decision is the Olmstead case, which requires states to develop plans for serving persons with disabilities in the community, has increased state interest in the program.

Examples of State Transitioning Programs

Maine

The Alpha One Center for Independent Living in Maine instituted a state demonstration program in 1997 to move 40 adults under age 60 out of nursing homes. An independent evaluator is currently using the MDS database to profile and track individuals who leave the nursing home* and compare their characteristics with those of a similar population that remains in the nursing home.

The demonstration will track and compare functional status and quality of life changes. The results will yield a profile of required supports for successful community living. Another component of the evaluation will determine policy problems in the state that create barriers to community living.

Vermont

As part of its "one to One" transition program, Vermont has developed an assessment instrument, using a formula derived from the MDS to profile those individuals with a high potential for success in the community. Individuals are targeted for transition based on this assessment, their resource utilization groups (RUGs) classification, and other factors, including preference for community placement.

*For the individuals who leave the nursing home a modified MDS must be used, because the MDS itself is used only in an institution context.

Colorado

Deinstitutionalization Pilot Project

A single entry point (SEP) program integrates multiple providers in a system that delivers long-term care services to persons with a wide range of conditions and service needs in a way that appears seamless to the clients. Colorado has expanded the role of its SEP program to provide case management services to residents in nursing facilities who can and choose to be supported in community settings. The SEP program was established in 1993 to provide integrated referral and assessment of potential clients for the state's HCBS waiver and state-only community care programs. Under the pilot program, the Colorado Department of Health Care Policy and Financing and the SEP program worked closely with nursing homes to identify potential clients. The state evaluated the transition program's cost and processes and measured client pre-and post transition satisfaction.

The evaluation found that the nursing home staff were the most frequent source of referrals and a critical resource for identifying candidates for successful transition. Factors associated with successful transition included the availability of family support and the use of case management services. Age and functional limitations did not appear to be significant determinants of a successful transition. Most successful transitions occurred for those individual residing in the nursing facility for less than one year.

Hawaii
System for Transitioning People with Serious Mental Illness to the Community
In response to a Federal court consent decree, the Hawaii Department of Health, Adult Mental Health Division developed a program to identify persons residing in Hawaii State Hospitals who could more appropriately be served in the community. Each patient was assessed by clinical staff at the hospital and a discharge plan was developed for those so identified. These discharge plans were also used to develop a community service plan, which includes a variety of clinical, residential, and support services. State funds were used to develop new services, including case management, assertive community treatment, and housing. Medicaid funding pays for many services, but not for housing. As a result of this program, between 1997 and 1999 the state experienced an approximately 34 percent increase in discharges from the State Hospital.

Source: Understanding Medicaid Home and Community Services: A Primer, Chapter 6, U.S. Department of Health and Human Services, October 2000

Appendix F

A Preview of Independence & Transition to Community Living: The Role of Independent Living Centers

by Bonnie O'Day

Part I

Editor's Note

In summer 1993, ILRU initiated a study of how centers could assist consumers to move from nursing homes and into the community. We asked Bonnie O'Day to take the lead in conducting this important study, which consisted of:

- Reviewing the literature and legislation and convening a focus group of center directors and service delivery staff experienced in providing assistance in this area
- Identifying centers currently providing such transitional services,
- Selecting and conducting in-depth interviews with staff of centers with substantial involvement in assisting consumers to move out of nursing homes
- Writing a report which summarizes her findings and presents a set of recommendations for increasing services to this group of people, whom our friends at ADAPT would call our incarcerated brothers and sisters.

We are taking this opportunity to give you a preview of findings from the study while the monograph is being printed. This month's preview features background information on why centers should make assistance to people living in nursing homes a centers-wide priority. Next month, we will preview the portion of the report addressing recommendations for increasing transition to community living services.

Background

Since the beginning of the disability rights movement, a major thrust of independent living centers has been to enable individuals with significant disabilities to leave nursing homes and to live independently in the community. Significant gains have been made in closing state institutions, and in many locations, nursing-home placement is no longer seen as the only option. Currently, about 80 percent of elders who have some type of disability are living in the community. Over two-thirds of these individuals live in single family houses and over one-third live with a spouse (Leutz, Capitman, MacAdam, & Abrahams, 1992).

Nursing Home Demographics

On the other hand, both data reported in the literature as well as anecdotal evidence suggest that approximately 1.9 million people of working age and older still live in long-term care facilities and nursing homes. The Institutional Population component of the 1987 National Medical Expenditure Survey found roughly 231,000 users of nursing homes who are under age 65, representing 10.3 percent of the total nursing home population. The number of male and female nursing home residents reflects the distribution of the general population in contrast to residents 65 and older, where women constitute the vast majority (71.8%) of nursing home residents. This survey also reveals that younger nursing home residents (between the ages of 18 and 55) are predominantly single or divorced (about 83%) and contain a higher percentage of blacks than are represented in the larger community (20% as compared with 11.8%). More than 36 percent of nursing home residents in this age group have disorders of the central nervous system, such as cerebral palsy, multiple sclerosis, paralysis, or epilepsy. Over 34 percent are diagnosed with psychoses, including organic brain disorders, 33.9 percent have nonpsychotic mental disorders, and 23.5 percent are classified as mentally retarded (Lair, 1992).

About 100,000 people still live in intermediate care facilities for the mentally retarded (ICF/MR)-- institutions with more than 16 residents. About 38,000 people with mental retardation or developmental disabilities (MR/DD) live in Medicaid-financed nursing facilities, approximately the same number as in 1977 (Mangan, Lakin, & Prouty, 1995).

Not surprisingly, most residents come to the nursing home from another facility. Only about one-third of nursing home users between the ages of 18 and 54 move from independence in the community to the nursing home. About 12 percent come from retirement centers, group or boarding homes, or the street. The rest come from hospitals, other nursing homes, state institutions, or other health care facilities. On average, the length of stay in a nursing home for this age group is approximately 6.2 years. A shocking 20 percent of residents aged 18 to 54 have been institutionalized for ten years or more (National Medical Expenditure Survey, 1992).

Cost: Nursing Homes Vs. Community Living

Institutionalization is the most expensive form of long-term care offered to elderly and disabled Americans. Annual institutional costs per person range from $30,000 to $60,000, while the annual costs of in-home services are estimated by Nosek and Howland (1993) to be $8,000 to $15,000 and by ADAPT (1995) to be about $27,000 for people who use 24-hour care. Even people who require assistance from a ventilator and need intensive in-home services can live more cheaply in the community. According to one study of 20 ventilator-dependent individuals, institutional costs were 274 to 304 % greater than community placement. Daily institutional costs were $648 to $719 per day, while community placement costs, including personal assistance services (PAS), equipment, transportation, prescriptions, SSI, and rent supplements were $134 to $312 per day (Bach, Intintola, Alba, & Holland, 1992).

The relatively poor cost-effectiveness of nursing homes as compared to community living is demonstrated by the following real-life situations of people with significant disabilities:

> A married couple living in a nursing home was unable to move into the community simply because funds to make an apartment wheelchair accessible were not available. For lack of a one-time investment of a few thousand dollars, the couple was forced to live in a dependent situation which cost the state tens of thousands of dollars annually.
>
> An elderly man was placed in a nursing home because he was unable to cook meals for himself. This was his only functional limitation (Nosek & Howland, 1993).

Despite this overwhelming evidence of cost savings, federal financial arrangements encourage the use of nursing homes when other types of care may be more appropriate. Medicaid covers nursing home costs, but may not pay for PAS, homemaker/chore services, home modification for accessibility, or adaptive equipment. These policies unnecessarily force people into skilled care facilities purely for financial reasons. As Leutz states,

> . . . resources are too often misallocated toward expensive tertiary care and life support to the neglect of primary prevention, public health, and basic social supports. Medicare will spend small fortunes for aggressive acute care for 85-year-olds; Medicaid will do the same to keep an individual alive for years in a vegetative state; but help is unlikely to be available for an overburdened, aging woman struggling to lift her disabled husband from a bath. Our public and private insurance systems pay for expensive machinery that substitutes for failing kidneys, lungs and hearts, but they are not yet ready to pay for a simple service that may substitute for a failing or absent family caregiver. Leutz, et al, 1992

Numerous studies also demonstrate the detrimental effects of nursing homes on individual well-being. Physical and mental functioning may deteriorate (Avorn & Langer, 1982), and dependency tends to increase. One study examined 341 nursing home residents with developmental disabilities to compare changes in functioning among individuals who moved into the community with those who stayed in the nursing home. This two-year study found that residents who moved into community settings experienced significant health benefits, while those who remained in nursing homes experienced deterioration or no significant changes. Decreases in anemia, obesity, overall health problems, number of days of hospitalization, and mobility limitations were observed among those who left the nursing home. Persons who remained in the nursing home experienced increased speech impairment, circulation disorders, and level of adaptive functioning (Heller, Factor, & Hahn, 1995).

Most people strongly prefer to stay at home rather than enter a nursing home or other form of institutional care (Zedlewski, Barnes, Burt, McBride, & Meyer, 1989). Nursing home or institutionalized living that allows little opportunity for self-determination has been shown to have a strong negative impact on life satisfaction (Vallerand, O'Conner, & Blais, 1989). But, moving from nursing homes or remaining in the community after onset of a disability is a formidable challenge requiring considerable planning, problem-solving, and emotional fortitude. People who wish to move from institutions into the community face a wide array of obstacles, including lack of PAS, social stigma, inaccessible housing, lack of independent living skills, few financial resources to make the move, and inadequate transportation. Inadequacy of support systems in place to allow for comfortable and safe community living makes the move impossible for many citizens. However, people who have made a successful transition from residential care and nursing homes to independent community living express a sense of greater well-being, have lower costs associated with care, and are more involved in community activities than those who remain nursing home residents (Nosek & Howland, 1993).

The Role of Centers

As increasing numbers of people with significant disabilities live independently and as more institutions are closed in favor of community options, some centers have turned away from persons still in nursing homes or institutions. One reason for this trend might be that only three percent of people with spinal cord injuries, the original independent living constituency, are placed in nursing homes today; the percentage was much higher in the past (Berkowitz, Harvey, Greene, & Wilson, 1992). Today's nursing home population is more severely disabled than in the past and requires a broader and more complex array of services and supports to live independently. Another problem is that most residents of large, state institutions have mental retardation--a disability group that historically has been underserved by independent living centers. But, as Jerry O'Bryan, board member and former peer counselor for the Endependence Center of Hampton Roads explains, "Nursing home residents have just as much right to center services as people already living in the community. People in nursing homes tend to have the least financial resources of anyone in our society; many have no family or social supports. They need the gamut of independent living services, especially advocacy. If centers are not serving this population, we are not truly living up to our mission."

The testimony of Harry Richardson brings the dependence, degradation, and frustration of institutional life into clear focus:

> I am 67 years old and have cerebral palsy and have been in an institution since I was ten years old. . . . My wish to leave the nursing home is finally coming true. I am going to get out of the nursing home in a week. I wish they would close the nursing home. I have seen with my own eyes many things. Someone at the nursing home recently asked for help, and the staff said they were busy. . . . Sometimes the staff won't get me out of bed, and won't help when I have passes to leave the home. A driver wouldn't take me to a movie . . . I still have problems, and sometimes I have to wait ten minutes for an elevator, [and I miss my ride] because the staff won't take me on time. I don't think that it is right that I have to pay [for my transportation], even when I miss my rides. I always have to wait until they take me. . . . This won't happen when I have my own attendant.
>
> In the nursing home, there is no freedom for me. There are no services available for people like me. I sued the state on my behalf and others. Now, I will have my own apartment and my own attendant, and my dream is finally coming true. There are many people, including many not as disabled as myself, who are still waiting for attendant care services. This is why we need home and community based attendant care services so that people don't have to spend their whole lives in a nursing home--so people can have a choice of living. Home and community based care will allow us to attain and have personal freedom. It will mean that people in nursing homes will have an opportunity to make their dreams a reality.
>
> --National Council on Disability, 1994

Independent living centers can be a vital link for people wanting to move from long-term rehabilitation facilities into community settings. By providing information and referral about resources in the community, peer counseling, independent living skills training, individual and systems advocacy, and assistance in obtaining accessible housing and PAS, centers enable hundreds of individuals with severe disabilities to leave custodial care for independence in the community every year. Although centers have a long history of successful advocacy and service in this area, little information is available about the extent to which centers assist people in making the move and about what services contribute to a successful transition to community living. Surprisingly, "how-to" information to assist centers in establishing successful transitional efforts is scarce.

As part of its research and training center, the Independent Living Research Utilization (ILRU) Program initiated a study of the "state of the art" of center-based transitional services to support community entry for people with significant disabilities. The purposes of this project were:

- Obtain information on exemplary approaches being used by centers to assist people with disabilities in making the transition from long-term rehabilitation facilities to community living, and
- Provide centers around the country with appropriate information and technical assistance to assist them in providing transitional services in an effective manner.

A major focus of the project was to determine the extent to which programs exist to help people with significant disabilities make a transition into the community. The outcome was a monograph, which highlights the "best practices" of six centers and examines policy barriers that inhibit community living.

A Preview of Independence & Transition to Community Living: The Role of Independent Living Centers

by Bonnie O'Day

Part II

Editor's Note

Last month's Readings in Independent Living was the first of two previews of a study on how centers can assist consumers to move from nursing homes into the community. As you may recall, we asked Bonnie O'Day to take the lead in conducting this important study.

Last month's preview featured background information on why centers should make assistance to people living in nursing homes a center-wide priority. In this issue, the preview focuses on O'Day's recommendations for increasing efforts to assist people to live in their communities.

Background

In July of 1993, ILRU sent a brief three-page survey to all in its directory of centers in the U.S. to obtain an overview of the extent of center involvement in assisting consumers to leave nursing homes for life in the community. The survey asked centers to explain services offered and how these services were funded, to describe formal and informal relationships with nursing homes or other institutions, to highlight specific efforts to serve minority populations, and to list major problems people with disabilities face in making a smooth transition to the community.

The top two problem areas identified by centers in the survey were lack of accessible, affordable housing and inadequate PAS. These are analyzed in the monograph--the analysis being based upon a literature review, legislation and other legal documents, and interviews with center staff and other leaders of the independent living movement. Based upon these responses, six exemplary programs were selected for further study. They include ENDependence Center of Hampton Roads, Norfolk, Virginia; Liberty Resources, Inc., Philadelphia, Pennsylvania; Wyoming Independent Living Rehabilitation, Inc., Casper, Wyoming; Topeka Independent Living Resource Center, Topeka, Kansas; Independent Living Center of Amsterdam, Amsterdam, New York; and Independent Living Resource Center, San Francisco, California.

These exemplary programs represent a cross section of centers including large and small centers, those serving urban and rural areas, and those with formal contracts with state agencies to provide transitional services, as well as those which provide services more informally. The author interviewed each executive director or other center personnel by telephone. Interviews lasted one and one-half to two hours each, not including follow-up telephone calls to obtain additional clarification. Persons interviewed had an opportunity to review the final draft of their chapters in the monograph for completeness and accuracy.

Overview

Moving from nursing homes or remaining in the community after onset of a disability is a formidable challenge requiring considerable planning, problem-solving, and emotional fortitude. People who wish to move from institutions into the community face a wide array of obstacles, including lack of PAS, lack of independent living skills, few financial resources to make the move, social stigma, inaccessible housing, and inadequate transportation. This inadequacy of support systems in place to allow for comfortable and safe community living makes the move impossible for many citizens.

However, over the last 15 years, independent living centers have been a vital link for people wanting to move from nursing homes and other long-term care facilities into the community. By providing information and referral about community resources, peer counseling, independent living skills training, individual and systems advocacy, and assistance in obtaining accessible housing and PAS, centers enable hundreds of individuals with severe disabilities to leave custodial care for independence every year and have allowed thousands more to stay out of nursing homes and remain in the community.

This project has shown that centers are fulfilling one of their original missions--assisting people to leave nursing homes for community integration. Almost all centers who responded to ILRU survey (96%) said that they served nursing home residents, providing assistance ranging from an informal array of traditional independent living services to more formalized arrangements where one or several center staff are dedicated to helping residents move out. Over half of the centers responding said they had assisted more than five residents and about ten percent said they had assisted more than 20 consumers to make the move.

However, much work remains to be done to reach the thousands of people of all ages still incarcerated in institutions. Because most of these individuals are elders, members of racial or ethnic minority groups, or people with severe physical and mental disabilities, centers must creatively expand their services to reach populations that have traditionally been excluded from living independently. The six exemplary programs highlighted in this monograph present innovative approaches that can be used as prototypes for centers wishing to serve nursing home residents more effectively.

Recommendations

While centers' transition programs vary depending upon the needs of the local community and the target population, the following conclusions and recommendations can be drawn from the six exemplary programs.

The major thrust of transition programs should be advocacy for systems change to prevent institutionalization. Long-range planning and a strong, united advocacy effort are required for maximum success. Centers should agree among themselves upon strategies and outcomes before advocacy is initiated.

Centers, local communities, and society at large all benefit from avoiding institutionalization. Allowing people to remain in the community minimizes personal trauma for the consumer and saves valuable staff time and financial resources. Centers should advocate for expansion of Medicaid waiver programs to include a broader array of services and supports. Even minimal policy changes, such as redefining funding for home modifications and adaptive equipment, can mean the difference between remaining at home or moving to an institution.

The Idell S. case, brought under the Americans with Disabilities Act (ADA), offers strong implications in support of de-institutionalization. Independent living centers and other proponents of community integration should work with legal service organizations to seek compliance with the ADA's "most integrated setting" mandate in their state long-term care and Medicaid programs.

To insure effective prevention of unnecessary institutionalization, center boards, staff, and consumers should become knowledgeable about the nursing home reform amendments of OBRA '87 as well as how Medicaid waiver programs are being implemented in their state.

Centers should insure that a higher proportion of minorities are served in nursing home transition programs than is reflected in the general population, since people of color are disproportionately represented among nursing home residents. While no conclusion can be drawn about whether or not distinct services for multicultural populations are needed, it is clear that center board and staff composition should reflect the racial and ethnic mix of the consumer population. Most important multicultural issues should be considered at the program design stage, not as an afterthought. Additional information is needed about how various populations can be served effectively. NIDRR should consider setting aside additional funds for studies specifically addressing multicultural issues.

Board members, staff, and volunteers who have been institutionalized and have made a successful transition to independence can have a powerful impact on convincing nursing home residents, medical professionals, and others of the viability of independent living. These formerly interred individuals should be used at all levels of program design and implementation, especially in the provision of direct services and advocacy. A consumer group of nursing home residents can also be an important vehicle for obtaining consumer participation and involvement.

A common problem observed during the research for this monograph was that centers did not keep accurate statistics on how many consumers left nursing homes or remained in the community as a result of center programs. Centers commonly stake claims for additional funding upon cost savings of community versus institutional living and should bolster these claims with accurate documentation.

Administration and staff of independent living centers must have a strong commitment to independent living philosophy and must guard vigilantly against the tendency to move toward a medical model program. Resistance of officials in the DD/MR system is a major barrier to the involvement of centers in de-institutionalization. Services for people leaving state hospitals are still based upon a medical model-based philosophy with an over-emphasis on case management. Many centers have stayed away from provision of highly concentrated service and the necessity of meeting medical requirements, such as a staff nurse, because these demands are believed to be antithetical to the philosophy of independent living.

Assisting people with the most significant disabilities, especially those with no other options, to live in the community should be the mission of centers. They should not use stiff medical and administrative requirements as an excuse not to serve people with severe cognitive disabilities but should advocate for programs that are less medical and more consumer controlled.

Centers often identify attitudes of medical professionals and lack of outreach as barriers to successful transition out of institutional settings. Most centers are not well known among hospital personnel, and many referrals are obtained after the individual has already been placed in a nursing home. Since the medical community is still not familiar with independent living philosophy, centers need to step up efforts to educate the medical establishment and related service entities

Centers should recognize that administration of a formalized transition program is extremely challenging and should seek out additional administrative resources and financial expertise before project initiation. Centers should obtain in-depth information about administrative requirements from the sponsoring agency and should visit similar programs to observe record keeping systems. The decision to undertake a formalized, complex transition program can change the very essence of a center, and board members, staff, and consumers should make this decision with as much foreknowledge and with as much commitment as possible.

In Conclusion

In sum, the most important ingredient for any successful transition program is a gut-level understanding of independent living philosophy and the basic belief that everyone, irrespective of disability or degree of disability, has the right to live in the community. Centers must understand that the real obstacles are bigotry and lack of creativity, not the disabilities or characteristics of individuals denied the right to self-determination or consigned to institutional living.

A consumer PAS program and accessible, affordable housing are key necessary ingredients. Staff must learn to be good "scroungers," knowing where to locate a used refrigerator, couch, or kitchen appliances. A slush fund that can be used to purchase household items is also a plus. Finally, a willingness to be a strong advocate, even at the cost of incurring hostility or anger, will make a center more successful.

An effective center will allow consumers the freedom to succeed or fail; this is the price of true independence.

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Appendix G

Living in the Community

by James E. Sturdivant, Lori E. Baskette, and Jamey E. George

September 2000

James E. Sturdivant, Lori E. Baskette and Jamey E. George describe the elements of their successful program to move people out of nursing homes and into the community:

- Providing funding for deposits, first month's rent and other necessities, including assistive technology;
- Providing training and the other core services before and after consumers leave the nursing home;
- Developing relationships with housing and other service providers.

The Issue - Let Freedom Ring

In Maryland, approximately 9.7% of nursing home residents are under the age of 65. The issue we, at MCIL Resources for Independent Living (MCIL) in Baltimore, MD, are trying to resolve is the unnecessary placement of non-elderly persons who have incurred severe disabilities, through trauma, disease or complications at birth, into nursing homes against their will.

Often times, the family members are well-intentioned, but become overwhelmed and believes that they cannot care for the individual. In many instances there are no family members who can care for the individual. In addition, many individuals find themselves in nursing homes because they lose their place in the community through foreclosure of their home or inability to pay rent due to being in rehabilitation and/or unemployed. Finally, many individuals have found themselves in situations where their Social Security benefits/assets are claimed by the nursing home to cover the cost of their stay.

The placement in a nursing home of an individual who can lead an independent life in the community is both inappropriate and costly:

- The cost of keeping a person with quadriplegia who requires 24 hour live-in provider care in a nursing home is about $87,000 annually, while the cost for the same individual living in an apartment in the community is only about $33,000.
- Institutional life-style creates various undue limitations on residents.
- Persons residing in nursing homes are denied their rights to freedom, of choice and privacy.
- The family as a unit is divided by losing a member to the nursing home, which can cause duress leading to unnecessary crises.
- Nursing home residents experience deterioration in health, resulting in an increase of hospitalizations and deaths.

Once a person is placed in a nursing home, it is difficult, if not impossible, to get out. This is especially so if the person relies on a small monthly allowance for any and all personal items (e.g., clothing, cigarettes, toiletries, candy, private telephone line, cable TV, durable medical equipment, and any other incidentals). If the consumer does manage to save their allowance, and they have Medical Assistance, they can't save more than $2,000. If they do, they risk losing Medical Assistance and, therefore, could be discharged from the nursing home. The sad result is they are left homeless. To further complicate a difficult situation, Medicare and Medicaid do not cover the cost of durable medical equipment of nursing home residents. Consequently, they will never be able to save the monies necessary to get out of the nursing home (e.g., for security deposits for housing, utilities, telephone, furniture).

A Viable Program with Funding

Funding for MCIL's Living in the Community program was obtained through a grant from the United Way of Central Maryland and a Community Development Block Grant from Baltimore County Government. Obtaining the funding was not easy -United Way questioned why a person would want to leave a nursing home, and Baltimore County initially just threw the request in the trash. Finally, when we met with United Way's independent living panel, we took two individuals whom we previously assisted to return to the community, and one individual who was still imprisoned in a nursing home. This allowed us to explain to the panel what it was like to be in a nursing home and how much better it is to live in the community. The panel was impressed and we were awarded funding for the program. The Baltimore County funding was finally awarded after the chairperson of the County's Commission on Disabilities intervened on our behalf.

The United Way funds were used for start-up costs for an apartment, including security deposit, first month's rent, gas, electric, and telephone deposits, food, personal assistance services (PAS), prescriptions and rental of medical equipment if needed. Furniture was purchased in a collaborative effort with second-hand furniture stores such as Goodwill, and also with other nonprofits such as United Stand against Multiple Sclerosis and Catholic Charities. If the Social Security paperwork had not been processed following the first month of discharge, a check equivalent to one's SSDI / SSI benefits was issued to the consumer using these funds.

The Baltimore County funds were used for the purchase of assistive technology and adaptive equipment. These purchases would not be covered by medical insurance while the consumer was still in the nursing home, and many individuals could not leave the nursing home without this equipment. This made for a smoother transition by the individual with a disability to the community. Types of assistive technology purchased included power wheelchairs and scooters, environmental control units, remote control speakerphones and stairglides. Adaptive equipment included hand-held shower nozzles, bathtub handrails, transfer tub benches, shower chairs, a full size hospital bed and ramps. These funds could be used to purchase other types of assistive technology and adaptive equipment that would enable persons with disabilities to reach or increase their level of independence in the community. These other items included augmentative communication devices, universal control switches, CCTV, voice-activated equipment for the visually impaired, visual aids for the hearing impaired, reachers, adaptive dishes, utensils, cookware and kitchen equipment.

Implementation of an Effective Program

In order to implement this program, we visited many nursing homes, talking to administrative personnel and other staff about our "Living in the Community" program. Social workers assisted us in identifying persons about to be discharged, which included many individuals with no place to go. They provided some brief background history about the consumer, his/her disability and family. Physical and occupational therapists provided input as to independence levels, transfer capabilities, equipment needs assessments of individuals wanting to live in the community. Consultation with these therapists also provided information as to the various levels of care that might be needed by consumers, as opposed to what they could do for themselves. A better understanding of what supports the individual would need in the community was also accomplished by working with family members where applicable.

To ensure maximum success, we worked diligently with consumers to prepare them for transitioning to the community. This included the four CIL core services. Based on a needs assessment done in the nursing home, consumers received training in independent living skills, including meal planning, food preparation, personal hygiene, money management, home safety, tenant responsibilities and socialization skills. Resources were provided to consumers to improve and increase their independence levels (i.e., paratransit, Division of Rehabilitation Services (DORS), schools and trainings in the area, and employment and volunteer opportunities). Peer mentoring was provided to nursing home residents by staff members and volunteers with disabilities to alleviate concerns and fears of returning to the community. In many instances, the newly disabled residents had not experienced the reaction of others in the community to their disabilities. They had not had the opportunity to experience and adjust to living within their own community and facing attitudinal barriers. Through advocacy, we acted on their behalf to promote individual and systemic changes. Consumers learned their basic civil rights so that they could advocate for themselves.

Through years of experience working with Wallace H. Campbell Management Company, we were often afforded the opportunity to be notified first of affordable, accessible housing vacancies. This allowed us to place consumers in housing in a prompt manner. Utilizing our housing registry, which consists of listings and a database that we created and compiled, we began to develop relationships with other apartment management companies and landlords. Through collaboration with Baltimore County

Department of Housing, we managed the HUD Section 8 mainstream program. This program consisted of 100 Section 8 vouchers specifically earmarked for persons with disabilities. We assisted consumers with screening and gathering all information needed for the interviews and also attended interviews to advocate on behalf of consumers. As a result, some of our consumers qualified for Section 8 vouchers. Some consumers were even able to take advantage of the Baltimore Regional Housing Opportunity Program, which receives some HUD funding and assisted them with locating housing and with security deposits.

Once out of the nursing home, our goal was for the MCIL Disability Advocates to continue working with consumers, providing the four core services as well as community support services to empower individuals to lead self-directed, independent and productive lives in the community. The community-based services included beginning or returning to school or work, utilizing DORS and job fairs. Department of Social Services provided food stamps, Medical Assistance, and help with gas and electric expenses. Transportation needs were handled by MCIL contract with Maryland Mass Transportation Administration. Travel trainers registered persons for the paratransit system or trained individuals to use the fixed-route bus service. The transportation training also allowed for social and/or volunteer opportunities that greatly enhanced independence, prevented isolation and promoted total inclusion in society.

Results and Follow-up

Our success with the program was astounding. In our original grant application, we stated that we would "free" six to ten persons with disabilities between the ages of 18 and 64 who were needlessly "imprisoned" in nursing homes. However, because of the resourcefulness of the staff, we were able to free 16 "POW's" into the community, an impressive 160 percent of the original goal.

To evaluate the success of our program, we utilized the services of two occupational therapy college students to compile a satisfaction assessment survey and interview consumers who had transitioned from nursing homes to the community. The Canadian Occupational Performance Measure (COPM) was used by the surveyors as a guide to formulate questions for the satisfaction survey. The Model for Health Education Planning (MHEP) was used to structure the MCIL program initiated by the students. This model would allow for adjustments to be made to the program on an as needed basis as the program progressed. The program was based on secondary data collection as obtained through staff interviews, consumer interviews, chart and literature reviews. The information was compiled to determine which of our offered services have been most beneficial to consumers. Below are some of the questions asked of consumers in the survey:

- How have things been since you left the nursing home?

- What do you consider to be the best part of your life now compared to when you were in the nursing home?
- Do you feel like you were adequately prepared for the transition from the nursing home to independent living?
- How would you categorize your overall satisfaction with MCIL support since moving out to live independently in the community?

Another measure of satisfaction was letters from consumers stating how this program had enhanced their quality of life. These are a few of their comments:

> *MCIL makes love, care and independence possible so you can do what you need to do. MCIL helped me overcome hurdles I thought were impossible.*
>
> *I have my own freedom-nobody to tell me nothing, like when I wake up or when I eat.*
>
> *I think they're (MCIL) wonderful. If it wasn't for them, I never would have gotten out.*
>
> *I got my own freedom, better food and everything. Get up when I want, go to bed, do what I want.*
>
> *This apartment- it gives me space, it's the best part of my life.*

These letters are not only used to document our success, but they are also used for other grant applications in order to help continue to free our people from imprisonment in nursing homes. Here are some examples of what some consumers are doing since returning to the community:

- A husband and wife were reunited and are living together in their own apartment.
- A consumer is enrolled in a vocational rehabilitation program, is learning to drive through the Driver's Ed program and will be able to find employment once training is completed.
- A consumer is now attending a vocational program.
- A consumer was able to rejoin his wife and family at home.
- A consumer was able to leave the nursing home and move to Georgia to find her own apartment and be with family.
- A consumer will be able to die at home with dignity and family at his side.
- A consumer has started a family.

In the two years that the "Living in the Community" program has been funded, two separate funds were maintained. One set of funds was for start-up costs for housing and the second fund was for assistive technology. We feel that it would be most effective to combine all sources of funding to meet the requirements of the program. As an example, this year we ran out of the start-up cost funding and were only able to use the assistive technology funds. The only way we could get someone out of a nursing home was if they had an existing residence to go to. Most individuals trying to get out of a nursing home need all services. We have formed a waiting list of these individuals and have applied for funding from the ABELL Foundation that we hope will accomplish our goal.

We are also advocating for legislators in Maryland to support the MICASSA Bill, S. 1935. This bill will allow individuals with disabilities to use their Medicaid funding to choose whether they want to live in the community or in a nursing home. It is our hope that MICASSA will be passed into law and individuals who can and want to live in the community will be freed from nursing homes to live full and productive lives.

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Appendix H

The Homecoming Project:

Wisconsin's Nursing Home Transition Demonstration

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The MEDSTAT Group

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INTRODUCTION

Across the broad spectrum of public policy, American society is increasing opportunities for persons with all types of disabilities, including people with the physical disabilities and frail older persons, to live lives of their own choosing, in places of their own choosing. Recent policy initiatives in civil rights, health and long term care, income assistance, employment, and housing have a common objective--to create systems of supports and services that allow persons with disabilities, even the most severe impairments, to live independently in accordance with their own choices and decisions. President Bush's New Freedom Initiative provides additional impetus for the continued expansion of community-based supports and services and continued reduction of the nation's reliance on institutional models of care for persons of all ages with disabilities.

Nursing Home Transitions Demonstration: 12 states were awarded grants under the Nursing Home Transitions Demonstration program.

The Centers for Medicare & Medicaid Services (CMS), in association with the Assistant Secretary of Planning and Evaluation (ASPE), sponsored the Nursing Home Transitions Demonstration Program. Under the Demonstration program, CMS and ASPE awarded grants to 12 states between 1998 and 2000 to help nursing home residents move to the community.1 CMS and ASPE selected The MEDSTAT Group to evaluate the Demonstration Program. The evaluation methodology employed is a case study approach, based upon site visits to nine Demonstration states. The case studies will provide useful information to other states as they begin or continue nursing home transition programs, particularly the states that received 2001 and 2002 Systems Change Grants for Community Living from CMS to affect Nursing Facility Transitions.2

The Homecoming Project

The Wisconsin nursing home transition program, called The Homecoming Project, awarded funds to Wisconsin's eight Centers for Independent Living (CILs) to facilitate transitions. During a site visit conducted in August 2001, MEDSTAT interviewed staff from the State of Wisconsin Department of Health and Family Services (DHFS) who coordinated the project, as well as staff from one of the CILs that implemented the program. MEDSTAT interviewed staff from two additional CILs during conference calls soon after the site visit. MEDSTAT staff also interviewed six consumers who left nursing homes with the help of The Homecoming Project and staff from a county agency responsible for approving the home and community-based services many consumers used after leaving nursing homes. The CILs' final reports for the project and several unpublished reports from the state also informed this case study. Wisconsin contracted with Centers for Independent Living (CILs) to transition nursing home residents.

The report begins with a description of The Homecoming Project, followed by a summary of the program's results. The report then discusses how project staff responded to barriers to nursing home transitions, how nursing home transitions continued after the Demonstration project ended, and how the project informed requests for 2001 Systems Change Grants for Nursing Facility Transitions from CMS. Key observations that may be particularly helpful for states that are planning to implement nursing home transition programs of their own conclude this report.

PROGRAM DESCRIPTION

Wisconsin received a $500,000, one-year Nursing Home Transition grant in September 1999 to fund the Homecoming Project. Wisconsin's Department of Health and Family Services (DHFS) contracted with Centers for Independent Living (CILs) to transition nursing home residents in their service area to community settings. The state established goals to help 150 people leave nursing homes, and to help an additional 150 people begin the transition process and possibly transition after the grant period ended. An additional objective was to facilitate the development of a greater role for CILs in long-term care by improving the relationships between CILs and counties, which provide local administration for home and community-based services programs.

Wisconsin provided $10,000 to each CIL for staff time related to nursing home transitions. Table 1 lists the eight CILs and the cities in which they are located. CILs facilitated most of the transitions under the project, but some of Wisconsin's 72 counties also facilitated transitions under the project. The counties, which administer the state's home and community-based services programs, did not receive grant funds for staff time. The state reserved over $325,000 of the $500,000 Demonstration grant for transition expenses with no other identified funding source. Wisconsin hired a project coordinator to develop the contracts with the CILs, provide training and technical assistance, and approve the use of The Homecoming Project funds for transition expenses.

TABLE 1. CILs Funded by the Homecoming Project

CIL	Location
Access to Independence	Madison
Center for Independent Living for Western Wisconsin	Menomonee
Great Rivers Independent Living	La Crosse
IndependenceFirst	Milwaukee
Midstate Independent Living Consultants	Rhinelander
North Country Independent Living	Superior
Options for Independent Living	Green Bay
Society's Assets	Racine

The Role of Centers for Independent Living

Each CIL designated a Regional Homecoming Coordinator to work with nursing home residents who wanted to live in the community. According to state staff, the state encouraged CILs to hire consumers. At least two of the coordinators interviewed for this report have a disability. Some CILs used Homecoming Project funds to hire a new part-time person specifically responsible to facilitate transitions. Other CILs used the funds to pay for part of a current staff person's time, so that person could spend a higher percentage of his or her time facilitating transitions.

Wisconsin gave local CILs flexibility to develop their own transition processes.

Wisconsin did not develop a standard process for facilitating nursing home transitions. Each of the eight CILs devised its own process for facilitating transitions. The three CILs interviewed for this report differed in the level of formality applied to the process. Before the grant period, one CIL with prior experience facilitating transitions had already developed an assessment tool to identify items the consumer should consider or address before moving, including housing, service, and transportation needs and preferences. This CIL's coordinator preferred consumers complete this assessment themselves as much as possible. The other two CILs did not have an assessment tool, but identified similar needs using the expertise of their Regional Homecoming Coordinators, one of whom had moved from a nursing home and had experience helping other people move.

In addition to the Regional Homecoming Coordinator, other CIL staff supported people leaving nursing homes in the course of their normal responsibilities. Many residents received independent living skills training (which covers a wide range of activities, including budgeting, shopping, food preparation, and using public transportation) and peer support to help them prepare for living in the community and adjust to living with a disability in the community. One CIL created a peer support group comprised exclusively of former nursing home residents, enabling Homecoming consumers to help each other through their common experience. CILs also offered benefits counseling, the support of a housing specialist, and a loan center for assistive technology.

Some CIL staff indicated a key challenge was setting realistic consumer expectations. Some consumers and family members reportedly underestimated the level of assistance they would need in their own home or apartment. According to one Regional Homecoming Coordinator, some people initially expressed preferences for non-essential household items like entertainment equipment and later realized a table and cookware may be more urgent needs. One CIL staff person stressed the importance of working with, not ahead of, the consumer. For example, she encouraged consumers to develop a long-term goal, even if she believed it was unrealistic, and then helped them identify intermediate steps toward attaining that goal.

Consumers interviewed by MEDSTAT staff highlighted several aspects of the CILs' assistance that were important in helping them leave nursing homes. Several consumers had worked toward moving before the CIL was involved, but were unable to pay for necessary goods and services (e.g., apartment deposits, furniture) or were not able to find housing on their own. One consumer said developing a plan for moving was important. Another cited the moral support from CIL staff.

Setting realistic expectations with consumers was one key challenge.

CIL staff said they continued to support consumers for several months after they had moved back to the community. The amount of time consumers and CILs kept in touch depended on the consumers' needs and preferences. CILs made its other services, including peer support and independent living skills training, available to former residents. Peer support was particularly important for many consumers. For some consumers, leaving a nursing home was a first step to further independence. Some consumers interviewed for this report were taking steps to enter the workforce and one was enrolled in college.

Role of State Project Coordinator

Wisconsin hired a project coordinator to develop contracts with the CILs, provide training and technical assistance, and approve the use of The Homecoming Project funds for transition expenses. The project coordinator worked in the state's Office for Persons with Physical Disabilities (OPPD) within the Bureau of Aging and Long Term Care Resources, the state agency that manages home and community-based services for elderly people and people with physical disabilities.

The state project coordinator's principal strategies for orientation and training of the Regional Homecoming Coordinators were video conference calls and site visits. During the monthly videoconferences, all eight CILs updated the state and each other on their progress and discussed effective strategies. CIL staff with less experience facilitating transitions reported learning from other CILs' experiences, while CIL staff with more experience did not find the conference calls valuable. CIL staff provided few comments on the site visits, in which the project coordinator visited each CIL to learn more about local differences in the project and to provide technical assistance.

Transition Expense Payment Process

Most of the Demonstration grant was reserved to cover the costs of expenses directly related to individual transitions.

Wisconsin set aside most of the $500,000 grant, $325,000, for one-time transition expenses. Table 2 describes the process by which CILs and counties applied for transition expenses on a consumer's behalf. For each transition expense, the CIL or county faxed a completed form, along with either receipts or cost estimates, to the state project coordinator. Wisconsin contracted with Age Advantage, an Area Agency on Aging based in Madison, to act as a fiscal intermediary. After the project coordinator approved the expenses, she authorized the fiscal intermediary to issue a check to the CIL or county. This arrangement allowed the state to bypass the state purchasing requirements and reimburse CILs based on receipts submitted.

TABLE 2. Original Transition Expenses Payment Process

Agency	Action
CIL or County	Sends request to use Homecoming funds.
State	Approves or denies payment.
CIL or County	If state approves payment, purchases item(s) and sends receipt to state.
State	Forwards receipt to Age Advantage.
Age Advantage	Sends payment to CIL.

The approval and reimbursement process did not work as efficiently as the state planned. During the grant, the state adjusted the approval process. The state allowed CILs and counties to obtain advance approval based on undocumented cost estimates (e.g., $500 for items necessary to set up a household) and then follow up with documentation for each item purchased.

Identifying Candidates for Nursing Home Transition

The state targeted The Homecoming Project funds to Medicaid-eligible residents who had been in a nursing home at least three months. One CIL reported that several people interested in Homecoming were not eligible because they were not eligible for Medicaid. The Homecoming Project focused on people with disabilities under age 65. Due to the short time frame of the project, however, the state did not set an age limit and encouraged CILs and counties to help as many people as they could regardless of age.

CILs reported they did not deny transition assistance based on level of disability or on any other criteria. Due to the short duration of the project and the high demand for assistance, some Regional Homecoming Coordinators focused on people who they perceived as "ready to move". Indicators of readiness included:

- an ability to live safely in the community without skilled services (e.g., registered nurse, therapist),
- an ability to signal for help,
- an existing support system, either through family or social service agencies,
- cooperation from the nursing home discharge planner,
- the consumer's progress toward making a transition before the CIL became involved, and
- the consumer's willingness to do his or her share of the work required to move.

Some CIL staff considered the last two criteria particularly important, because they believed consumers would be more satisfied with the transition and more likely to continue living independently if they performed much of the work necessary for transition themselves. For example, one CIL provided a consumer a list of apartment buildings with accessible, affordable apartments, but the consumer was responsible for calling the apartments, visiting them, and choosing an apartment.

Wisconsin publicized The Homecoming Project in newsletters sent by the Office for Persons with Physical Disabilities and through a pilot project called Family Care. The state also sent a memo about The Homecoming Project to county, tribal, and Area Agency on Aging staff. State staff presented the project to nursing home ombudsmen, including specific instructions on how to refer a consumer to the project. State staff also sent a press release to local media, which led to newspaper articles about the project.

In addition to statewide outreach efforts, Wisconsin required CILs to perform an outreach mailing to nursing homes in the CIL's service area. The state provided a memo and brochure for the CILs to mail to nursing home administrators or discharge planners. Some CILs performed additional outreach. A CIL in a rural area received some response from local newspaper articles and advertisements; this CIL had little success with radio announcements and flyers that were made available in libraries, grocery stores, and other public places. One CIL gave presentations to discharge planners and nursing staff in each nursing home in its thirteen-county service area as an outreach activity. The staff person who gave these presentations believed these face-to-face presentations were the most effective form of outreach.

Two of the three CILs interviewed for this report received more requests for transitions than they could serve. CILs learned about transition candidates from the candidates themselves, family members, nursing home ombudsmen, nursing home discharge planners, hospital discharge planners, and county agencies that manage home and community-based services.

CILs' Relationships with Nursing Homes

CIL staff reported that nursing homes were generally cooperative with the project, especially once informed that people have a legal right to leave. For some rural nursing homes, extensive effort was required to convince nursing homes that they could not legally prevent CIL staff from visiting a resident who had invited the CIL staff into the home. According to CIL staff, nursing home discharge planners were particularly cooperative and a good referral source and nursing home rehabilitation professionals sometimes helped the consumer and CIL prepare for transition.

Nursing homes were reportedly cooperative in general, especially once informed that people have a legal right to leave.

Some consumers indicated more resistance from nursing homes. Other consumers said nursing home staff were willing to help but did not know how or had limited time to do so. One consumer recommended additional outreach with nursing home discharge planners, which may also increase awareness of community options among nursing home staff.

CILs' Relationships with Community Long Term Care Programs

The Homecoming Project required CILs and counties to work together to ensure that community housing and services were available as soon as a consumer left a nursing home.

One of the state's goals for The Homecoming Project was to improve the relationship between CILs and counties. Wisconsin's 72 counties and one American Indian tribe are responsible for authorizing public home and community-based services. Most consumers accessed supportive services through the Community Options Program Waiver, a Medicaid home and community-based services (HCBS) waiver for people with disabilities and older people. County staff determine eligibility for home and community-based services and help consumers select their services. According to state staff and some CIL staff, the CILs have often had adversarial relationships with counties, due to the CILs' advocacy role and the counties' role in providing home and community-based services. However, one CIL staff person reported good relationships with the counties in its service area before the grant.

The Homecoming Project required CILs and the counties to work together to ensure community housing and services were available as soon as consumers left the nursing home. Three months into the project, Wisconsin began requiring that county staff conduct assessments of Homecoming Project consumers before they left the nursing home. This required cooperation between CILs and counties, gave Homecoming Project consumers quicker access to services, and addressed the concern of some counties that people may be leaving nursing homes without adequate services. If the resident was eligible for the HCBS waiver, county staff also visited the resident one or two days after the move to develop a plan of care for waiver services. In addition to working with CILs, some counties also facilitated transitions on their own. Most people assisted by county staff were either on the county's waiting list for Medicaid waiver services or residents of a nursing home scheduled to close.

DEMONSTRATION RESULTS

The $500,000 Demonstration grant served people from October 1, 1999 through December 31, 2000. The grant was originally a one-year grant, but CMS approved Wisconsin's request for a three-month, no-cost extension. As shown in Chart 1, about 65% of grant funds were allocated to transition expenses, including home modifications, rental deposits, and household items. Wisconsin paid 16% of the grant to CILs to cover staff time. The remaining funds were used to cover the costs of the fiscal intermediary and the state project coordinator's salary and expenses.

During the fifteen-month federal grant period, 81 nursing home residents transitioned to community living. CILs facilitated transitions for 56 of these people. Counties helped an additional 25 people relocate from nursing homes using Homecoming funds. An additional 85 residents worked with CIL staff toward moving from a nursing home. Several nursing home residents continued to prepare for transition after the grant period ended. The number of people who left nursing homes was well short of the state's goal of 150 people, but is comparable to the number of people relocated by other Demonstration states.

Eighty-one nursing home residents transitioned to community living during the grant period.

The Homecoming Project focused on people under the age of 65 with physical disabilities. As Chart 2 shows, about half of the 81 people transitioned during the grant period were within this target population. An additional 15 former nursing home residents were under age 65 with a diagnosis of mental illness and/or developmental disability. Thus, more than two-thirds of transitioned residents were under age 65. By comparison, in 1999 only 7% of Wisconsin nursing home residents were under age 65 (Wisconsin Bureau of Health Information, 2000).

Nationally, nursing home residents are most likely to leave in the first three months of their residency (Gabrel and Jones, 2000). In contrast, Wisconsin focused The Homecoming Project on people who had been in a nursing home three months or longer. The state intended to focus resources on persons less likely to leave the nursing home without assistance. Only three consumers had been in a nursing home for less than three months. Chart 3 presents nursing home length of stay data, which were available for 67 consumers. A majority of Homecoming Project consumers (36) had been in a nursing home for three to twelve months. Twenty-eight consumers had been residents for more than one year, and the longest length of stay was almost 18 years. These data suggest that the program was successful in targeting nursing home residents who probably would not have returned to the community without special assistance.

Of the 75 people for whom living arrangement data were available, nearly two-thirds of consumers moved to their own home (15) or apartment (33). As shown on Chart 4, other consumers usually moved to congregate living facilities, either adult foster care homes or assisted living facilities. People who moved to a congregate living facility were more likely to have been helped with their transition by county staff.

None of The Homecoming Project consumers returned to a nursing home during the grant period. At the time of the site visit, the three CILs interviewed for this report had helped 41 people leave nursing homes (28 during the grant period and 13 after the grant period). At that time, between 3 and 18 months after discharge, three of these 41 people had returned to a nursing home.

The most expensive transition services were home modifications.

The Homecoming Project did not measure the overall cost of facilitating a transition because it did not measure the staff time to assist residents in transition. The project did measure the cost of one-time items and services purchased to help a person transition. The cost for these transition services ranged from $0 to $38,104. For the 65 people that used Homecoming Project funds for transition expenses, the average cost was $4,722. The most expensive transition services were home modifications.

State staff and some CIL staff indicated that relationships with counties and CILs generally improved as a result of The Homecoming Project. One CIL indicated it had good relationships with counties before the project. According to state staff, county staff became more aware of the wide variety of services and resources offered by CILs, in addition to their advocacy function. However, CIL and state staff indicated tense relations remained between some counties and some CILs. One CIL staff person reported rural counties and counties far away from a CIL were more resistant to the CIL's involvement because county staff perceived CIL staff as outsiders.

BARRIERS TO COMMUNITY TRANSITION AND HOW ADDRESSED

State staff and most CIL staff interviewed for this report said the two most significant barriers to transition were: (1) a lack of affordable, accessible housing; and (2) a low supply of home and community-based services.

Housing

The lack of affordable, accessible housing and a shortage of home and community-based services were identified as the two biggest barriers to moving people out of nursing homes.

State staff and the CIL serving Milwaukee reported a lack of affordable, accessible housing was the most significant barrier to community relocation. People often had to wait several months for subsidized housing or looked for non-subsidized housing because the wait was so long. Housing was even more difficult to find because most consumers required accessible residences. Some consumers did not require accessible residences because their primary diagnosis was mental illness. According to one CIL, many consumers had financial histories that made it difficult to obtaining private housing. Credit card debt was most common, either from medical bills or basic living expenses. Delinquent phone and utility bills also complicated the housing search.

One Regional Homecoming Coordinator reported home modifications were often delayed due to a lack of reliable contractors with the knowledge and skills to make modifications in compliance with the Americans with Disabilities Act. Indoor modifications were particularly difficult to complete in the summer and fall because contractors wanted to complete their outdoor work before winter.

Housing was not the most significant barrier for all geographic areas and target populations. One CIL serving several rural counties reported housing was a less significant barrier than securing home and community-based services, but it was still a significant barrier. One CIL staff person said elderly people were more likely to prefer moving to a child's home, which made housing a less significant barrier if the child was willing and able to live with the consumer. Publicly financed assisted living was not available for younger people with disabilities in Wisconsin, which further limited housing and service options for that population.

How addressed: CILs interviewed for this report employed a variety of methods to help residents obtain housing. These methods included:

- employing housing specialists to connect consumers with public and private housing resources,
- providing home modification assessments and coaching people to work with landlords to allow home modifications,
- financing home modifications with Community Development Block Grant funds or the U.S. Housing and Urban Development Department's Home Investment Partnerships Program (a.k.a. the HOME program),
- working with a developer to dedicate housing units to people leaving nursing homes,
- referring consumers with poor credit to the Wisconsin Coalition for Advocacy, a source for attorneys doing pro bono work, so the consumer could start bankruptcy proceedings to reduce his or her debt burden, and
- negotiating with the local phone company to settle delinquent claims for phone services.

Home and Community-Based Services

Most Homecoming Project consumers required home and community-based services (HCBS) after their transition, and most accessed services under a Medicaid HCBS waiver. In most counties, there are waiting lists for the state's largest waiver program, the Community Options Program Waiver (COP-W). The average time that new waiver applicants spend on a waiting list varies by county. CIL and state staff estimated that the time spent on a waiting list ranged from two to seven years.

CIL staff also indicated that few service providers were available even when financing was available. Several home health agencies and personal care agencies went out of business in 2000, and there was a general shortage of direct service workers. One CIL staff person said a lack of confidence in the home and community-based services infrastructure made some family members and consumers less likely to choose a return to the community.

How addressed: Two state programs that preceded The Homecoming Project helped address the shortage of home and community-based services. The Community Integration Program II (CIP II), administered within a Medicaid home and community-based services waiver, is specifically designed for people who leave nursing homes. Under CIP II, every time a nursing home closes and a former nursing home resident moves to the community, additional funds are allocated to the CIP II to support one consumer living in the community. These funds are initially available to the person leaving the closed nursing home. If this person does not use waiver services, these funds are then available for other people leaving nursing homes.

One program within a Medicaid home and community-based services waiver is specifically targeted to people leaving nursing homes.

Wisconsin reserved some CIP II openings for people served by The Homecoming Project. Some county and CIL staff criticized this practice because it allowed Homecoming Project consumers to receive waiver services before other waiver applicants who had been waiting longer. At least one person was concerned that this arrangement, if continued over the long-term, would create an incentive for some people to enter nursing homes.

Wisconsin had also implemented a pilot project called Family Care. In the five counties in which all components of Family Care are available, home and community based services are considered an entitlement and these counties do not have waiting lists, enabling quick access to services. Family Care is also operated as a managed care model, which gives counties a financial incentive to help people leave nursing homes, since the counties are financially "at risk" for the total costs of long term care services provided in the county. One CIL said that Family Care counties were more willing to help relocate consumers. On the other hand, another CIL considered Family Care an obstacle during The Homecoming Project because CIL and county staff started the project in a newly changed system with new rules they did not yet know how to follow.4

Transportation

According to CIL staff, public transportation is not readily available in Wisconsin, particularly outside Milwaukee County. CIL staff reported transportation services specifically for older people and people with disabilities can be unreliable, insufficient, and expensive. CIL staff reported transportation was a barrier both before and after a person left a nursing home. For example, arranging for peer support was difficult because usually either the peer or the consumer needed accessible transportation.

How addressed: CILs tried to improve access to transportation in several ways. One CIL typically accompanied people when they visited a potential apartment to be sure the consumer considered proximity to public transportation. One CIL bought a van to meet their staff, volunteers, and consumers' transportation needs; however, this CIL believed most CILs in Wisconsin could not afford vans. One consumer used a motorized scooter to run errands, and recommended it for other people. Several community and church fundraisers paid for a van with a lift for another consumer.

Guardianship

Legal guardians could be either a barrier or an advantage for Demonstration participants.

Depending upon individual circumstances, guardians could be either a barrier or an advantage for a person trying to leave a nursing home. Consumers, state staff, and CIL staff mentioned several examples of guardians who resisted nursing home transition, usually due to safety concerns. Resistant guardians reportedly were often corporate guardians or family members who were informal caregivers when the consumer was in the community. Some family members, who reportedly were burned out from their caregiving responsibilities before nursing home admission, were characterized as reluctant to put themselves at risk of burn out again if consumers were to return to community living. Also, the shortage of personal care workers and lack of nearby medical services in rural areas caused guardians to be concerned about potential health and safety risks.

How addressed: One CIL connected guardians who were reluctant to support transition with guardians who had been involved in successful transitions. Some guardians were reportedly willing to support transition after learning about a successful example.

Summary of Methods to Address Barriers

Table 2 summarizes methods to address transition barriers encountered in The Homecoming Project.

TABLE 2. Addressing Barriers to Nursing Home Transition

Barrier	How Addressed
Housing	Housing specialist to identify resources Home modification assessments Funding home modifications through other federal sources Legal assistance in bankruptcy proceedings to reduce debt burden Settling delinquent phone bill claims
Shortage of Home and Community Services	Home and community-based services program specifically for people leaving nursing homes Pilot project in which home and community-based services are an entitlement, with incentives to help people leave nursing homes
Transportation	Encourage consumers to consider transportation availability when selecting housing Motorized scooter for consumers Community fundraisers for accessible van CIL purchase of van to help staff and volunteer transportation
Guardianship	Connect guardians reluctant to support transitions to guardians who have allowed successful transitions

NEXT STEPS FOR THE NURSING HOME TRANSITION PROGRAM

Wisconsin did not continue funding The Homecoming Project after the federal grant period ended in December 2000, but nursing home transitions continued nevertheless. CILs continued to facilitate nursing home transitions, although at a reduced level, since no funding was available for transition services or CIL staff time. Counties also continued transitions because more nursing home closures were occurring. State staff anticipated more closures because companies which owned an estimated 10% to 15% of Wisconsin's nursing homes were in bankruptcy.

Transitions are likely to continue, especially since more nursing home closures are likely.

Late in 2001, the state set aside approximately $1.9 million to pay for one-time transition expenses and for ongoing home and community-based services for people leaving nursing homes. Wisconsin set aside an additional $1.3 million in 2002 for the same purpose. The money included Medicaid HCBS waiver funds for ongoing services and state funds for services that are not covered by a Medicaid HCBS waiver. Wisconsin added any money spent on ongoing services to its home and community-based services programs budget in future years, so the money would be available as long as the former residents lived in the community. Using this money and the Community Integration Program II mentioned in the "Barriers" section, 153 people left Wisconsin nursing homes in 2001. Both CILs and counties facilitated these transitions.

Both the state and the CILs used their experience in The Homecoming Project to develop proposals for the Nursing Facility Transition Grants under the Systems Change Grants for Community Living program in the spring of 2001. Wisconsin submitted two proposals for Nursing Facility Transition Grants, one from the CILs and one from the state. In September 2001, CMS awarded the state a $800,000, three-year grant and the CILs a $450,000, three-year grant.

The state grant will continue transition funding for people with physical disabilities and older people while expanding transition efforts to people with mental illness and people with developmental disabilities in intermediate care facilities for people with mental retardation. Wisconsin will also use the grant to start initiatives to increase the supply of direct support workers and affordable, accessible housing. The state's grant, like The Homecoming Project, set a goal of improving the relationship between a non-profit advocacy group and the publicly funded long-term care system. According to state staff and some CIL staff, the Homecoming Project successfully improved relationships between CILs and counties, and the state proposed to replicate this experience with another target population and advocacy organization. For the second grant, the state plans to partner with Grassroots Empowerment, an advocacy organization for people with mental illness, and increase its involvement in the long-term care system for people who are dually diagnosed with developmental disabilities and mental illness.

The grant to the CILs is similar to The Homecoming Project. One difference is that Great Rivers Independent Living Services in La Crosse (now Independent Living Resources, Inc.), the CIL managing the grant, will distribute most of the grant funds directly to the CILs. Instead of requiring a central project manager to approve expenditures, CILs can use grant funds both for staff and for transition services without prior approval. CILs will also use the grant to improve outreach efforts and to provide more peer support to nursing home residents.

DISCUSSION

In summary, the one-year Wisconsin Homecoming Project helped 81 residents leave nursing homes and return to community living. The state relied primarily on the existing infrastructure of its eight Centers for Independent Living to identify potential candidates for transition and to work with home and community-based service program staff to plan the activities necessary for a nursing home resident's successful transition back to community life.

State and CIL staff considered CILs to be good organizations to facilitate transitions due to their experience in de-institutionalization and their knowledge of the social service system. CILs believed facilitating transitions fit well within their organizational mission. The CILs' core services -- advocacy, peer support, information and referral, and independent living skills training -- complemented the efforts of Regional Homecoming Coordinators. Consumers who left nursing homes often used one or more of these services before their transition.

While CILs continue to help consumers transition from nursing homes to community settings, Wisconsin's counties also make important contributions to nursing home transitions. Counties facilitated almost one-third of the transitions during the grant period. Counties do not provide most of the services CILs provide that support transition efforts -- although counties offer information and referral -- but counties have a strength Wisconsin's CILs do not have. Counties determine eligibility for publicly funded home and community-based services and provide ongoing case management required in the state's HCBS programs. Since they do not need to coordinate with another organization, counties are well suited to quickly facilitate transitions. During the grant, counties were more likely to facilitate transitions when a nursing home was closing -- a situation that required a quick response.

KEY OBSERVATIONS

Two elements of Wisconsin's experience in the Nursing Home Transition Demonstration Program may offer lessons for other states: the use of CILs as transition facilitators, and the system for payment of transition services.

CILs as Transition Facilitators

Like several other states awarded Nursing Home Transition Demonstration grants, Wisconsin contracted with Independent Living Centers to be the lead facilitators of nursing home transitions for the Demonstration. The rationale for contracting with CILs to take the lead in facilitating transitions is an obvious one--the entire mission of CILs is to promote community living for persons with severe disabilities, and the staff of CILs, many of whom have lived in nursing homes at some point in their lives, have "real world" experience of what it really takes to assist someone to move back to community life.

CILs are logical lead agencies for facility nursing home transitions, but they have limited capacity.

However, the level of resources allocated to the CILs under The Homecoming Project was limited ($10,000 each). CIL staff report that they spent far more on nursing home transition efforts during the project than they were awarded under the Demonstration grant. Most of the CILs were involved in nursing home transition efforts prior to the grant, and all continued their activities after grant was over. Thus, the grant simply provided additional resources, and a renewed focus, on nursing home transitions to the community.

While CILs were a logical choice for leading nursing home transition efforts, they also have limited capacity. There are only eight CILs in Wisconsin. The high demand for community placements in Wisconsin, particularly due to nursing home closures, was a factor in the state's decision to shift resources for transition services to county long-term care agencies.

Payment for Transition Services

Wisconsin reserved the majority of Demonstration funds (about two-thirds) for transition expenses directly attributable to individual placements. Instead of allocating these transition expenses directly to the CILs, the state retained these funds in a centralized pool, which CILs could access as placements were made. The advantages of this approach were: (1) transition funds could be allocated directly in accordance with where nursing home transitions were occurring, in case some CILs were more successful in facilitating transitions than others; and (2) the state retained greater control over how transition expenses were utilized, rather than delegating these decisions to the CILs. Although there were initial slow-downs in the reimbursement process, the state managed to speed up the reimbursement time with feedback from CILs.

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INTERVIEWS

Wisconsin Department of Health and Family Services, Bureau of Aging and Long Term Care Resources
Donna McDowell
Dan Johnson
Judith Zitske

Great Rivers Independent Living Center (La Crosse-based Independent Living Center, now Independent Living Resources, Inc.)
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North Country Independent Living (Superior-based Independent Living Center)
Dee Truen
John Nedden-Durst

Milwaukee County Adult Services Division
Ellen Boettcher
John Kaminski
Six Consumers and One Consumer's Sister (and Guardian)

NOTES

In 1998, Colorado, Michigan, Rhode Island, and Texas were awarded grants of between $160,000 and $175,000 each. In 1999, New Hampshire, New Jersey, Vermont, and Wisconsin received grants of $500,000 each. In 2000, Arkansas, Florida, Pennsylvania and Nebraska received grants of $500,000 each.

For more information on the Systems Change Grants for Community Living, see the following website: www.hcfa.gov/medicaid/systemschange/.htm

References for these reports can be found in the bibliography at the end of this report.

For a more complete discussion of the initial implementation of the Family Care Demonstration, see the Wisconsin Family Care Implementation Process Evaluation Report, which can be found at the following website:
http://www.legis.state.wi.us/lab/Reports/00-0FamCaretear.htm

Appendix I

Community Integration Strategies

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Table of Contents

Identification

- Review your waiting list. Go visit the people. Who is in a NF or other institution? Who is at imminent risk of institutionalization?
- These people are qualified individuals with a disability who are appropriate for the community and qualified for HCBS.
- Help them assert their rights.
- Fulfill your duty to perform one of the four core services, individual and systems advocacy under the Rehab Act. 29 U.S.C. § 796f-4(b).
- Assert the right of access and visitation of a resident of a NF. ILAs should go visit NFs. 42 C.F.R. § 483.10(j)(2).

ILS Questions

- Would you like to live in your own home or apartment?
- Did you know you have a right to live in the community if you are qualified?
- Explain your ILC, its basis in the Rehabilitation Act, its services, and how it can help the person transition to the community.

HCBS

- First, get the person assessed for HCBS and see if they are qualified.
- Ensure SSI.
- Ensure income and asset eligibility.
- Ensure disability eligibility.
- Do everything in writing. Confirm everything in writing. Print your screens.

Civil Rights

- Once the person is on the HCBS waiting list, file complaints with DOJ, KHRC, and your local HRC if you have one.

- Elements:
  1. Person is a qualified individual with a disability.
  2. Person is qualified to live in the community.
  3. Person wants to live in the community.
  4. Person is unnecessarily institutionalized.
  5. State is discriminating against person by unnecessarily institutionalizing them and failing to reasonably accommodate them.

- Contact an attorney to represent the Center.

- See if the consumer wants representation.

Civil Rights – Medicaid

- If the consumer has been inappropriately screened by the AAA with the PASARR they can and should appeal for a Medicaid Fair Hearing. Their PASARR certificate is supposed to inform them of their rights. 42 C.F.R. § 483.200 et seq.

- If a consumer's plan of care has been cut arbitrarily or below medical necessity, help the consumer file for a due process appeal. The appeal process is outlined in the KEESM on the SRS website.

Transition Planning

- HCBS qualification.
- Housing. Transition Housing. Section 8 application. Public Housing. Tenant based certificates.
- Medicaid resource spend-down.
- Household goods.
- Explore all other social services.
    - Safety and competency
    - A person is competent until proven otherwise and ordered by the court.
    - A person retains their constitutional and civil rights at any level of disability until a court orders otherwise.
    - Doctors, social workers, nurses and nursing homes do not have legal authority to negate a person's rights.
    - Initial Competency screening. See, Ethical Considerations When Representing a Client Who is "Under a Disability," Marilyn A. Mahusky et al., Vermont Bar Journal, June 2002, Vol. 28, page 62.

- Get an expert opinion from a psychologist or psychiatrist after testing.

- Guardianship standards

- An adult with an impairment in need of a guardian.

- "In need of a guardian", means a person who because of *both* an impairment and the lack of appropriate alternatives for meeting essential needs, requires the appointment of a guardian.

"Appropriate alternatives" means any program or service, or the use of a legal device or representative, which enables a person with an impairment to adequately meet essential needs for physical health, safety, or welfare. It includes, but is not limited to POAs, DPOAs, POA for Health Care, Living Will, Trust, or joint tenancy or representative payee.

- "Meet essential needs for physical health, safety, or welfare" means making those determinations and taking those actions which are reasonably necessary in order for a person to obtain or be provided with shelter, sustenance, personal hygiene or health care, and without which serious illness or injury is likely to occur.

- 2002 Kan. Sess. Laws Ch. 114, New Section 2.

Handling Problems

- HCBS
- Get application and assessment.
- If denied, appeal for Medicaid Fair Hearing.
- If accepted and put on waiting list, file complaint with DOJ, KHRC, Local HRC.
- Write a letter asking for a reasonable accommodation. Ask for emergency exception.
- Housing
- Purchase a transition house.
- Know your local housing authority.
- Submit application for public housing, Section 8 project based.
- Submit application for Section 8 tenant based certificate.
- Consider 811 projects or alternatives.
- Transition Goods
- Create a Rent and Deposit Fund.

- Create a used furniture bank.
- Create a household goods start-up fund.
- Create a new and used household goods bank.
- Use SSI/SSDI resource spend down funds if available.
- Nursing Homes
- Review and have a working knowledge of consumer's constitutional and civil rights.
- Review and have a working knowledge of consumers rights as a NF resident.

Appendix J

Constitutional and Civil Rights of People with Disabilities

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Table of Contents

Constitutional Rights

Constitutional Rights apply to "State Action" including state laws.

Federal Bill of Rights

1st Amendment: Free speech, freedom of religion, right to peaceably assemble, right to petition government.

4th Amendment: right to be secure in person, house, papers, and effects against unreasonable search and seizure.

5th Amendment: right not to self-incriminate oneself and federal due process.

7th Amendment: right to a jury trial.

8th Amendment: right against cruel and unusual punishment.

14th Amendment: due process and equal protection from state action. Liberty.

15th & 19th Amendment: right to vote.

Kansas Constitution-Bill of Rights

§ 1 Equal rights to life, liberty, and the pursuit of happiness.

§ 2 All political power is inherent in the people.

§ 3 Right to peaceably assemble and petition.

§ 5 Right to trial by jury.

§ 7 Religious liberty

§ 11 Free speech

§ 15 Right of the people to be secure in their persons and property against unreasonable searches and seizures shall be inviolate.

§ 18 Justice without delay-remedy by due course of law.

Constitutional Rights- Case Law

14th Amendment: liberty interest in reasonably safe conditions of confinement, freedom from unreasonable bodily restraints, and such minimally adequate training as reasonably might be required by these interests.
Youngberg v. Romeo, 457 U.S. 307 (1982).

14th Amendment: involuntarily civilly committed person with a disability has a liberty interest to live in their own home and not be confined in an institution if they are not dangerous and can safely live in their own home.
Mere public intolerance or animosity cannot constitutionally justify deprivation of a person's physical liberty.
O'Connor v. Donaldson, 422 U.S. 563 (1975)

14th Amendment: Right to Marry
Loving v. Virginia, 388 U.S. 1 (1967)
Zablocki v. Redhail, 434 U.S. 374 (1978)

14th Amendment fundamental right to marriage and procreation.
Skinner v. Oklahoma, 316 U.S. 535 (1942)

14th and 9th Amendment right to Privacy and to control of one's body.
Griswold v. Connecticut, 381 U.S. 479 (1965)
Roe v. Wade, 410 U.S. 113 (1973)

14th Amendment liberty interest includes the right to refuse unwanted medical treatment.
Cruzan v. Missouri, 497 U.S. 261 (1990).

14th Amendment right to due process, notice, and a fair hearing.
Goldberg v. Kelly, 397 U.S. 254 (1970).
Parham v. J.R., 442 U.S. 584 (1979).
Blum v. Yaretsky, 457 U.S. 991 (1982).

The Right to Travel.
Saenz v. Roe, 526 U.S. 489 (1999).

The Constitutional liberty interest includes the right to be free in the enjoyment of all of one's faculties; to be free to use them in all lawful ways; to live and work where one will; to earn any livelihood or avocation.
Allgeyer v. Louisiana, 165 U.S. 589 (1897).
Grosjean v. Am. Press, 297 U.S. 233 (1936)
Conservatorship of Mildred G, 707 P.2d 760 (1985).

Liberty means more than freedom from servitude, and the constitutional guarantee is an assurance that the citizen shall be protected in the right to use his or her powers of mind and body in any lawful calling.
Smith v. Texas, 233 U.S. 630, 636 (1914).

Liberty is not confined to mere freedom from bodily restraint. Liberty under law extends to the full range of conduct which the individual is free to pursue, and it cannot be restricted except for a proper governmental objective.
Bolling v. Sharpe, 347 U.S. 497, 499-500, (1954).

Every citizen has an interest in and the right to freedom of travel, association, and speech; in essence, an interest in and right to all the incidents of freedom "implicit in the concept of ordered liberty."
Palko v. Connecticut, 302 U.S. 319, 325 (1937).

A state law that made the "status" of narcotic addiction a criminal offense violated the 8th Amendment's prohibition against cruel and unusual punishment.
Robinson v. California, 370 U.S. 660 (1962).

An individual has a liberty interest in avoiding the unwanted administration of antipsychotic drugs under the Due Process Clause of the Fourteenth Amendment.
Washington v. Harper, 494 U.S. 210, 221-22 (1990)
Jurasek v. Utah State Hospital, 158 F.3d 506, 510 (10th Cir. 1998).

Person who is subject to involuntary civil commitment has a constitutional right to:
Notice, due process, fair hearing, presumption of competency, burden of proof on state, right to counsel,

right not to self-incriminate self, access to reports, witnesses, and doctors, and the right to preliminary hearing before being detained more than 48 hours.
Lessard v. Schmidt, 349 F. Supp. 1078 E.D. Wis. 1972)

People involuntarily committed through non-criminal procedures to institutions for the mentally retarded have a constitutional right to receive such individual habilitation as will give each of them a realistic opportunity to lead a more useful and meaningful life and return to society.
Wyatt v. Stickney, 344 F. Supp. 387, 390 (M.D. Ala. 1972)

Adequate and effective treatment is constitutionally required because, absent treatment, the hospital is transformed into a penitentiary where one could be held indefinitely for no convicted offense.
Wyatt v. Stickney, 344 F. Supp. at 390.

The purpose of involuntary hospitalization for treatment purposes is *treatment* and not mere custodial care or punishment.
Wyatt v. Stickney, 344 F. Supp. at 390.
Affirmed by *Wyatt v. Aderholt*, 503 F.2d 1305 (5th Cir. 1974).

Constitutional Rights - Case Law

A guardianship proceeding to determine competency should invoke the full panoply of procedural due process rights comparable to those present in involuntary civil commitment because no less loss of liberty and freedom is at stake.
Guardianship of Hedin v. Gonzales, 528 N.W. 2d 567, 574 (IA 1995)

Right to Live in The Community

Unnecessary institutionalization is discrimination. A person who lives in an NF, who is qualified for HCBS, has a civil right to live in the most integrated setting appropriate to their needs, usually their own home.
Olmstead v. L.C., 527 U.S. 581, 587, 607 (1999).

Rights of Persons in a NF

A resident has a right to a dignified existence, self-determination, and communication with and access to persons and services inside and outside the facility. A facility must protect and promote the rights of each resident, including each of the following rights:
42 C.F.R. § 483.10

(1) The resident has the right to exercise his or her rights as a resident of the facility and as a citizen or resident of the United States.
(2) The resident has the right to be free of interference, coercion, discrimination, and reprisal from the facility for exercising his or her rights.
42 C.F.R. § 483.10(a)(1),(2).

(3) In the case of a resident adjudged incompetent under the laws of a State by a court of competent jurisdiction, the rights of the resident are exercised by the person appointed under State law to act on the resident's behalf.
42 C.F.R. § 483.10(a)(3).
See 2002 Kan. Sess. Laws Ch. 114, New Section 26.

Duties of A Guardian

A guardian does not have the power to:
1.Prohibit marriage or divorce.
2.Consent to termination of parental rights.
3.Consent to adoption of ward.
4.Consent to psychosurgery, removal of any bodily organ, amputation of any limb, unless it is an emergency.
2002 Kan. Sess. Laws, Ch. 114, Sect. 26.

A guardian cannot
5. consent to sterilization.
6. consent to experimental biomedical or behavioral procedure.
7. consent to withholding or withdrawal of life-saving or life sustaining medical care.
8. exercise any control over the ward's estate.
2002 Kan. Sess. Laws, Ch. 114, sect. 26(c).
9. Place the ward in a treatment facility.
2002 Kan. Sess. Laws, Ch. 114, Sect. 26(c).
The guardian is prohibited from doing any of the above 9 things unless he or she first obtains a court order.
Ask for the court order.

More Rights in a NF

In the case of a resident who has not been adjudged incompetent by the State court, any legal-surrogate designated in accordance with State law may exercise the resident's rights to the extent provided by State law.
42 C.F.R. § 483.10(a)(4).

See Kan. Stat. Ann. § 58-610 et seq.-DPOA

Notice of Rights
The facility must inform the resident both orally and in writing in a language that the resident understands of his or her rights and all rules and regulations governing resident conduct and responsibilities during the stay in the facility.
42 C.F.R. § 483.10(b)(1).

The resident has a right upon an oral or written request, to access all records pertaining to himself or herself including current clinical records within 24 hours (excluding holidays and weekends); and copies at community standard cost within 2 days.
42 C.F.R. § 483.10(b)(2).

The resident has the right to be fully informed in language that he or she can understand of his or her total health status, including but not limited to, his or her medical condition.
42 C.F.R. § 483.10(b)(3).

The resident has the right to refuse treatment, to refuse to participate in experimental research, and to formulate an advance directive as specified in paragraph (8) of this section;
42 C.F.R. § 483.10(b)(4).

The facility must inform each resident who is entitled to Medicaid benefits, in writing, at the time of admission to the nursing facility or when the resident becomes eligible for Medicaid of what Medicaid covers and what the NF may charge the resident for in excess of Medicaid.
42 C.F.R. § 483.10(b)(5).

The facility must furnish a written description of legal rights which includes-
A description of the manner of protecting personal funds;
A description of the requirements and procedures for establishing eligibility for Medicaid;
A posting of names, addresses, and telephone numbers of all pertinent State client advocacy groups.
42 C.F.R. § 483.10(b)(7).

The facility must inform the resident in writing that they have a right to file a complaint with KDHE concerning resident abuse, neglect, misappropriation of resident property in the facility, and non-compliance with advance directives.
42 C.F.R. § 483.10(b)(7).

The facility must inform each resident of the name, specialty, and way of contacting the physician responsible for his or her care.
42 C.F.R. § 483.10(b)(9).

Notification of changes:
A decision to transfer or discharge the resident from the facility; a change in the room or roommate assignment; or a change in resident rights.
42 C.F.R. § 483.10(b)(11).

Protection of Resident Funds.
The resident has the right to manage his or her financial affairs, and the facility may not require residents to deposit their personal funds with the facility.
42 C.F.R. § 483.10(c)(1).

The facility must deposit any residents' personal funds in excess of $50 in an interest bearing account (or accounts) that is separate from any of the facility's operating accounts, and that credits all interest earned on resident's funds to that account.
42 C.F.R. § 483(c)(3)(i).

The facility must establish and maintain a system that assures a full and complete and separate accounting, according to generally accepted accounting principles, of each resident's personal funds entrusted to the facility on the resident's behalf.

The system must preclude any commingling of resident funds with facility funds or with the funds of any person other than another resident.
42 C.F.R. § 483.10(c)(4)(i-ii).

Notice of Certain Balances:
1.$200 less than the SSI resource limit for one person. ($2000)
2.That the resident may lose SSI and Medicaid eligibility if resources are above $2000.

The resident has the right to:
1.Choose a personal attending physician;
2.Be fully informed in advance about care and treatment and of any changes in care;
3.Participate in planning care and treatment or changes (Unless there is a court order of guardianship.)
42 C.F.R. § 483.10(d).

The resident has the right to personal privacy and confidentiality of his or her personal and clinical records. Personal privacy includes accommodations, medical treatment, written and telephone communications, personal care, visits, and meetings of family and resident groups, but this does not require the facility to provide a private room for each resident.
42 C.F.R. § 483.10(e)(1).

A resident has the right to voice grievance without discrimination or reprisal.
42 C.F.R. § 483.10(f).

The resident has the right to examine the results of the latest survey by KDHE. The NF must place the survey results in a place that is readily accessible.
The resident has the right to receive information from agencies acting as client advocates, and be afforded the opportunity to contact these agencies.
42 C.F.R. § 483.10(g).

The resident has the right to work or not work.
The resident has the right to privacy in written communications, to send and receive mail unopened, and access to the means to create correspondence.
42 C.F.R. § 483.10 (h) and (i).

An NF must provide reasonable access to any resident by any entity or individual that provides health, social, legal, or other services to the resident, subject to the resident's right to deny or withdraw consent at any time.
42 C.F.R. § 483.10(j)(2).

The resident has the right to have reasonable access to the use of a telephone where calls can be made without being overheard.
42 C.F.R. § 483.10(k).

The resident has the right to retain and use personal possessions, including some furnishings, and appropriate clothing, as space permits, unless to do so would infringe upon the rights or health and safety of other residents.
42 C.F.R. § 483.10(l).

Married couples have the right to share a room if they both want to.
A resident may refuse a transfer to another room within the institution if the purpose of the transfer is to locate the resident of a SNF to a NF wing, or a NF wing to a SNF wing.
42 C.F.R. 483.10(m) and (o).

A resident has certain rights pertaining to admission, transfer, and discharge. The resident has a right to not be transferred or discharged unless the NF can show necessity and give proper notice.
A NF cannot charge, solicit, accept, or receive anything in addition to Medicaid for a person eligible for Medicaid.
42 C.F.R. 483.12

A resident has the right to be free from any physical or chemical restraints imposed for purposes of discipline or convenience, and not required to treat the resident's medical symptoms. A resident has the right to be free from verbal, sexual, physical, and mental abuse, corporal punishment, and involuntary seclusion.
42 C.F.R. §483.13(a) and (b).

A NF must promote care for residents in a manner and in an environment that maintains or enhances each resident's dignity and respect in full recognition of his or her individuality.
42 C.F.R. § 483.15(a).

The resident has the right to choose activities, schedules, and health care consistent with his or her interests, assessments, and plans of care; to interact with members of the community both inside and outside the facility; and to make choices about aspects of his or her life in the facility that are significant to her.
42 C.F.R. § 483.15(b).

A resident has the right to reside and receive services in the facility with reasonable accommodation of individual needs and preferences, except when the health and safety of the individual or other residents would be endangered; and
To receive notice before the resident's room or roommate is changed.
42 C.F.R. § 483.15(e).

The facility must provide activities, social services and a safe, clean, comfortable, and homelike environment.
42 C.F.R. 483.15(f), (g), and (h).

A NF must conduct initially and periodically a comprehensive, accurate, standardized, reproducible assessment of each resident's functional capacity.
A NF must develop a comprehensive care plan for each resident that includes measurable objectives and timetables to meet the resident's medical, nursing, and mental needs.
42 C.F.R. § 483.20(b) and (k).

Each resident must receive and the facility must provide the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care.
The resident's ability to perform ADLs must not diminish unless it is unavoidable.
42 C.F.R. § 483.25.

A resident who has difficulty adjusting to the NF must receive appropriate treatment.
A resident who has not used antipsychotic drugs should not be given these drugs unless therapy is necessary to treat a specific condition as diagnosed and documented in the clinical record. Drugs should be reduced unless not possible.
42 C.F.R. § 483.25(f) and (k).

NF Services

Every facility must provide nursing services, dietary services, physician services, rehab services, dental services, pharmacy services, infection control, adequate facilities, and administrative services to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident.
42 C.F.R. 483.30-.75.

PASARR & CARE Assessments

The Dept. on Aging, through the AAAs, is responsible to perform PASARR evaluations of all persons who have mental illness or mental retardation.
If a person has mental illness or mental retardation the state must provide or arrange for the provision of specialized services for the person while they reside in the NF.
42 C.F.R. § 483.116(b)(2).

PASARR & CARE

In general, a nursing facility is not an appropriate placement for a person with mental illness or mental retardation.

Placement of a person with MI or MR in a NF is only appropriate when the individual needs NF level of care and their individual needs for specialized treatment can be met.

42 C.F.R. § 483.126

Appendix K

Independent Living Centers Frontline of Freedom

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Table of Contents

Basis for CIL Advocacy

- Context: Many segments of state government are hostile to CIL advocacy.
  - Adult Protective Services: Safety first.
  - Guardianship and Conservatorship.

- Many Nursing Facilities are hostile.

- CILs: Freedom, liberty, integration, independence and safety.

Statutory Framework for ILCs

- Rehabilitation Act of 1973, 29 U.S.C. § 701

Findings of Congress (a)(3) - disability is a natural part of the human experience and in no way diminishes the right of individuals to—

(A) live independently
(B) enjoy self-determination

Rehab Act Findings Continued

(C) make choices

(D) contribute to society

(E) pursue meaningful careers, and

(F) enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society.

(a)(5) individuals with disabilities continually encounter various forms of discrimination in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, *institutionalization*, health services, voting, and public services;

(a)(6) the goals of the Nation properly include the goal of providing individuals with disabilities with the tools necessary to—
(A) make informed choices and decisions; and
(B) achieve equality of opportunity, full inclusion and integration in society, employment, independent living, and economic and social self sufficiency

Rehab Act Purpose

1. The purposes of this Act are—
to empower individuals with disabilities to maximize employment, economic self-sufficiency, independence, and inclusion and integration into society, through—
   - (A)statewide workforce investment systems;
   - (B)independent living centers and services;
   - (C) research;
   - (D) training;
   - (E) demonstration projects; and
   - (F) the guarantee of equal opportunity; and

2\. . . .assisting States and providers of services in fulfilling the aspirations of such individuals with disabilities for meaningful and gainful employment and independent living.

Policy of the United States

It is the policy of the United States that all programs, projects, and activities receiving assistance under this Act shall be carried out in a manner consistent with the principles of

(1) respect for individual dignity, personal responsibility, self-determination, and pursuit of meaningful careers, based on informed choice, of individuals with disabilities

(2) respect for the privacy, rights, and equal access (including the use of accessible formats), of the individual;

(3) inclusion, integration, and full participation of the individuals;

(4) support for the involvement of an individual's representative if an individual with a disability requests, desires, or needs such support, and

(5) support for individual and systemic advocacy and community involvement.

Rehabilitation Act of 1973

29 U.S.C. § 701

What is a CIL

The term “center for independent living” means a consumer-controlled, community-based, cross-disability, nonresidential private nonprofit agency that –

(A) is designed and operated within a local community by individuals with disabilities;

(B) provides an array of independent living services.

29 U.S.C. § 796a(1)

CIL Consumer Control

The term “consumer control” means, with respect to a center for independent living, that the center vests power and authority in individuals with disabilities.

29 U.S.C. § 796a(2)

Requirements for CILs

The center shall promote and practice the independent living philosophy of –

(A) Consumer control of the center regarding decision-making, service delivery, management, and establishment of the policy and direction of the center;

(B) Self-help and self-advocacy;

(C) Development of peer relationships and peer role models; and

(D) Equal access of individuals with significant disabilities to society and to all services, programs, activities, resources, and facilities, whether public or private and regardless of the funding source.

29 U.S.C. § 796f-4(b)(1)
34 C.F.R. § 366.60

CIL Duty to Provide Services

The center shall provide services to individuals with a range of significant disabilities. The center shall provide services on a cross-disability basis.

29 U.S.C. § 794f-4(b)(2)

IL NET TRAINING PROJECT

How to Free Our People: Real Life Solutions

May 21 – 23, 2003

Seminar Evaluation Form

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	Not at all		Average		Excellent
Was the seminar content:					
Organized?	1	2	3	4	5
Interesting?	1	2	3	4	5
Useful?	1	2	3	4	5
What you hoped it would be?	1	2	3	4	5
Overall content rating	1	2	3	4	5
Did the trainers know the subject?					
Kirk Lowry	1	2	3	4	5
Bruce Darling	1	2	3	4	5
Did the trainers hold your attention?					
Kirk Lowry	1	2	3	4	5
Bruce Darling	1	2	3	4	5
Did the trainers use relevant examples?					
Kirk Lowry	1	2	3	4	5
Bruce Darling	1	2	3	4	5

Overall trainer rating					
Kirk Lowry	1	2	3	4	5
Bruce Darling	1	2	3	4	5
How likely is it that you will use what you learned at this training?	1	2	3	4	5
Overall training conference rating	1	2	3	4	5

How well did this training develop your skills and knowledge for...

	Low				**High**
1. Demonstrate an understanding of the laws and regulations that support transition?	1	2	3	4	5
2. Identify methods used to recognize consumers for transition?	1	2	3	4	5
3. Identify supports needed for successful transition?	1	2	3	4	5
4. Develop a plan of action for use in the center or community?	1	2	3	4	5

Please list 2 or 3 of the most important things you learned from this training.

What else do you wish you would have learned at this training?

What do you wish the training had spent more time on?

What do you wish the training had spent less time on?

What might prevent you from using the information back on the job?

What other topic would you like to see IL NET do as an on-site training?

What other topic would you like to see IL NET do as a teleconference?

General comments

Thank you for the gift of your time.

Kristy Langbehn

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