DOCUMENT RESUME

ED 350 798 EC 301 611

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TITLE	Adults with Mental Retardation and Other Developmental Disabilities Waiting for Community-Based Services in the U.S.
INSTITUTION	Minnesota Univ., Minneapolis. Research and Training Center on Residential Services and Community Living.
SPONS AGENCY	Administration on Developmental Disabilities (DHHS), Washington, D.C.; National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
PUB DATE	Aug 92
CONTRACT	90DD145102; H133B89948; H133G2027
NOTE	17p.
AVAILABLE FROM	Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr., S.E., Minneapolis, MN 55455.
PUB TYPE	Collected Works - Serials (022) -- Reports - Research/Technical (143)
JOURNAL CIT	Policy Research Brief; v4 n3 Aug 1992
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	Adults; *Community Programs; *Delivery Systems; *Developmental Disabilities; Government Role; Human Services; *Mental Retardation; National Surveys; *Needs Assessment; State Agencies; State Government; State Programs
IDENTIFIERS	*Waiting Lists

ABSTRACT

A survey was conducted of the number and needs of adults with mental retardation or other developmental disabilities (MR/DD) currently waiting for community services. Survey data were obtained for 46 states and the District of Columbia. Respondents included directors of state mental retardation/developmental disabilities programs, state developmental disabilities planning councils, state protection and advocacy agencies, and other agencies and individuals. Results are analyzed in terms of type of agencies that maintain waiting lists (by state), number of people waiting for various types of services (by state), characteristics of the waiting lists, and characteristics of people waiting for services. The study concluded that: (1) few states gather waiting list information that can be useful for planning and for program development; (2) few states track who needs services and what type of services are being sought; (3) many states have written procedures to prioritize service requests, but these procedures are typically centered around crisis situations; (4) there are thousands of people waiting for every type of MR/DD service throughout the country; (5) every state is faced with growing demands for community-based services; and (7) the MR/DD service delivery system primarily provides services to people who are currently in the system, rather than those who live at home with their families. The study identified problems related to identifying adults waiting for services, and noted issues that states should address in providing an equal opportunity service system. (Contains approximately 90 references.) (JDD)

Policy Research Brief

CENTER ON
RESIDENTIAL SERVICES
AND COMMUNITY LIVING
COLLEGE OF EDUCATION
UNIVERSITY OF MINNESOTA

Adults with Mental Retardation and Other Developmental Disabilities Waiting for Community-Based Services in the U.S.

Introduction

Adults with mental retardation and other developmental disabilities (MR/DD) have a higher likelihood of experiencing limitations in major life activities than persons with any other major class of chronic mental, physical, or health conditions (LaPlante, 1991). They also have the highest likelihood of needing ongoing, life-long assistance in basic activities of daily living throughout their lives. Consequently, access to long-term care and related supports for adults with MR/DD has been a long standing concern among people with MR/DD, family members, advocates, professionals, and policymakers.

Historically, long-term care and related services were primarily provided within large, segregated congregate care facilities. However, due to legal, social, and philosophical forces, there has been a dramatic decline in the number of people with MR/DD living in large institutions and an increase in the number living in community-based housing. Between 1977 and 1990, the number of residents with MR/DD in facilities with 15 or fewer residents increased from 40,400 to 149,700, while the number of people in facilities with 6 or fewer residents grew from 20,400 to 98,900 (Lakin, White, Prouty, Bruininks, & Kimm, 1991).

Today, the vast majority of people with MR/DD live in non-institutional settings. According to the National Health Interview Survey (LaPlante, 1988), there are approximately two million people with developmental disabilities living in the United States. About 15.6% live in institutional settings and 84.4% live in non-institutional settings. Of those living in non-institutional settings, the vast majority live at home with their families. Consequently, families play a significant role within the MR/DD service delivery system (Smull, 1989). In fact, families provide more support and services to people with developmental disabilities than all of the formal components of the service system, but many are doing so without any type of formal assistance from the MR/DD service delivery systems (Lakin & Bruininks, 1985).

Despite the major successes of states in achieving the goals of deinstitutionalization and the accompanying development of a community-based service delivery system, a crisis threatens the community-based program movement. As Smull (1989) points out:

> *Demands and expectations have risen faster than funding. The "slack" in the system that was used to cope with unanticipated problems is gone. Institutions are operating programs at capacity with plans to reduce their census. Many communities have few vacancies and no plans to expand. For those waiting, the practice of offering no support and only serving the truly desperate is maintaining a backlog of people in crisis. As the community service system, the institutions, and the "waiting list" all move into more acute crisis they create a set of mutually reinforcing pressures (p.2).*

Recent studies not only support Smull's assertion that there is a growing demand for community-based services, but also that waiting lists have become a common reality for state agencies. In a 1984 national survey, 22 states reported that they had an average of 335 persons waiting for MR/DD day or employment services (McDonnell, Wilcox, & Boles, 1986). In a more recent national survey of day and employment programs for persons with MR/DD, 27 MR/DD agencies reported that they maintain state level information on the number of individuals who currently need day and/or employment services but are not receiving these services (McGaughey, Lynch, Morganstern, Kiernan, & Schalock, 1991). However, only 22 states were able to supply these

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

data. For these states, an average of 1,177 people per state were waiting for day or employment services.

A national survey of state directors of the Association for Retarded Citizens (Arc) estimated that over 63,000 people were waiting for community residential services, while over 76,000 were waiting for daytime programs (Davis, 1987). Although limitations to the study included varying methods of data source identification and data collection across states, few state respondents believed that all people in need of community-based residential services and day programs had been identified. The author concluded that the total number of people reported to be waiting for services was a substantial underestimate of the unmet service needs of individuals with MR/DD. Furthermore, the Arc study and the later summary of the 1990 reports of the State Planning Councils on Developmental Disabilities both observed that there are a number of pressures inhibiting the nations's capacity to provide a sufficient supply of community services.

These pressures include the level of federal and state funding that remain committed to institutional care, despite the steadily decreasing institution populations and state budgets that have not increased sufficiently to meet the needs of people in the community. With respect to providing community services to people not yet receiving services, the Arc directors noted pressures that focus attention on people already in the system. For example, many states are under court order or legislative mandate to move people who live in state-operated institutions to community settings. Furthermore, many states are challenged to meet the Omnibus Budget Recommendation Act (OBRA-1987) requirements to develop alternative living options for many people with MR/DD who live in nursing homes.

The effect of these pressures is most evident for three groups of people: residents of state-operated institutions; persons residing in Medicaid reimbursed nursing facilities; and people living with their families awaiting initial entry into residential, vocational and/or habilitation service settings. For the latter group, the lack of adequate expansion of the service delivery system is being most severely felt by three segments of the population: a) young adults graduating from special education programs who are waiting for vocational and habilitation services and community residential services; b) parents of adult children with MR/DD who want their family members to remain at home, but are seeking respite care and other support services; and c) elderly parents of adult children who are seeking out-of-home placement and, in addition, vocational and habilitation services for the first time.

Although the need to move people from institutional settings to community residences is an important priority, policymakers are also challenged to address the needs of greater numbers of people seeking access to the community-based MR/DD services and programs. The reasons for doing so are not merely humanitarian. As a recent interagency report to the Secretary of the U.S. Department of Health and Human Services noted:

> *Even people with the most severe impairments have no guaranteed access to services after they exit programs provided through the public schools ...Without a greater public commitment to community services, many of these young adults could end up losing most of the gains made through special education and, in the process, begin a new trend toward increased institutionalization (Assistant Secretary for Planning and Evaluation, 1988).*

For growing numbers of critics, the focus solely on people within the system represents abdication of society's responsibility to others equally in need. Ironically, the most serious problems in access to MR/DD programs today appear to be for families who have kept their adult-children at home long beyond the age that most children typically leave home. Therefore, it is important for persons with MR/DD, family members, advocates, professionals, and policymakers to understand the magnitude of the problem and to identify factors that are causing the growth of waiting list so that they can take proactive approaches to resolving the problem.

■ Purpose and Method of the Study

In 1990, the Center on Residential Services and Community Living at the University of Minnesota undertook a study was undertaken to identify and summarize current information and statistics available within states to document the number and needs of persons currently waiting for community services. Specifically, the survey obtained information related to the following questions:

- By whom are current waiting lists maintained?
- How many people with MR/DD are waiting for community-based services?
- What are the characteristics of waiting lists?
- What are the characteristics of the people who are waiting for services?

The process of identifying, obtaining, screening, and verifying states' data on persons waiting for services took place between March 1, 1990, and June 1, 1992. During Spring 1990, 355 letters were mailed to directors of state MR/DD programs, state developmental disabilities planning councils, state protection and advocacy agencies, University Affiliated Programs, and other agencies and individuals potentially having access to or knowledge of statistics on persons with MR/DD who were waiting for services. The letters solicited information regarding related reports or studies that these agencies may have generated that addressed the four previously mentioned questions and about individuals that would be important to contact regarding the existence of such documents.

To insure that information was obtained from each state, there were five subsequent follow-up mailings to people who did not respond to the previous mailing(s) or who were nominated as potentially useful referrals. These mailings included a form that asked the respondent to forward any reports and, if they did not have related materials, to identify the name, address, and telephone number of anyone who may have the information. A postage paid reply envelope was enclosed.

After six mailings, information was obtained from all but four states (CT, DE, IN, ME) and the District of Columbia. During April and May of 1991, follow-up telephone calls were made to each of their MR/DD agencies. Several people were contacted in each state. At least one response was obtained from each of these four states and the District of Columbia.

There were 149 reports identified and screened. The MR/DD agencies sent 74 reports, the state planning councils on developmental disabilities sent 71 reports, and state protection and advocacy agencies sent 4 reports. Of the 149 reports, 44 met the initial criterion for inclusion, which was that the report needed to contain information that related to one or more of the study questions. However, there was no reliable information available from 19 states. Therefore, follow-up telephone calls were made to the MR/DD state agencies of those 19 states from November 1, 1991, through December 20, 1991. Through these telephone calls, the best available estimate of the total number of people waiting for services was obtained.

The nature and quality of data varied considerably from state to state. Some states clearly indicated the type of service (e.g., residential, day habilitation, vocational, and respite), where other states could not. To provide some type of uniformity and consistency, the following classifications were developed:

- **Residential Services:** People who requested community-based residential placements.
- **Day Programs:** People who requested placement in day activity centers, adult day care, and/or adult life skills programs.
- **Vocational Services:** People who requested placement in vocational programs, work activity centers, work adjustment programs, sheltered workshops, supported employment programs, and/or vocational evaluations or job placements.
- **Residential and Vocational Services:** People who requested both residential and vocational services.
- **Support Services:** People who requested individual or family support services, adaptive/therapeutic equipment, respite care, and/or personal assistance services.
- **Other Services:** People who requested any one of the following services: behavioral intervention, case management, counseling, daily living skills training, dental care, early intervention services, family subsidy, infant and toddler programs, intake assessment, patient services, recreation and leisure activities, and transportation.

As the screening process proceeded, the level of detail within these documents proved to be inadequate and, as a result, the initial criterion for inclusion was expanded to assure data were derived from the most current and reliable source. For example, many reports from state planning council on developmental disabilities identified classes of people who were in need of services, but did not provide estimates or the number of people within each class. Therefore, the final decision to include data in this report was based on the following rules that were applied in the following hierarchical order:

- Report data collected from 1989 through 1992.
- Report data from a state MR/DD agency or from the state data base.
- When there were no data available from a state MR/DD agency, report follow-up telephone calls made to state-agency personnel.
- When there were no data available from a state MR/DD agency, report data from a state planning council on developmental disabilities.
- When there were no data available from a state MR/DD agency or planning council, report data either from a state protection and advocacy agency or from a private consultant who was employed by the state MR/DD agency to evaluate the MR/DD service delivery system.
- When there were no data available from a state MR/DD agency, state planning council on developmental disabilities or state protection and advocacy agency, report data from Davis (1987). Data from this study were collected in 1986. Confirmation of current reasonableness of the estimate was obtained.
- There were numerous occasions where different numbers were provided for one type of service or program within one state. Report data that appeared most accurate for each type of service or program were used. When it was unclear which statistic was most appropriate, follow-up telephone calls were made. When it was not possible to identify the most

appropriate statistic, the more conservative number was reported.

Once the synthesis of information was completed, letters were mailed to respondents on February 15, 1992, to request verification of the data and to obtain clarification if needed. Respondents were told that if they did not respond to the letter within six weeks, it would be assumed the information provided was correct. Thirty-two states responded to this final request.

■ Results

Type of Agencies That Maintain Waiting Lists

As presented in Table 1 (see page 5), 36 states maintain waiting lists, 9 states do not maintain lists (CA, ID, IL, IA, KY, MI, ND, WV, WY), and 6 states did not clearly indicate whether or not they maintain lists (AK, DC, GA, OR, RI, VT). Of the 36 states that maintain lists, 8 have more than one agency collecting information (AL, LA, NJ, OH, TN, UT, VT, WA), 15 have a single state agency (AZ, DE, FL, HI, KS, ME, MD, MA, MT, NE, NM, NY, OK, SD, TX), 6 have a regional or district agency (CO, CT, IN, MO, NV, NH), 4 have a county agency (MN, PA, SC, WI), and 3 have service providers collect information (AR, MS, NC).

Number of People Waiting for Services

• **Reported Number.** As shown in Table 2 (see pages 6-7), 60,876 people were reported to be waiting for residential services in 37 states. Another 35,095 persons were reported to be waiting for day habilitation or vocational services, in 32 states. Four states reported that 6,320 people were waiting for both residential and vocational services. There were 32,902 people reported to be waiting for some type of support services in 18 states, and 14,273 individuals were reported to be waiting for some other type of services in 20 states. With 45 states reporting, people with MR/DD were identified as waiting for 186,272 separate community-based services.

• **Estimate for Missing Data.** Since 6 states did not provide any information, estimates for missing data from these six states were desired. A proportional adjustment based on the total number of people living in non-reporting states by the total number of people in reporting states yielded an estimated additional 39,480 people waiting for services or 225,752 people waiting for MRDD services in the United States.

• **Adjustment for Duplication.** To try to estimate the actual number of people who are waiting for services, states were asked if reported numbers were a duplicate count and, if yes, what percentage of the total count would they attribute to duplicate counting. Of 32 states that responded to the question, 26 states provided information regarding whether all or parts of their reported statistics included duplicate count. Based on these reports it was estimated that 19.5% of the reported number of people waiting for services could be attributed to duplicate counting. As a result, the total number of services being waited for by people with MR/DD in the United States was adjusted to 181,835.

Characteristics of the Waiting Lists

• **Waiting List Tracking System.** During the final mailing, states were asked if they had a computerized system to maintain data related to people who are waiting for services. Of the 26 states that responded to the question, 46.2% said they had a fully operational computerized system, 30.8% indicated that they were in the process of developing a computerized system, and the remaining 23.1% said their system was not computerized.

When asked what type of information is contained in their waiting lists, 26 states responded. These states indicated that 20.8% of the respondents said they collect demographic characteristics of each individual; 19.8% include the date of entering the system; 18.8% list the types of programs and/or funding sources for which each individual is eligible to receive; 16.6% provide information related to an individual's personal characteristics; 10.9% collect assessment information related to an individual's needs, strengths, and limitations; 10.9% indicate if the individual is receiving complete and appropriate services; and 2.0% provided other information.

When asked what type of services are requested by individuals, 25 states responded. These states reported that 15.6% needed residential services, 14.9% needed adult day training and habilitation, 12.3% needed supported employment, 11.7% needed supportive living or semi-independent living services, 11.7% needed family support services, 11.0% needed respite care, 9.7% needed competitive employment, 7.1% needed case management, and 5.8% needed specialized transportation services. Only 7.1% of the 25 states stated that they determine if individuals do not receive complete and appropriate services.

Table 1
By Whom are Current Waiting Lists Maintained

State	Type of Agency				Other Responses	
	State Level	Regional/ District Level	County Level	Service Providers	Unknown	No One
AL	--	✓	✓	✓	--	--
AK	--	--	--	--	✓[5]	--
AZ	✓	--	--	--	--	--
AR	--	--	--	✓[1]	--	--
CA	--	--	--	--	--	✓
CO	--	✓	--	--	--	--
CT	--	✓[1]	--	--	--	--
DE	✓[2]	--	--	--	--	--
DC	--	--	--	--	✓	--
FL	✓	--	--	--	--	--
GA	--	--	--	--	✓	--
HI	✓	--	--	--	--	--
ID	--	--	--	--	--	✓
IL	--	--	--	--	--	✓
IN	--	✓[1]	--	--	--	--
IA	--	--	--	--	--	✓
KS	✓[2]	--	--	--	--	--
KY	--	--	--	--	--	✓
LA	✓	✓	--	--	--	--
ME	✓	--	--	--	--	--
MD	✓[2]	--	--	--	--	--
MA	✓[3]	--	--	--	--	--
MI	--	--	--	--	--	✓
MN	--	--	✓[4]	--	--	--
MS	--	--	--	✓[2]	--	--
MO	--	✓	--	--	--	--

State	Type of Agency				Other Responses	
	State Level	Regional/ District Level	County Level	Service Providers	Unknown	No One
MT	✓	--	--	--	--	--
NE	✓	--	--	--	--	--
NV	--	✓	--	--	--	--
NH	--	✓[2]	--	--	--	--
NJ	✓	✓	--	--	--	--
NM	✓[2]	--	--	--	--	--
NY	✓	--	--	--	--	--
NC	--	--	--	✓[2]	--	--
ND	--	--	--	--	--	✓
OH	✓	--	✓[1]	--	--	--
OK	✓[2]	--	--	--	--	--
OR	--	--	--	--	✓	--
PA	--	--	✓	--	--	--
RI	--	--	--	--	✓	--
SC	--	--	✓	--	--	--
SD	✓	--	--	--	--	--
TN	✓	✓	✓	--	--	--
TX	✓	--	--	--	--	--
UT	✓	✓[2]	--	--	--	--
VT	✓	--	--	✓	--	--
VA	--	--	--	--	✓	--
WV	--	--	--	--	--	✓
WA	✓	✓	✓	--	--	--
WI	--	--	✓[3]	--	--	--
WY	--	--	--	--	--	✓
Total #	22	12	8	5	6	9

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[1] Data submitted to state agency.
[2] In process of implementing a computerized system to maintain data.
[3] Data are collected for persons with mental retardation.
[4] Computerized system to maintain data is not being utilized.
[5] Data submitted to Governor's Planning Council on Developmental Disabilities.

Table 2
Type of Services People Are Waiting for by State

State (Reference Number[1])	Date data were	Type of Services/Supports					Total
		Residential[2] collected	Day Habilitation &/ Vocational Services[3]	Residential &/ Vocational[4]	Support[5]	Other[6]	
AL (6)	6/9/90	1,086	1,325	--	776	--	4,018
AK (20)	5/1/90	--	--	--	517	601[7]	1,118
AZ (21)	12/11/90	145	416	--	--	701	1,262
AR (37)	1990	271	272	--	7	338	888
CA (28)[8]	3/9/92	--	--	--	--	--	--
CO (41)	11/30/90	1,616	1,202	--	--	15	2,833
CT (24)	1/1/92	937	453	--	--	--	1,390
DE (27)	4/1/91	179	24	--	--	--	203
DC (48)	10/2/91	210	52	--	--	--	262
FL (32)	1/14/91	--	--	--	--	--	4,673
GA (51)	11/29/89	1,179	--	--	--	--	1,179
HI (53)	9/30/90	201	277	--	--	--	478
ID (n/a)[8]	--	--	--	--	--	--	--
IL (9) (29)	1986	10,000	1,989	--	--	--	11,989
IN (42)	4/31/91	2,048	1,096	--	--	--	3,144
IA (9)	1986	2,000	1,700	--	--		3,700
KS (39)	1/15/91	932	672	--	156	48	1,808
KY (31)	11/15/91	4,503	3,087	--	--	807[10]	8,397
LA (45)	4/18/90	0	550	--	1,400	1,750	3,700
ME (2)	1/91	732	872	--	--	1	1,605
MD (46)	7/1/91	2,392	2,968	--	3,917	--	9,277
MA (25)	2/18/92	1,749	513	265	2,000	--	4,527
MI (n/a)[8]	--	--	--	--	--	--	--
MN (15)	1991	560	1,272[9]	--	340	--	3,135
(16)	1991	---	--	--	--	963[10]	
MS (36)	5/31/91	240	--	--	--	--	240
MO (3)	1/1/92	1,617	--	--	--	1.925	3,542
MT (7)	1/27/92	719	852	--	561	--	2,132
NE (33)	4/20/90	--	--	--	--	--	539
NV (4,13,18,22)	11/13/91	116	--	--	--	171	287
NH (34)	12/91	494	381	--	104	--	979
NJ (14)	2/92	3,023	360	--	--	1,089[11]	4,472
NM (8)	12/18/91	127	274	--	172	442	1,015
NY (19)	2/15/92	9,674	5,251	--	16,007	--	30,932
NC (38)	1989-90	--	1,727[12]	--	--	300	2,027
ND (30)[8]	1/15/91	--	--	--	--	--	--
OH (49)	10/91	2,719	1,242	--	535	227	4,723
OK (17)	5/20/91	391	--	--	486	306[13]	2,158

Table 2 (cont'd.)

State (Reference Number[1])	Date data were collected	Type of Services/Supports					Total
		Residential[2]	Day Habilitation &/ Vocational Services[3]	Residential &/ Vocational[4]	Support[5]	Other[6]	
OR (23)	1987[14]	--	--	2,000	4,600	--	6,600
PA (44)	1990-91	3,995	--	--	--	--	3,995
RI (12)[8]	--	--	--	--	--	--	--
SC (1)	7/17/90	847	441	--	--	--	1,228
SD (5)	7/91	--	--	--	--	--	174[15]
TN (35)	12/31/91	544	869	--	--	--	1,413
TX (43)	1989	--	--	--	--	--	25,313
UT (52)	12/2/91	370	205	207	43	1,262	2,087[16]
VT (50)	12/91	140	160	--	72	194	566
VA (11)	1991	2,100	--	--	--	--	4,479
(19)	1989	--	1,130	--	--	1,249	
WA (47)	7/90	1,640	2,208	3,848		--	7,696
WV (n/a)[8]	--	--	--	--	--	--	--
WI (40)	9/1/90	1,380	1,255	--	1,209	1,884	5,728
WY (26)	1989	--	--	--	--	--	4,301
Total Reported		**60,876**	**35,095**	**6,320**	**32,902**	**14,273**	**186,272**

[1] Reference number is the number preceding each entry in the *Data Reviewed* section.

[2] Residential services include people who requested community-based residential placement.

[3] Day programs include people who requested placement in day activity centers, adult day care, and/or adult life skills programs. Vocational services include people who requested placement in competitive employment, sheltered workshops, supported employment programs, vocational evaluations or job placements, vocational programs, work activity centers, and/or work adjustment programs.

[4] Residential and vocational services include people who requested both residential and vocational services.

[5] Support services include people who requested individual or family support services, adaptive/therapeutic equipment, respite care, and/or personal assistance services.

[6] Other services include people who requested any one of the following services: behavioral intervention, case management, cash subsidies, counseling, daily living skills training, dental care, early intervention services, family subsidy, infant and toddler programs, intake assessment, patient services, recreation and leisure activities, and transportation.

[7] Alaska indicated that, at a minimum, 250 people in rural areas are not identified or receiving services and 351 people requested services and were on the state's waiting list for services.

[8] Data are unavailable or not collected.

[9] Data was obtained from Davis (1987).

[10] Number of people waiting to receive Title XIX Home and Community-Based Services (HCBS).

[11] Number of people for whom services are presently being sought. They are individuals who are known to the service delivery system but are not actively seeking services.

[12] North Carolina indicated that there were 990 people currently unserved/unfunded, 305 inappropriately served and needing vocational activation services, and 432 who can not be served in supported employment because no transportation is available.

[13] Oklahoma reported 875 people currently receive Title XIX Home and Community-Based Services (HCBS) and 35% of this group require additional or more complete services.

[14] Only 29 counties responded to state survey.

[15] South Dakota indicated that 94 people are "truly waiting" for services where 80 people are on the planning list. The planning list includes people whose needs (e.g., medical conditions or behavioral problems) are such that the community services system cannot serve them. They will wait until the state expands the system.

[16] Utah indicated that 1,456 people were provided with case management.

• **Prioritization for Service Delivery.** During the request for verification of the data, states were asked if they had written or informal policies for choosing the order in which persons with MR/DD will receive services. Of the 32 states who responded, 40.6% indicated that they had written procedures, 15.6% said they had informal policies, 40.6% said they had no formal or informal policies, and 3.1% said they did not know of any policies. When asked to characterize these policies, 18 states responded. Specifically, 36.2% indicated that they serve people based upon the urgency of their situation or their level of need. Approximately 15% said they consider the timeline for placement. Others (10.6%) indicated they determine their responsibility to a particular individual. Only 10.6% consider the reason for the service request. About 6% consider the location of the service provider and 6.4% assess the potential for the recipient to become more independent. Finally, others consider the cost of the program and/or services (4.3%).

Documents obtained through the six mailings identified 10 states with specific guidelines to prioritize requests for community-based services (CO, CT, DE, GA, MD, NE, NH, SD, TX, WA). Since this information was not specifically requested, it should not be inferred that only these states have such guidelines. In fact, there often appeared to be an almost implicit understanding that people living in state-operated facilities, nursing homes, or benefiting from a court order or a legislative mandate would receive preferential treatment. For example, a report from Oklahoma observed that "new clients are out in the cold because funds are allocated to implement community programs to comply with the court order" (See Reference No. 17). An Oregon report noted that people who reside in state hospitals get preferential treatment in the allocation of resources (See Reference No. 23).

The reports from the 10 states that provided information contained notable differences in prioritization systems. South Dakota indicated two lists: the "waiting list" includes people for whom "a bed or funding" is being actively sought, and the "planning list" includes people whose needs are such that the state can not serve them until it is able to expand the service delivery system (See Reference No. 5). Texas' priority population consists of persons with mental retardation who are judged most in need, including those with severe health needs or physical impairments, with severe behavior problems, with severe or profound levels of retardation, with mild and moderate levels of mental retardation who need vocational and independent skills training, and with mental retardation who are criminal offenders (See Reference No. 43).

New Hampshire designates people who are in crisis or who are graduating from special education programs as their first priority to obtain services (See Reference No. 34). Colorado has a timeline for placement into which people are placed based upon the following categories: as soon as possible, within one year, within 2 years, and within 3-5 years (See Reference No. 34). Delaware employs a system whereby referrals are placed in three types of categories (i.e., crisis resolution, crisis prevention and transitioning individuals) (See Reference No. 27). Maryland categorizes referrals by type of need (i.e., critical; urgent, in crisis; urgent, but stable; service is highly desirable; and individual wants service in the future).

Several states employ two-tier systems, and one state has a six-tier system. For their residential planning process, Connecticut identifies referrals by four types of priorities (i.e., emergency, priority 1, priority 2, and priority 3) and by 3 types of referral categories (i.e., mandate, obligation, and responsibility). Georgia identifies referrals by urgency of need (i.e., emergency, critical, near future, and future planning) and by reason for request (i.e., caregiver or family member with MR/DD have self-care, behavioral, or medical issues; the individual with MR/DD has a dual diagnosis; there was a previous hospitalization and the person is seeking placement in a less restrictive environment). Nebraska collects data related to the reason for the service request (i.e., graduation from school, change in service need, change in medical needs, change in family status, death in the family, and referrals related to the OBRA-1987 requirements and the level of need (i.e., high, moderate, and low).

Washington established a six-tier priority system for authorizing family support services. Priority 1 includes families involved with child or adult protective services; Priority 2 is families in which a member is at risk of out-of-home placement within one or two months; Priority 3 includes families in which the primary caregiver is experiencing difficulties <u>and</u> the family member needs physical assistance, has challenging behaviors, or has involved health conditions; Priority 4 is families in which the primary caregiver is experiencing difficulties; Priority 5 includes the family members who need physical assistance, has challenging behaviors, or has involved health conditions; and Priority 6 is families in which respite from caregiving is desired.

States were also asked to rank order six groups of adults with MR/DD by the priority that they would receive services within their state. Of those responding, 22 states ranked adults who are living at home and are in a state of crisis as their first priority. Seventeen states ranked persons living in state-operated facilities as second. Eighteen states ranked young adults graduating from special education programs needing residential and/or day habilitation/vocational services as third. Eighteen states ranked adults living at home with elderly parents who are not in a state of crisis, but they are waiting for out-of-home placement and/or day habilitation as fourth. Those living in nursing homes were ranked as fifth by 18 states. Finally, 13 states ranked adults living in large, private institutions as sixth.

Characteristics of People Waiting for Services

Information received on the characteristics of persons waiting for services varied across states. Few states reported much detail on the characteristics of people who were waiting for services. No state had statistics related to clients' levels of mental retardation, functional limitations, and adaptive or maladaptive behaviors. However, many states provided statistics related to a class of people that included the number of people living at home, the number of elderly parents maintaining an adult child at home, and the number of older adults with MR/DD. Again, because these data were not directly requested initially requested, it cannot be assumed that they were not available where not reported.

- **Place of Residence.** During the final mailing, states were asked to indicate what groups of people were included in the reported numbers. Of the 31 states who responded, 30.9% were living with their family or in their own homes; 25.5% were living in non-state operated facilities other than nursing homes; 20.2% were living in state-operated facilities other than nursing homes; 19.1% were living in nursing homes; and 4.3% were living independently, in other states, in non-certified residences, or in community-based facilities and waiting to be transferred to another residence.

- **Number of People Living at Home.** Seven states provided information related to the number of people living with their families (CA, CO, GA, IN, MD, NH, OH). California expects an increasing demand for community living options from people who are living at home and who are aging. A report by the California Department of Developmental Disabilities (1990) indicated the following:

> *Between 1983 and 1989, the number of community clients 22 years of age and older increased by 61 percent as compared to a 23 percent increase in clients under 22 years of age. As clients age, they are less likely to be cared for in their families' homes. Consequently, although only a small portion of children live out-of-home, a large proportion of adults do. Put in another way, 87 percent of community clients under the age of 19 now live with their families, but only 51 percent of community clients aged 19 to 49 live with family members. Among community clients aged 50 or older, only 23 percent live with their families (See Reference No. 28, p. 1-5).*

Other states provided statistics, such as Ohio which reported that of 6,035 people waiting for service, 41% currently live with their family (See Reference No. 49). Georgia noted that 44.5% of 1,179 people waiting for services currently live with family or relative (See Reference No. 51). Of all individuals needing a residential program in Colorado (N= 2,442), 56.5% currently live at home (See Reference No. 41). For adults and children with MR/DD who live in Indiana and are waiting for services (N=2,290), 67.3% are currently living with family members (See Reference No. 42).

As of July 1, 1989, 3,506 adults were waiting for services and lived in Maryland (Gold, Bowen, & Smull, 1990). Of this number 56.8% lived with parents or relatives (See Reference No. 46). Of surveyed caregivers of adults over the age of 21 (N=1,028), 53% reported that caring for a family member was a moderate to severe problem. Of caregivers who reported their own health status (N=2,195), about 42% indicated their health was a moderate to severe problem. Finally, New Hampshire (See Reference 34, Addendum) conveyed the difficulty that many families face:

> *Persons of this waiting list [adults living at home with families] can change priority need at a moment's notice, with the death of a parent, or an increase in the health or behavior needs of the disabled family member, or a stroke or heart attack afflicting one of the parents can require an immediate need for alternative residential services for the person with a developmental disability. The waiting list should therefore, be seen as dynamic, with the needs of the individuals and families changing at any time. Over time, some of these individuals will become number one priority clients in their need for residential services. (See Addendum p. 1)*

- **Elderly Parents.** Four states provided information related to people with MR/DD who are living with elderly parents (MD, NH, OH, WA). Washington stated that "there are 353 clients ... who are 40 years of age or older and are living with parents or relatives. These people will likely need residential support in the future" (References No. 47, p. 36.). New Hampshire reported:

> *... the daily demands for supervision placed by developmentally disabled persons on their families take a tremendous toll on their parents and siblings. Many of these families have been on these waiting lists for several years, including families who felt that they would get immediate relief as a result of [a court order] in the early 1980's. Typically, these parents are in their 50's and 60's and still have their son or daughter living with them, with many of the family members in their 30's or 40's, well past the time when "non-disabled children would have left the family home." (See Reference No. 34, Addendum, p. 1)*

For the 3,506 adults over the age of 21 and in need of services, Maryland found 37% of the caregivers were over

60 years of age, 12% were over 70 years of age, and 1% were over 80 years of age. Moreover, 23% of the aging caregivers were single caregivers, and 44% were employed outside the home (See Reference No. 46). Oregon indicated that for a sample of 200 people residing in the community, and waiting for vocational or residential services or both, almost 25% of the persons identified as primary caregivers were 61 years of age or older.

- **Older Adults with MR/DD.** Five states indicated the number of elderly people with MR/DD (CO, OH, OR, NY, WA). Colorado found that of 843 adults over 21 years old requesting day services, 87.9% are between the ages of 21 to 55 years, and 12.1% are 55 years old or older. Of 1,677 adults over 21 years old who are in need of residential services, 91.2% are 21 to 55 years old and 8.8% are 55 or older.

Ohio reported that of 6,035 adults over the age of 40 waiting for services, 22.9% were 40 to 55 years old, 10.5% were 56 to 69 years old, and 2.9% were 70 years old or older. In a similar analysis, New York found that out of 5,673 people waiting for services, 62.9% were 22 to 40 years old, 8.8% were 45 to 59 years old, and 2.7% were 60 years old or older. Similarly, in an Oregon sample of 238 people living in the community who were waiting for services, 16% were 31 to 40 years old, 10% were 41 to 50 years old, 3% were 51 to 60 years old and 1% were 61 to 70 years old.

Within the state of Washington, 76.6% of the 3,033 unserved people were 22 to 59 years old and 4.5% were 60 years old or older. (See Reference No. 47) A report for the Washington Planning Council on Developmental Disabilities noted:

> *Increasing life expectancy, efforts to reduce nursing home placement of people with developmental disabilities, and the increasing number of clients 55 to 64 years old are all factors which suggest that the population of people with developmental disabilities 65 years and older is likely to increase substantially by the end of the decade (Reference No. 47, p.36).*

- **Young Adult Graduates.** Eight states provided information related to the number of people graduating from special education programs (CO, MD, MA, OH, OR, NY, TX, VT). Persons leaving special education services are a special concern for Oregon because, like their counterparts in other states, they have no guarantee of gaining entry to the adult services system. A recent planning document reported:

> *The number of persons with unmet needs grows every year by at least the number of high school special education graduates for whom no adult services are available. According to Division staff, this number totals as many as 2100 individuals per year. Recent development of supported employment opportunities tied specifically to graduating high school students has dented this problem, but there are more graduating students in need than there are committed resources. In light of the state's considerable investment in educating students with developmental disabilities, it is troubling that the support they need to maintain their gains and continue as productive citizens is in many cases lacking (See Reference No. 23 p. 34).*

A report from Massachusetts indicated that it has a program named, "Turning 22", for recent school graduates. In 1989, there were 1,200 people in this program. In 1990, Colorado reported that 367 people enrolled in public school needed day services, and 66.2% were between the ages of 18 and 20.9 years. Moreover, 344 needed residential services, and 58.7% were between the ages of 18 and 20.9 years.

Reports from Vermont and New York noted the current problems in providing access to community services to students "aging out" of educational services. Of the 5,673 individuals reported in need of residential services, 15.5% are between the ages of 18 to 21 years and 62.8% are between the ages of 22 to 44 years old (See Reference No. 19, p. 2).

As of February 1990, Texas had 29,372 persons with mental retardation and 1,091 persons with autism in the public school system. Of this group, 1,721 left the system in 1988-89. A recent Texas state strategic plan noted that "on graduation there are often few, if any, services that help students leaving the public school to continue their individual development and that help their integration in the community" (See Reference No. 43, p. 28). The Texas Department of Mental Health and Mental Retardation estimated that 632 of these people will be part of the state's priority population. The state intends to seek special funding for 258 people who require intensive services. Another 374 people will require less intensive services, such as prevocational and vocational services. They further stated that, at the same time, transition planning for persons who will leave the public school system will take place for 2,814 persons.

■ Discussion

Reliably estimating the number and characteristics of people on waiting lists for services is problematic at best. The study found a series of problems related to identifying adults with MR/DD who are waiting for needed services and supports. These problems include:

- Less than half of the states have formal data collection systems; the remaining states are either in the process of developing a state-wide data collection system, do not have a data collection system, or they may have an informal system.
- States who do have some type of data collection system collect data in a variety of ways and typically do not collect statistics related to demographic or personal characteristics.
- Few states believe they can accurately identify all of the people with service needs.
- Eligibility for services is dependent upon whether or not the state uses the federal definition of developmental disability or other functional definitions.

In addition, some state agencies only report numbers of people with a particular developmental disability (e.g., mental retardation and autism) who are waiting for services but not persons with other types of disabilities (e.g., brain trauma injury, spina bifida). Furthermore, the waiting lists include only people who contacted the local or state authorities, and, as a result, the numbers do not include people who, for one reason or another, did not request services. Therefore, the numbers repoted in this study are underestimates of the true number of people waiting for services and supports.

Despite these problems, at least six conclusions can be drawn from the study:

- There is a large number of states that maintain waiting lists. However, few states gather information that can be useful for planning and for finding the means or methods to serve people who are unserved or underserved.
- Few states track who needs services and what type of services are being sought.
- Many states have written procedures to prioritize service requests, however, these procedures are typically centered around crisis situations.
- There are thousands of people waiting for every type of MR/DD service throughout the country.
- Virtually every state is faced with growing demands for community-based services that will most likely continue to increase, rather than decrease, over time.
- The MR/DD service delivery system primarily provides services and supports to people who are currently in the system, rather than those who live at home with their families. Persons living at home and in need of services and support typically include young adults who recently graduated from high school, older adults who live with elderly parents, and elderly people with MR/DD.

Waiting lists for community-based services can be a meaningful tool for planning and policy development. These lists can provide information regarding individuals' ages, levels of mental retardation, functional limitations, adaptive behaviors, presence of challenging behaviors, and other demographic and personal characteristics that can assist policymakers in developing the amounts and types of services needed. Waiting lists can serve as a safety valve to take immediate pressure off the system to respond to individuals who are in need of assistance. However, waiting lists can also become permanent indicators of society's inability or unwillingness to respond to the need of individuals. At their worst, lists are indicators of system crisis and failure. This study presents waiting lists as a reflection of a service delivery system that is driven by crisis, underrepresenting those who are in need of services and supports, and unable to distinguished what services are needed or who needs the services and supports.

States that want to provide a system where everyone with MR/DD has an equal opportunity for services, will need to address four issues:

- **Institution population decline.** The federal government continues to support institutions that serve a dwindling population at a great expense to taxpayers. Braddock et al. (1990) predicts the U.S. institutional census will drop below 60,000 in the year 2000, yet more than $6 billion may well be associated with the financing of institutional care that year.
- **Preferential treatment.** Recent litigation suggests that the federal government will continue to support the preferential treatment of persons who are institutionalized over their counterparts who live at home. The Philadelphia Police and Fire Association for Handicapped Children brought a class action against the City of Philadelphia on behalf of persons with mental retardation living at home to challenge the constitutionality of cuts in services (874 F.2d 169 [3rd cir. 1989]). The Appellate Court found the reduction or elimination of benefits for the class did not violate equal protection or due process. The Court stated:

> *Philadelphia could have believed that residents who lost habilitative services and therefore regressed would be more likely to be institutionalized than their counterparts who live with their families. The families, which already have demonstrated their devotion to their retarded children by caring for them at home, might be willing to keep them at home after they have regressed. In contrast, the residences might not be able to continue to care for such residents who, because of their regression, place greater demands on the residential staff. The district court characterized the situation as*

> *follows: "[I]t is as if [Philadelphia and the Commonwealth] seek to capitalize upon the love and dedication of the families of the class members." (Dist.Ct.Op. at 1113, App. 844). Whatever our individual beliefs about the desirability of such a policy may be, such reliance on family dedication is not irrational because it may serve to minimize institutionalization.*

- **Financing limits.** Federal and state budget deficits and the recession reduce the likelihood that states will be able to receive additional funding to expand the current service delivery systems. Therefore, states need to develop creative finance strategies to reallocate current budgets away from institutional care toward the community-based service system.
- **Option cost.** Many people with MR/DD who live in large Intermediate Care Facilities for People with Mental Retardation (ICF-MR) can benefit from living in less costly options. Most ICF-MR funding is being used to finance large, residential living arrangements. Braddock et al. (1990) noted that a 1986 National Study of Public Expenditures found 87% of ICF/MR reimbursements that year were associated with supporting placements in large congregate care facilities with 16 or more beds.

In addition to these issues, an examination of constraints against community service development must occur, and strategies to overcome these constraints need to be identified. State MR/DD directors identified a number of private sector and federal, state, and local government constraints against community-based services and supports (Hemp, Braddock, Bachelder, & Hassen, 1990). For example, federal constraints include restrictions, adverse interpretations, and institutional incentives inherent in the federal Medicaid program. Additionally, state constraints include insufficient funding, inappropriate or low reimbursement systems, and funding restrictions and interpretations.

We need to better understand creative finance strategies that will enable governments and the private sector to provide services and supports to all citizens with MR/DD. A number of strategies that states can employ include flexible and individualized funding approaches, increased family support services, and improved state government collaboration with communities, local governments and community service providers. (Hemp, 1992). In addition, we need to examine the methods and procedures for service delivery employed by the community-based service delivery system.

Conclusion

The service delivery system for persons with MR/DD is at a crossroad. As people in the late 1960's had the foresight to promote the development of community-based services, we are now in the position where we must decide whether or not we will strive to make the necessary adjustments to the current system to include and support everyone. We can either continue to avoid confronting the issues raised, or we can begin to take action. We can continue to serve primarily people who are currently in the MR/DD service delivery system, or we can develop a more inclusive model for service delivery. We can continue to fiscally pit people who live in institutional settings against those who live in the community. If we fail to respond, the current problems within the system will take hold and will continue to grow until the MR/DD system becomes completely unresponsive to the people it serves. If we choose to take action, we will need to re-conceptualize how the MR/DD system will develop and deliver community programs and, as a result, will be more likely to attain the system that was first envisioned.

References

Data Reviewed: Sources of Information

(1) Anderson, D.A. (personal communication, correspondence, February 28, 1992). Department of Mental Retardation (Data Management and Research). Columbia, SC.

(2) Braddick, J. (personal communication, correspondence, April 22, 1991). Planning and Advisory Council on Developmental Disabilities (data was from the Bureau of Mental Retardation). Augusta, ME.

(3) Bright, J. (personal communication correspondence, February, 1992). Department of Mental Health (Division of Mental Retardation and Developmental Disabilities). Jefferson City, MO.

(4) Bynum, D. (personal communication, correspondence, January 24, 1991). Department of Human Services (Division of Mental Hygiene and Mental Retardation, Northern Nevada Mental Retardation Services). Sparks, NV.

(5) Campbell, E. (personal communication, telephone conversation, November 13, 1991). Department of Human Services (Division of Developmental Disabilities). Pierre, SD. *Data confirmed by response to 2/14/92 mailing.*

(6) Campbell, V.A. (personal communication, correspondence, April 17, 1992). Department of Mental Health and Mental Retardation (Applied Research Bureau), University of Alabama. Tuscaloosa, AL. *Data confirmed by 2/14/92 mailing.*

(7) Crosbie, D. (personal communication, correspondence, February 28, 1992). Department of Social and Rehabilitation Services (Developmental Disabilities Division). Helena, MT.

(8) Dalessandri, T. (personal communication, telephone conversation, December 2, 1991). Department of Health and Environment (Division of Developmental Disabilities). Santa Fe, NM.

(9) Davis, S. (1987). A National Report on Waiting Lists of People with Mental Retardation for Community Services. Arlington, TX: Association for Retarded Citizens. *Data Confirmed by response to 2/14/92 mailing.*

(10) Department of Mental Health, Mental Retardation and Substance Abuse Services (September, 1989). Virginia Comprehensive State Plan: 1990-1996. Richmond, VA: Author.

(11) Department of Mental Health, Mental Retardation and Substance Abuse Services (1991). Mental Retardation System Review: Directions for the Year 2000. Richmond, VA: Author.

(12) DiMaio, F. (personal communication, telephone conversation, December 3, 1991). Department of Mental Health, Mental Retardation, and Hospitals (Division of Retardation and Developmental Disabilities). Cranston, RI. *Data are not available.*

(13) Dodd, S. (personal communication, telephone conversation, November 12, 1991). Department of Human Services (Division of Mental Hygiene and Mental Retardation, Southern Nevada Mental Retardation Services). Las Vegas, NV.

(14) Fettweis, P. (personal communication, correspondence, March 30, 1992). Department of Human Services (Division of Developmental Disabilities, Program Support Unit-Community Services). Trenton, NJ.

(15) Fields, T. (personal communication, telephone conversation, October 1991). Department of Human Services. Minneapolis, MN. *Data confirmed by response to 2/14/92 mailing.*

(16) Franczyk, J. (personal communication, telephone conversation, November 14, 1991). Department of Human Services. St. Paul, MN. *Data confirmed by response to 2/14/92 mailing.*

(17) Goodell, D. (personal communication, telephone conversation, May 20, 1991). Department of Human Services (Division of Developmental Disabilities, Community Services Programs). Oklahoma City, OK.

(18) Guidera, S. (personal communication, telephone conversation, November 12, 1991). Department of Human Services (Division of Mental Hygiene and Mental Retardation). Carson City, NV.

(19) Hanley, A. (personal communication, correspondence, February, 1992). State Office of Mental Retardation and Developmental Disabilities (Program Research Unit). Albany, NY.

(20) Hoke, T. (personal communication, correspondence, May 1, 1990). Department of Health and Social Services (Division of Mental Health and Developmental Disabilities). Anchorage, AK.

(21) Holmes, D. (personal communication, correspondence, December 11, 1990). Department of Economic Security (Division of Developmental Disabilities). Phoenix, AZ.

(22) Hosselkus, D. (personal communication, telephone conversation, November 12, 1991). Department of Human Services (Division of Mental Hygiene and Mental Retardation, Rural Nevada Mental Retardation Services). Carson City, NV.

(23) Human Services Research Institute (August, 1990). Oregon Long Range Plan for Developmental Disability Services: Commitment to Community. Manmouth, OR: Author.

(24) Johnson, L. (personal communication, telephone conversation, March, 1992). Department of Mental Retardation (Strategic Planning). East Hartford, CT. *Data confirmed by response to 2/14/92 mailing.*

(25) Keilson, J. (personal communication, correspondence, March, 1992). Department of Mental Retardation (Community Programs and Operations). Boston, MA. *Data confirmed by response to 2/14/92 mailing.*

(26) Kor, R. (1990). *Wyoming: Developmental Disabilities Two-Year Transitional Plan: 1990-91.* Governors Planning Council on Developmental Disabilities. Cheyenne, WY. *Data confirmed by response to 2/14/92 mailing.*

(27) Love, W.E. (personal communication, correspondence, April 1, 1991). Department of Health and Social Services (Division of Mental Retardation). Dover, DE. *Data confirmed by response to 2/14/92 mailing.*

(28) Marlowe, R.A. (personal communication, correspondence, March 9, 1992). Department of Developmental Services (Information Systems). Sacramento, CA. *Data confirmed by response to 2/14/92 mailing.*

(29) McIntosh-Wilson, Eranell. (personal communication, correspondence, March 4, 1992). Department of Mental Health and Developmental Disabilities. Springfield, IL. *Data confirmed by response to 2/14/92 mailing.*

(30) Noble, S. (personal communication, telephone conversation, November 12, 1991). Department of Human Services (Division of Developmental Disabilities). Bismarck, ND.

(31) O'Connell, G. (personal communication, telephone conversation, November 15, 1991). Department of Mental Health and Mental Retardation (Division of Mental Retardation). Frankfort, KY.

(32) Putnam, C. (personal communication, correspondence, March 4, 1992). Department of Health and Rehabilitation Services (Developmental Services). Tallahassee, FL.

(33) Randall, V. (personal communication, correspondence, January 10, 1991). Department of Public Institution (Office of Mental Retardation). Lincoln, NE. *Data confirmed by response to 2/14/92 mailing.*

(34) Reed, B. (personal communication, correspondence, March 25, 1992). Department of Health and Human Services (Division of Mental Health and Developmental Services). Concord, NH.

(35) Riggall, G. (personal communication, correspondence, February, 1992). Department of Mental Health and Mental Retardation (Division of Mental Retardation). Nashville, TN.

(36) Romine, L. (personal communication, correspondence, July 12, 1991). Department of Mental Health (Bureau of Mental Retardation, Community Mental Retardation Services). Jackson, MS. *Data confirmed by response to 2/14/92 mailing.*

(37) Routon, J. (personal communication, correspondence, 1990). Department of Social Services (Developmental Disabilities Services). Little Rock: AR. *Data confirmed by response to 2/14/92 mailing.*

(38) Sabula, M. (personal communication, memorandum to Regional Directors, July 12, 1990, regarding 1989-90 ADAP Program Survey and Cost Findings). Department of Human Resources (Division of Mental Health, Developmental Disabilities and Substance Abuse Services). Raleigh, NC. *Data confirmed by response to 2/14/92 mailing.*

(39) Sherraden, L.D. (personal communication, correspondence, January 15, 1991). Department of Social and Rehabilitation Services (Mental Health and Retardation Services). Topeka, KS.

(40) Stanek, S.J. (personal communication, correspondence, February, 1991). Council on Developmental Disabilities. Madison, WI. *Data confirmed by response to 2/14/92 mailing.*

(41) Struxness, L. (personal communication, correspondence, January 3, 1991). Department of Institutions (Division for Developmental Disabilities). Denver, CO. *Data confirmed by response to 2/14/92 mailing.*

(42) Swaim, N. (personal communication, correspondence, April 31, 1991). Department of Mental Health (Integrated Field Services). Indianapolis, IN.

(43) Texas Department of Mental Health and Mental Retardation (February, 1990). *Draft: Strategic Plan - FY 1992-1997.* Unpublished manuscript.

(44) Toth, M. (personal communication, Telephone conversation, December 3, 1991). Department of Public Welfare (Office of Mental Retardation). Harrisburg, PA. *Data confirmed by response to 2/14/92 mailing.*

(45) Vincent, J.J. (personal communication, correspondence, February 17, 1992). Department of Health and Hospitals (Office of Human Services, Division of Mental Retardation). Baton Rouge, LA. *Data confirmed by response to 2/14/92 mailing.*

(46) Wacker, W.T. (personal communication, correspondence, March 18, 1992). Department of Health and Mental Hygiene (Developmental Disabilities Administration, Planning and Statistics). Baltimore, MD. *Data confirmed by response to 2/14/92 mailing.*

(47) Washington Developmental Disabilities Planning Council (January 25, 1991). Analysis of Selected Agencies Proposed Budgets for the 1991-1993 Biennium. Olympia: Author. *Data confirmed by response to 2/14/92 mailing.*

(48) Wells, R. F. (personal communication, correspondence, October 2, 1991). Department of Human Services (Mental Retardation and Developmental Disabilities Administration). District of Columbia.

(49) Wood, D. (personal communication, correspondence, May 28, 1992). Department of Mental Retardation and Developmental Disabilities (Office of Information System). Columbus, OH.

(50) Wood, T. (personal communication, correspondence, April, 1992). Department of Mental Health and Mental Retardation (Division of Mental Retardation). Waterbury, VT.

(51) Wrensen, G.M. (personal communication, correspondence, February 18, 1991). Department of Human Resources (Division of Mental Health, Mental Retardation, & Substance Abuse). Atlanta, GA.

(52) Wynkoop-Green, D. (personal communication, correspondence; February 26, 1992). Department of Human Services (Division for Services for People with Disabilities, Planning and Program Development). Salt Lake City, UT.

(53) Yamane, E. (personal communication, correspondence, December 3, 1990). Department of Health (Division of Developmental Disabilities). Honolulu, HI. *Data confirmed by response to 2/14/92 mailing.*

Other References

- Amado, A.N., Lakin, K.C., Menke, J.M. (1990). 1990 Chart book on services for people with developmental disabilities. Minneapolis: University of Minnesota, Center for Residential Services and Community Living, Institute on Community Integration (UAP).
- Beckman, P.J. (1983). Influence of selected child characteristics on stress in families of handicapped infants. American Journal of Mental Deficiency, 88, 150-156.
- Braddock, D. & Fuijiura, G.T. (1989). Politics, public policy, and the development of community services in the United States. Chicago: University of Illinois at Chicago, University Affiliated Program in the United States.
- Braddock, D., Hemp, R., Fujiura, G., Bachelder, L., & Mitchell, D. (1990). The state of the states in developmental disabilities. Baltimore: Paul H. Brookes.
- Cohen, S. (1982). Supporting families through respite care. Rehabilitation Literature, 43(1-2), 7-11.

- Cole, D. (1976). Out-of-home placement and family adaptation: A theoretical framework. American Journal of Mental Deficiency, 91, 226-236.
- Davis, S. (1987). A national status report on waiting lists of people with mental retardation for community services. Arlington, TX: Association for Retarded Citizens of the United States.
- Department of Developmental Disabilities (August, 1990) Long Range plan: 1990-95 Sacramento, CA: Office of Planning and Policy Development.
- Gallagher, J.J., Beckman, P., & Cross, A.H. (1983). Families of handicapped children: Sources of stress and its amelioration. Exceptional Children, 50(1), 10-19.
- Gold, L.C., Bowen, G.E., & Smull, M.W. (1990). 1990 source book: Individuals on the waiting list for services funded by the developmental disabilities administration. Baltimore: University of Maryland School of Medicine, Department of Pediatrics (Developmental Disabilities Program: Applied Research and Evaluation Unit).
- Halpern, A.S. (1985). Transition: A look at the foundations. Exceptional Children, 51, 479-486.
- Hasazi, S.B., Gordon, L.R., & Roe, C.A. (1985). Factors associated with employment status of handicapped youth exiting high school from 1979 to 1983. Exceptional Children, 56, 455-469.
- Hasazi, S.B., Hasazi, J.E., Gordon, L.R., Hull, M., & Johnson, R. (1989). Employment of youth with and without handicaps following high school: Outcomes and correlates. The Journal of Special Education, 23, 243-255.
- Heller, T. & Factor, A. (In press). Aging family caregivers: Changes in burden and placement desires. American Journal on Mental Retardation.
- Heller, T. & Factor, A. (1991b). Permanency planning for adults with mental retardation living with family caregivers. American Journal on Mental Retardation, 96(2), 163-176.
- Hemp, R. (1992). State agency and community provider perspectives on financing community services. Policy Research Brief, 4(1).
- Hemp, R., Braddock, D., Bachelder, L., & Haasen, K. (1990, April). Creative financing of community services: The state agency perspective - A working paper (Monograph No. 51). Chicago: Illinois University Affiliated Program in Developmental Disabilities, Institute for the Study of Developmental Disabilities and the School of Public Health.
- Jaskulski, T., Metzler, L., & Zierman, S. (1990). The 1990 reports: Forging a new era. Washington, DC: National Association of Developmental Disabilities Councils.
- Kiernan, McGaughey, Schalock, Lynch, & McNally (1991, April). National survey of state information systems related to day and employment programs. Boston: Training and Research Institute for People with Disabilities, Developmental Evaluation Center (UAP), and Children's Hospital.
- Knoll, J.A. (1990). Family support: A challenge for the 1990's. Exceptional Parent 28-34.
- Lakin, K.C. & Bruininks, R.H. (1985). Challenges to advocates of social integration of developmentally disabled persons. In K.C. Lakin & R.H. Bruininks (Eds.) Strategies for achieving community integration of developmentally disabled citizens. Baltimore: Brookes.
- Lakin, K.C., Bruininks, R.H., & Larson, S. (1991). The changing face of residential services. In L. Rowitz (Ed.), Mental retardation: Year 2000. New York: Springer-Verlag.
- Lakin, K.C., Jaskulski, T.M., Hill, B.K., Bruininks, R.H., Menke, J.M., White, C.C., & Wright, E.A. (1989). Medicaid services for persons with mental retardation and related conditions. Minneapolis: University of Minnesota, Institute on Community Integration.
- Lakin, K.C., Prouty, R.W., White, C.C., Bruininks, R.H., & Hill, B.K. (1990). Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR): Program utilization and resident characteristics. Minneapolis: University of Minnesota, Research and Training Center for Residential Services and Community Living.
- LaPlante, M.P. (1991). Data on disability from the National Health Interview Survey, 1983-1985. Washington, DC: U.S. Department of Education.
- LaPlante, M.P. (1991). Medical conditions associated with disability. In I. Fitzgerald & S. Thompson-Hoffman (Eds.), Disability in the United States. New York: Springer Publishing Co.
- McDonnell, J., Wilcox, B., & Boles, S.M. (1986). Do we know enough to plan for transition? A national survey of state agencies responsible for services to persons with severe handicaps. The Journal of the Association for Persons with Severe Handicaps, 11 (1), 53-60.
- McGaughey, M.J., Lynch, S.A., Morganstern, D.R., Kiernan, W.E., & Schalock, R.L. (1991, April). A national survey of day and employment programs for persons with developmental disabilities: Results from state MR/DD agencies. Boston: Training Research Institute for People with Disabilities, Developmental Evaluation Center (UAP) and Children's Hospital.
- Seltzer, G.B., Begun, A., Seltzer, M.M., & Krauss, M.W. (1991). Adults with mental retardation and their aging mothers: Impacts of siblings. Family Relations, 40, 310-317.
- Seltzer, M. M., & Krauss, M.W. (1989). Aging parents with adult mentally retarded children: Family risk factors and sources of support. American Journal of Mental Retardation, 94 (3), 303-312.
- Seltzer, M. M., Krauss, M.W., & Heller, T. (1990). Boston round table on research issues and application in aging and developmental disabilities. Boston: Gerontological Society of America.
- Smull, M.W. (1989). Crisis in the community. Baltimore: University of Maryland at Baltimore. Department of Pediatrics, School of Medicine (Applied Research and Evaluation Unit).

- Tausig, M. (1985). Factors in family decision-making about placement for developmentally disabled individuals. American Journal of Mental Deficiency, 89 (4), 352-361.
- Townsend, A., Noelker, L., Deimling, G., & Bass, D. (1989). Longitudinal impact of inter-household caregiving on adult children's mental health. Psychology and Aging, 4, 393-401.
- Turnbull, H.R. & Turnbull, A.P. (1989). Report of consensus conference on principles of family research. Lawrence, KS: University of Kansas, Beach Center on Families and Disability.
- Turnbull, A.P., Brotherson, M., & Summers, J (1985). The impact of deinstitutionalization on families: A family systems approach. In R.H. Bruininks & K.C. Lakin (Eds). Living and learning in the least restrictive environment. Baltimore: Paul H. Brookes.
- Wikler, L. M. (1986). Family stress theory and research on families of children with mental retardation. In J. J. Gallagher & P. M. Vietze (Eds.), Families of handicapped persons: Research programs and policy issues (pp. 167-196). Baltimore: Brooks.
- Wolf, M.M. (1978). Social validity: The case for subjective measurement or how applied behavior analysis is finding its heart. Journal of Applied Behavior Analysis, 11, 203-214.

Policy Research Brief • August 1992 • Vol. 4, No. 3

Policy Research Brief is published by the Research and Training Center on Residential Services and Community Living, Institute on Community Integration (UAP), College of Education, University of Minnesota. This publication was supported, in part, by Cooperative Agreements #H133B89948 and H133G2027 from the National Institute on Disability and Rehabilitation Research (NIDRR), and Grant #90DD145102 from the Administration on Developmental Disabilities (ADD). This issue was authored by Mary F. Hayden of the Research and Training Center on Residential Services and Community Living. Managing editor is Vicki Gaylord. The author would like to acknowledge the comments and support provided by Charlie Lakin, Bob Prouty, Paris De Paepe, and Richard Hemp. The opinions expressed are those of the authors and do not necessarily reflect the position of NIDRR, ADD, the Center on Residential Services and Community Living, the Institute on Community Integration, or the College of Education.

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