

## DOCUMENT RESUME

ED 352 757

EC 301 687

AUTHOR Hayden, Mary J.; And Others  
 TITLE Waiting for Community Services: Support and Service Needs of Families with Adult Members Who Have MR/DD.  
 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 Nov 92  
 CONTRACT 90DD145102; H133B89948; H133G2027  
 NOTE 13p.  
 AVAILABLE FROM Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr., S.E., Minneapolis, MN 55455.  
 PUB TYPE Reports - Research/Technical (143) -- Collected Works - Serials (022)  
 JOURNAL CIT Policy Research Brief; v4 n2 Nov 1992  
 EDRS PRICE MF01/PC01 Plus Postage.  
 DESCRIPTORS \*Accessibility (for Disabled); Adults; Agencies; Attitudes; Change Strategies; Community Programs; \*Delivery Systems; \*Developmental Disabilities; \*Family Problems; Mental Retardation; \*Needs Assessment; Program Development; Qualitative Research; Respite Care; Services; \*Social Services; Time; Transitional Programs  
 IDENTIFIERS Family Needs; \*Waiting Lists

## ABSTRACT

This policy brief reports on a study of how families and agencies cope with growing waiting periods for community services for adults who have mental retardation or developmental disabilities (MR/DD). Preliminary information looks at reasons for long waits, characteristics of families waiting for services, and impact of adult members with MR/DD on families. A qualitative study, which utilized four focus groups, participant observation of several families, and semi-structured interviews of adults with MR/DD, is then reported. Results are presented in terms of: contributions of adult family members with MR/DD to their families; stressors experienced by adult family members and their families; needs of adults with MR/DD and their families while waiting for services; services currently available to meet needs; services and supports needed but not currently received; barriers to families receiving existing services; involving others in supporting adult members and their families; and support needs during the transition from living at home to living elsewhere. The report concludes that families should not be disadvantaged because they decide to have their adult family member remain at home and that the MR/DD delivery system needs to be looked at in its entirety. (Contains 33 references.) (DB)

- ✓ This document has been reproduced as received from the person or organization originating it.
- Minor changes have been made to improve reproduction quality.
- Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

ED 352 757

# Policy Research Brief

CENTER ON  
RESIDENTIAL SERVICES  
AND COMMUNITY LIVING  
COLLEGE OF EDUCATION

UNIVERSITY OF MINNESOTA

## Waiting for Community Services: Support and Service Needs of Families with Adult Members Who Have MR/DD

### ■ Introduction

Our national policy directs the mental retardation/developmental disabilities (MR/DD) field to "promote the inclusion of all persons with developmental disabilities, including people with the most severe disabilities, in community life" (P.L. 101-496, Title 1, Sec. 101(b)5). Yet, we have a facility-based service delivery system that continues to have an institutional bias and, in addition, provides community services that are underfunded and fragmented. Of the two million people with developmental disabilities in this country, the majority live at home with their families. The system must change to better address the unmet service needs of these individuals and families.

Thousands of persons with MR/DD are waiting for services throughout this country. Virtually every state is faced with growing demands for community services, demands that will most likely continue to increase rather than decrease. A recent study of waiting lists in 45 states found that there are an estimated 181,835 unfilled services requests from individuals with MR/DD (Hayden, 1992). Findings from this study are consistent with others that have found long waiting lists for needed services (Davis, 1987; Sachs, Smull, & Bryan, 1986; Ward & Halloran, 1989). The largest group of people waiting for services, approximately 31% or 56,187 (Hayden, 1992), are those living at home with their families.

### Families Waiting for Services

The most serious obstacles in accessing the MR/DD service delivery system appear to occur for families who have kept their adult family members at home long beyond the age when most children typically leave home. There are

several reasons that adults with MR/DD are waiting for services while living at home. They include the following:

- Rising service costs in a time of tight state and local budgets.
- Disjointed and uncoordinated services.
- Inadequate planning and policy development to meet the needs of families who currently sustain the system while waiting for services.
- Ineffective attention to the growing concerns of families with members who present particularly high demands, such as persons with medical or physical disabilities or those who exhibit challenging behavior.
- More and more states targeting higher proportions of new community service development for persons being discharged from institutional settings.

Families waiting for services include:

- Families whose young adults graduated from special education programs and who are waiting for vocational, habilitation, and community residential services.
- Parents of adult family members with MR/DD who want them to remain at home, but are seeking respite care and other support services.
- Elderly parents of adult children who are seeking out-of-home placement as well as vocational and habilitation services for the first time.

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.

EC 301 687

The service requests of these families are typically modest. In one study, families frequently requested day habilitation services and at least one type of social support (Black Molaison, & Smull, 1990). In addition, the main reason for seeking assistance was to obtain normalizing activities that would promote the adult family member's independence. Although the service requests are reasonable and modest, our society virtually neglects families who choose to have adult family members with MR/DD remain at home. For example, a report to the Ohio Joint Legislative Study Committee on Community MR/DD Services (1990) estimated that these families save the Ohio taxpayers approximately \$376 million per year. In addition to monetary savings, families make personal and social contributions to their adult members with MR/DD. However, the cumulative personal, social, and economic costs associated with families waiting for services present a substantial counterbalance to the service dollar savings. These costs often include long-term financial instability, family dependence, and isolation from other community members.

Historically, service programs for families with adult members with MR/DD supplanted, rather than supported the family (Knoll, 1990). In other words, services became available to people with MR/DD only after leaving their families. Philosophically, this orientation has changed. Today it is recognized that family living offers much to family members with MR/DD. Moreover, families often provide a vehicle to community integration, employment, social relationships, and other opportunities that are not easily replicated in the service system. Although family support programs are steadily growing, they remain tentative and far fewer than the demand for them. As Knoll (1990) noted:

Each new fiscal year brings substantial change to the depth and breadth of family support programs around the country. Though much of the change is positive and reflects expansion, many programs no longer exist because they were pilot (short-term, trial) projects that did not become permanent. Further, many family-support initiatives are not firmly established by legislative mandate and, therefore, while they may continue, they are susceptible to the state budgetary process (p.28).

Waiting periods have been lengthy in recent years. In addition, budget limitations on service growth along with demographic pressures indicate that new ways must be found to meet at least the most important needs of families.

### **Impact of Adult Members with MR/DD on Families**

Almost all of the research related to "adjustment" of families with members who have MR/DD has focused on childhood. The literature related to the emotional adjustment to children with MR/DD implies an adjustment process was

initiated and completed in the stage following the birth of the child (Wolfensberger, 1970). The concept of the family life cycle represents the collective process of evolution and change as each family member moves through various life stages (Turnbull, Brotherson, & Summers, 1985). Evidence indicates that, as the person with MR/DD transitions from one life cycle stage to another, families make new emotional adjustments (Turnbull et al., 1985; Wikler, 1986). For example, the transition from school to adulthood is viewed as one of the most stressful periods, recognized as the loss of one major form of support (schools) in exchange for the challenges and uncertainty of other community services.

A recent study examined the family transition-related stress and concerns associated with adolescents and young adults with severe developmental disabilities who were about to move from student to adult roles (Thorin & Irvin, 1992). Researchers collected information from 42 members of 19 families. Data was summarized into 28 areas of concern within seven broad domains that included School Life, Work Life, Residential Services, Professionals and Agencies, Young Adult Daily Life, Family Life, and Future. The most stressful concerns for families, as reported by Thorin and Irvin (1992), were from the Residential Family Life and Professionals and Agencies domains. Concerns included the quality and availability of services, working with service providers, and family financial problems and disagreements.

Frequently, stressful periods can escalate to a point where families seek out-of-home placement for the person with MR/DD. For example, Tausig (1985) found significant differences between individual and family characteristics and requests for out-of-home placement. Families were more likely to request a placement if the individual was functioning at lower levels of mental retardation, had no expressive/receptive language skills, or if the frequency of behavior problems was daily or weekly. In addition, requests for placements frequently occurred if another family member had poor physical health.

Tausig (1985) also found that the presence of certain life event stressors (i.e., death of a family member) and specific stressors (i.e., family health, burden of care felt by family members, adult family member exhibited challenging behavior, and disruption within the family) played significant roles in a family's decision to request an out-of-home placement. Similar findings were noted in other studies. For example, Sherman (1988) found adult characteristics (i.e., older, more severe disabilities, and the presence of behavior problems) in conjunction with family characteristics (i.e., larger families and perceived disruption of caring for the individuals with MR/DD) predicted placement outside of the home. Others found that requests were related more to family stressors than to characteristics of the young adult or the participation in day habilitation services (Black et al., 1990).

For relationships between older parents and their adult children with MR/DD, gerontological literature suggests that long-term caregiving can become a burden for the caregiver because of prolonged exposure to stress (Seltzer, Krauss, & Heller, 1991). However, others propose that people naturally adapt to long-term caregiving. One way to adapt is to have the adult family member with MR/DD take on more responsibilities as time goes on. For example, one study found that many adult children with mental retardation providing inter-household care to their elderly parents exhibited stability, rather than regression, in their mental health over time (Townsend, Noelker, Deimling, & Bass, 1989).

Seltzer & Krauss (1989) conducted a cross-sectional analysis from a longitudinal study of aging mothers caring for adult family members with MR/DD, which showed the mothers had above average health for their age, relatively favorable life satisfaction, and about average levels of perceived burden and stress. The researchers found that maternal demographic variables (i.e., age, marital status, education, and income) correlated with maternal physical health and life satisfaction. In addition, adult child risk factors (i.e., level of mental retardation, having Down syndrome, physical health, and functional skills) related more strongly to parenting stress and burden. Additionally, the authors found that social climate was a better predictor of maternal well-being than were formal or informal supports.

Others found that mothers whose older children provided support to the adult with MR/DD had better well-being than mothers with no other children or no involved children (Seltzer, Begun, Seltzer, & Krauss, 1992). Others found that support resources play a significant role in reducing perceived caregiving burdens (Heller & Factor, 1992). These findings indicate that the greatest unmet needs for families, in order of frequency reported, were for residential program information, out-of-home respite care, recreation activities for the individual, financial planning information, guardianship information, case management, and support groups. Similar results were found in other studies. For example, the greatest needs reported by parents who were involved in planning for adult members with MR/DD who were in transition from school to adult roles were residential options, socialization opportunities, and employment/vocational opportunities (Brotherson, Turnbull, Bonicki, Houghton, Roeder-Gordon, Summers, & Turnbull, 1988).

It clearly would be misrepresentative to suggest that families derive only negative effects from adult family members with MR/DD. When asked, families articulate a wide range of contributions, joys, and benefits the adult with MR/DD brought to their families. As indicated by Seltzer, Krauss, and Heller (1990):

The "benefits" may be realized in all of the domains in which the "costs" are manifested: economic, social, and psychological. The issue of positive and negative

effects of family caregiving, and the balance between the two are particularly salient for older parents of adults with mental retardation, as they adapt to the consequences of their own aging in the context of ongoing parental responsibilities.

Clearly, there is a need for more information that examines family adaptation and change longitudinally. Such research needs to be sensitive to changes in individuals and families over time. It also needs to attend to "stressors" not as constant states, but as changing often in interaction with other aspects and events of daily life. The challenge to society appears to be to respond as effectively as possible to these stressors and the social, economic, and psychological situations that exacerbate them so that adult family members with MR/DD can contribute positively to their families and their families can provide functional and stable settings. It is time to examine how families and agencies cope with the growing waiting periods for services to adults with MR/DD.

---

## ■ Purpose and Method of Study

---

In 1992, the Family Services and Support Project at the Institute on Community Integration, University of Minnesota, examined how waiting for community services impacts adults with MR/DD and their families. Investigations centered around identifying stressors experienced by the families, as well as the supports, services, and programs needed by the families.

Methods employed to obtain information were qualitative in nature and included focus groups, participant observation of several families, and semi-structured interviews of adults with MR/DD. These methods provided first-hand information on aspects of waiting for MR/DD services.

### Focus Groups

Focus groups are a useful tool to obtain a specific type of information that would be difficult, if not impossible, to obtain using other methodological procedures (Krueger, 1988). Following guidelines outlined by Krueger (1988), four focus groups were formed:

- Group A: Nine parents of adult family members with MR/DD who were waiting for services and representatives from parent advocacy organizations who either had similar experiences or worked with families that had these experiences. Participants were from the five county Minneapolis/St. Paul metropolitan area and one person was from a large northern Minnesota county.

- Group B: Seven case managers from the five county Minneapolis/St. Paul metropolitan area.
- Group C: Four service providers, one county case manager from a southern Minnesota county, and one state employee from the Minnesota Department of Human Services (Division for People with Developmental Disabilities).
- Group D: Three professional advocates from the Minnesota Council on Developmental Disabilities, Protection and Advocacy agency, and Ombudsman's office met with three self-advocates with MR/DD.

Although many participants volunteered their time, they were reimbursed for lost wages and travel expenses.

Each focus group was four hours in length and was audio-taped. Discussion was on the following seven questions presented to each group:

- What contributions do adult family members with MR/DD make to their families?
- What types of stressors are experienced by adult family members with MR/DD and their families?
- While waiting for community services, what are the needs of adults with MR/DD and their families?
- What types of services are currently available to meet these needs?
- What kinds of services and supports do families and adult family members feel they need that they do not currently receive?
- What are the barriers to families getting existing services?
- What could be done to involve and support others (i.e., siblings, neighbors, extended family members) who support adult family members and their families?
- What could be done to support families and adult family members during the transition from living at home to living outside of the family home?

### **Participant Observation**

The goal of the participant observation component was to give individual parents the opportunity to convey their experiences about what life is like for families without adequate community supports. Two families were identified by staff of a parent advocacy organization. Staff members gained permission from both families to release their names to researchers. To maintain confidentiality, the names of individuals who participated were changed within this report. The families were paid for their participation.

Both parents were single mothers of adult children with autism. Two doctoral-level students whose specialties were anthropology and special education served as observers. Both visited each home during two separate three-hour periods. Each visit was audio-taped and transcribed.

To assure that similar information was obtained from each parent, a guide based upon the questions addressed in the focus groups was developed. Conversations during the observations were basically unstructured, with the course of topics followed as the mothers and others in the home developed them. The two mothers were from very different backgrounds, and had different experiences with the service delivery system. However, each had experienced ongoing difficulties gaining adequate supports and services. The following descriptions of each family are provided to serve as background for the quotes from each parent that are discussed within the Results section.

- Donna and Mike: Donna lives with her son, Mike, who is 26-years-old and has autism, and another adult-age child who does not have disabilities. Another sibling frequently visits the household. To make ends meet, Donna currently holds both full-time and part-time jobs. Mike currently attends a sheltered workshop each weekday and does a variety of paid vocational tasks. Donna is attempting to find a good person care attendant (PCA) to assist in the daily caregiving for Mike. Eventually, she would also like to find a good family-like group home in a nearby area so Mike can keep much of his routine that he currently experiences.
- Jan and Sue: Jan and Sue live in a house where they have lived for 15 years. Jan is in her 60s. Sue is 22 years old. Other extended family members live in the home. Sue graduated from high school over a year ago. She has not received day program services since graduation and, as a result, she stays home each weekday with her mother and Marie, a PCA. Marie works has worked with Sue for approximately one year.

### **Semi-structured Interviews**

Self advocates were included in the focus group process. However, their involvement during the group was limited. As a result, semi-structured interviews were added in an attempt to better gain the perspectives of persons with MR/DD. Four people were identified through county case managers. The case managers gained permission from these individuals and, where applicable, their guardians, to release their names to project staff. To maintain confidentiality, the names of interview participants were changed within this report. People were paid for their participation.

Two doctoral-level students whose specialties were anthropology, counseling, or special education served as

interviewers. Interviewers visited each individual once for 30 to 60 minutes. Each visit was audio-taped to insure reliability and valid reporting and the tapes were transcribed. Conversations were basically unstructured, with the course of topics again followed as the individuals and their parents developed them. However, to assure that similar information was obtained from each individual, a guide based upon the focus group questions was developed.

## ■ Results

In discussing the results, the goal is to highlight *different* perspectives on the problem of waiting for various community services and supports. Yet, there are compelling *similarities* between answers that also merit attention. Indeed, much of the force of this data derives from these similarities. That so many of the comments made during the participant observations and informal interviews are congruent with what was expressed during the focus groups must surely give anyone pause, quantification notwithstanding.

### Contributions of Adult Family Members with MR/DD to Their Families

All focus group participants agreed that adult family members with MR/DD contributed money in the form of monthly Social Security Income (SSI). Moreover, parents, case managers, and service providers all agreed that the family member contributed companionship. Parents, case managers, and advocates stated that completing chores around the house was a big contribution, especially for elderly parents. Parents and providers both concluded that adult family members with MR/DD gave the parents a stake in their communities and a sense of purpose.

The semi-structured interviews yielded a great deal of testimony to the contributions family members made to their families. For example, one of the fathers stated that he never regretted bringing his son, Jack, home :

"Oh man... We would have missed a lot... We've learned a lot, not only about Jack, but about society and... how other people react. I'll give you an example....I was talking to [a fella] and telling him about Jack... He said there aren't many people who would have done it 35 years ago, taking him home from the hospital when we were advised not to, and, just think all those years what we would have missed had we not taken him home..." His wife joined in. "I think it's done wonders for his brothers, too. They're more compassionate... Our grandchildren are used to him..." The father concluded, "I think they've learned a lot."

Don, a 46-year-old man with disabilities, talked about the help he gave his dad:

"... sometimes I help my dad working outside... Cause you know my dad can't do it because I gotta do it... I help him out because he's sick for a long time y'know ...  
"Well, sometimes I, like cutting grass or raking leaves..."

### Stressors Experienced by Adult Family Members and Their Families

All focus group participants identified anxiety over the future of the family member as a stressor. Parents, case managers, and service providers agreed that marital conflict was also a problem. Case managers, service providers, and advocates concurred that financial burdens and a lack of recreation and leisure time were also causes of stress. The case managers and service providers also identified medical problems and sibling rivalries as family stressors.

There was much less agreement among focus group participants about specific ways to lessen these stressors. Case managers, service providers, and advocates recommended empowerment; parents, case managers, and advocates felt that educating the community at large would lessen that stress. Parents and service providers also concurred that assistance in obtaining services would be helpful, while parents and case managers agreed that support groups would alleviate stress.

Problems with service providers and case managers occupied a significant role as a stressor, as reported by the focus groups, but there were other stressors as well. Donna spoke of the ongoing difficulties of being the primary caregiver for Mike and told us of the sacrifices that each member of her family had made:

"... Our whole life is their life (Mike and other adults with MR/DD), and that's pretty much how I see Mike. I don't have a life, my girls don't have a life, Mike has a life. And he runs the rest of us."

### Needs of Adults with MR/DD and Their Families While Waiting for Services

All stakeholders from the focus groups agreed that there was a clear need for recreation and leisure services and a need for training in independent living skills. Parents, case managers, and advocates expressed a need for improved medical services, while parents and service providers agreed on a need for crisis services and effective advocacy. Parents and case managers identified a need for improved assessment. Case managers and service providers believed there was a great need for support groups and counseling, while case managers and advocates concurred that adequate transportation was needed.

Different stakeholders expressed needs in different ways, however. Parents talked about specific problems they had in gaining access to community services, whereas case managers identified specific types of services. The service providers emphasized needs similar to those expressed by the case managers. In turn, the advocates concurred with the case managers and service providers, but added concerns that were specific to policy issues, such as the need for employment and employment assistance, community education, and residential options.

The need for day habilitation was forcefully articulated by Jan, Sue's mother, and Marie, her PCA. As Jan said:

"I think the longer she (her daughter) stays here, her mental thing will... lessen... She doesn't want to go out no more. She's gonna want to be stuck in there [her bedroom] for the rest of her life. You can't do that. A child like that can't be like that. They have to be out..."

During a previous visit, Marie had said that she had seen a decline in Sue's skills since she had been out of school:

"The more she's out... She gets used to it and she wants to do it more. The more she's in that room, then that's where she's rotting away. She's getting slower, her sign language is fallen... But if we're in the community... she's great... But once she's in here, her attitude can swing... So the more she's out, the better off she is."

### **Services Currently Available to Meet Needs**

Although a variety of community services available to families were identified, there were not enough services to meet everyone's requests. Parents and case managers emphasized the availability of respite and day programs, while parents and providers concurred that support groups were also available. Case managers and service providers agreed that recreation and leisure opportunities, Medicaid Waiver Home and Community-Based Services program, and advocacy were available, while the providers and advocates concurred that family support programs were available. Apparent differences probably resulted from different groups of stakeholders emphasizing what others appeared to be taking for granted (e.g., parents mentioned case management, while case managers did not; case managers and service providers mentioned advocacy, while advocates did not).

PCA services are one type of service available to people who receive Medical Assistance (MA). Jan seems to have benefited greatly from these services. Jan and Marie appear to have a very close relationship. By having Marie in her home, Jan has more freedom than what she has experienced in the past. As Marie said:

"We talk... we do things together, we go shopping... It's like a family thing that we do all together here. We try to include mom as much as possible. On other occasions, we kind of let her do her own thing..." Jan continued, "Anytime that she (Marie) is already here, I can go shopping, go for walks, that kind of thing, 'cause she's here. And Sue knows that I'm gone, and... whatever she wants... she'll come to her and get the things she wants from her."

### **Services and Supports Needed but Not Currently Received**

There was much less agreement on this question than on any other. However, differences appear to be superficial. Parents and case managers emphasized a need for crisis care and respite services, while the service providers agreed that crisis mental health services were needed. Donna stated the need for crisis services in unequivocal terms:

So Mike threw this whopping, big temper tantrum, and I called 911. Usually what happens when 911 comes is that they don't know what to do, and they just kind of stand around... And most of them are not familiar with autism. They don't know of any services for me, 'cause I probably at that time need crisis intervention. But I don't need somebody to talk to me on the telephone. I need somebody here, *right now*, who can take charge and do something with this kid who's over six feet tall, and who is hitting, breaking, screaming, yelling, throwing.

Funding flexibility dominated the concerns expressed by the case managers, though both they and service providers also stressed the need for central sources of information and referral. Advocates, in turn, spoke about the need of basic services for people such as independent living skills training, recreation and leisure, housing, and client advocacy.

### **Barriers to Families Getting Existing Services**

There was more agreement on this item than on perhaps any other, primarily as it related to funding. Parents saw a cluster of issues related to funding, including priorities on deinstitutionalization, the level of funding for community services, and the service delivery system's lack of capacity to expand the numbers of family support services. The case managers agreed that funding was a major obstacle. One of their primary concerns was related to how the service delivery system is based upon "open slots" or "available beds", rather than the needs of each individual who is seeking services. Other concerns expressed by the case managers were that the overall level of funding is low and that there is a lack of capacity to expand the number of services to people. The service providers believed that

funding rules that gave a priority to people being deinstitutionalized were a barrier; the advocates saw the issues of funding level and a priority on deinstitutionalization as significant obstacles.

Other barriers parents identified included a conflict of interest for the case manager as a gatekeeper, a lack of available information, and a generally uncoordinated system both within and between counties. Case managers agreed with parents in so far as they conceded that a lack of information was significant and that the service delivery system was antagonistic. They cited their caseloads as a major problem for them in providing adequate services. Service providers agreed with both the parents and the case managers that the service delivery system does not provide adequate outreach to inform people of available services, such as MA, SSI, and Social Security Disability Income (SSDI). Like the parents, they viewed the system as uncoordinated both within and across counties, and like the case managers, they believed large caseloads were a major problem. They went further, however, arguing that regulations governing eligibility, assessment, and authorization were also obstacles to the provision of needed services.

When it came to alleviating these barriers, all agreed that funding needed to be increased and that it should be allocated for individuals rather than services. Both service providers and advocates agreed that funding for families with adult family members should gain some of the emphasis that deinstitutionalization has received. Changes in case management were mentioned by both advocates and parents. Parents suggested privatizing the system, while advocates saw a need for increasing the service.

The parents we visited had much experience with overburdened case managers and an antagonistic service system. Jan reported initiating Sue's transition plans to obtain day habilitation services two years before she was to graduate. At that time she was told that her case manager would have to pursue the matter:

"Actually, he (the case manager) didn't start until the last year before she was gonna be out of school, and then he had to talk to his teachers there, and everything, and, well... it just seemed like it was impossible... No matter how many times I'd call him up to talk to him, he just kept saying, 'Oh yeah. Things are going just fine. Things are going just fine.' But it never turned out that way. So now all we have to do is wait."

At our second visit, Jan was even more irate, complaining that her case manager went along with whatever the service provider told him. Jan stated that she was becoming increasingly frustrated with being unable to obtain day habilitation services for her daughter:

"He doesn't argue the matter... If I tell him, 'Well, they told me (next month),' he'll say, 'Well, that's fine.' Not to me. It isn't fine, 'cause it shouldn't take that long."

Donna's frustrations historically centered around having Mike determined eligible for MA. It took her nearly eight years to obtain MA. Donna related some of the problems:

"I could never get Mike on MA. Those people told me that if Mike lived at home, he lived on my income, and that he couldn't get MA... All my other friends, their handicapped kids were on MA, and I could never get Mike on MA. The guy would hang up on me. I'd call him and I'd say... 'Oh. You must be mistaken, because my friends have handicapped kids, and their kids are on MA.' (The) guy said, 'You're wrong lady... You can't get MA.' And he would just hang up on me... These people were just rude. ... They are indifferent. They are obnoxious. They have a lot of control, and they issue it all. I mean they can do whatever. I complained once to my social worker about that, and she's almost as bad because she never did anything either. She would listen to me and she would do nothing."

### **Involving Others in Supporting Adult Members and Their Families**

Parents, case managers, and providers agreed that economic incentives and education would be helpful, while parents, case managers and advocates stated that support groups could provide some needed assistance. Parents and case managers viewed early sibling involvement as crucial, while service providers and advocates also favored involving churches and developing mentor programs. The case managers also recommended that siblings be included in personal futures planning, and the parents recommended advocacy training. The need for some kind of sibling support or education was underscored by Donna:

"When his sister used to be at home, it was just the most traumatic time for him, 'cause she would come home in the evenings and go to her room and close the door... They don't talk to him. See with Mike and I, Mike knows where I am... He knows what I'm doing. I know what he's doing. But his (siblings) they come and go... Nobody ever talks to Mike. It's like he's totally nonexistent. Part of that is an anger that they have. (One sibling) thinks that her brother embarrasses her."

### **Support Needs During the Transition from Living at Home to Living Elsewhere**

Case managers, service providers and advocates stated that independent living skills training was essential, while



parents and case managers agreed that a mentor program and a slower transition facilitated by a defined planning process would be helpful. The service providers also recommended more widespread use of the Medicaid Waiver Home and Community-Based Services program and allowing the adult family member with MR/DD to earn money while keeping their SSI benefits. The advocates emphasized the need for coordinated services, integrated community education, transportation, and housing.

Donna spoke of how she was almost forced to take the first residential option offered to her when she had finally succeeded in having Mike determined eligible for MA:

"So now that he is on MA, he can qualify for things. We began to look at group homes. As a matter of fact, now I think everybody's real pushy about it. You know you have to be quick, do all this."

Later in the visit, she talked about her reluctance to be hasty in placing Mike:

"This isn't about me, this is about Mike... I can't do something for Mike that isn't fair for him either... It's like when we looked at this 100 bed residential facility... and I said, 'I can't. It's not fair.' Mike's lived at home all his life. Why would I want to put him in a hospital?"

Indeed, some adults with MR/DD are equally aware of the need to plan transitions. Peter, one of the individuals we interviewed, discussed his plans to move out of the home when he turned 26. The interviewer asked, "Do you look forward to living alone?" Peter responded, "Well, I feel kind of sad, but actually I don't have no choice. In the near future Mom and Dad won't be around." Peter was equally aware that there were life areas with which he would need help. When asked if he would want to keep his social worker after he left the home, Peter said, "Yeah... Somebody to check up on me once in a while, to see how I do."

## ■ Conclusion

Families provide more support and services to people with mental retardation and other developmental disabilities than all of the formal components of the service system, but many are doing so without any formal assistance from the MR/DD service delivery system (Lakin & Bruininks, 1985). Although families play a significant role in the service delivery system, society provides only a minimal amount of assistance to support them in their decision to have adult family members with MR/DD remain at home. This fact is reflected, in part, in their growing number waiting for community services.

Although these adult family members with MR/DD make contributions to their families, waiting for services can create additional stress and difficulties for families and, in addition, may have a negative impact on the individual's adaptive skills. The types of supports and services needed by adults with MR/DD and their families, in part, include recreation/leisure activities, training in independent living skills, day habilitation opportunities, respite care, crisis care services, and support groups. Increased residential program options will be critical for families who are seeking out-of-home placement.

There are a number of barriers that often make accessing these supports and services difficult. The barriers identified were primarily systemic in nature, and reflected the need for the federal government to change how they do business within the MR/DD service delivery system. These barriers include restrictions, adverse interpretations, and institutional incentives inherent in the federal Medicaid program. Moreover, insufficient funding at the state-level coupled with inappropriate or low reimbursement systems, funding restrictions, and adverse interpretations may continue to deter states from developing creative finance strategies to reallocate current budgets away from institutional care and toward people living in the community. The result of these barriers is a service delivery system that is unable to adequately respond to those who are living our national policy to include all persons with MR/DD in community life.

Families should not be placed at a disadvantage because they decide to have their adult family members remain at home. Moreover, situations should not have to escalate into crises to spur the service delivery system to provide services. We should strive toward a proactive, rather than a reactive, service delivery system, especially for families caring for adult family members with MR/DD while living at home. While the service delivery system works toward addressing families' needs, it needs to identify methods to support families while they wait for services.

We need to find the means to strike a balance within the MR/DD service delivery system. As Ashby (1969) stated:

Clearly, at any state of the whole, if a single part is not at equilibrium (even though the remainder are) their part will change, will provide new conditions for other parts, will thus start them moving again, and will thus prevent that state from being one of equilibrium of the whole. As equilibrium of the whole requires that all parts be in equilibrium, we can say metaphorically, that every part has a power of veto over the state's equilibrium of the whole (p.79).

Any proposal for change needs to look at the MR/DD service delivery system in its entirety. We need to understand that changes within one part of the system will affect

other parts of the system. In other words, if we shift our energies toward individuals with MR/DD who are currently living at home, we may neglect those who live in other settings. Any adjustments made to the MR/DD service delivery system need to be made in the spirit of equal access

to services. While we strive toward a new system, we cannot continue to expect families with adult family members with MR/DD to carry the burden of an ineffectual system. We need to find the means to identify and provide them with all needed supports while they wait for services.

## ■ References

- Ashby W.R. (1969). Design for a brain. London: Chapman and Hall, Science and Behavior Books.
- Black, M., Molaison, V. & Smull, M. (1990). Families caring for a young adult with mental retardation: Service needs and urgency of community living requests. American Journal of Mental Retardation, 95(1), 32-39.
- Black, M., Cohn, J.F., Smull, M.W., & Crites, L.S. (1985). Individual and family risk factors associated with risk of institutionalization of mentally retarded adults. American Journal of Mental Deficiency, 90(3), 271-276.
- Bogdewic, S. (1992). Participant observation. In B. Crabtree & W. Miller (Eds.), Doing qualitative research (pp. 45-69). Newbury Park: Sage.
- Brotherson, M.J., Turnbull, A., Bronicki, G.J., Haughton, J., Roeder-Gordon, C., Summers, J.A., & Turnbull, H.R. (1988). Transition into adulthood: parental planning for sons and daughters with disabilities. Education and Training in Mental Retardation, 23, 165-174.
- Bruininks, R. H., Meyers, C. E., Sigford, B. B., & Lakin, K. C. (Eds.) (1981). Deinstitutionalization and community adjustment of mentally retarded people (Monograph No. 4) Washington, D.C.: American Association on Mental Deficiency.
- Caires, K.B., & Weil, M. (1985). Developmentally disabled persons and their families. In M. Weil, J. M. Karls, & Associates (Eds.). Case management in human service practice: A systematic approach to mobilizing resources for clients (pp. 233-275). San Francisco: Jossey-Bass.
- Daly, K. (1992). The fit between qualitative research and characteristics of families. In J. Gilgun, K. Daly, & G. Handel (Eds.), Qualitative methods in family research (pp. 3-11). Newbury Park: Sage.
- 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.
- Ferguson, P. M., Ferguson, D.L., & Jones, D. (1988). Generations of hope: Parental perspectives on the transition of their children with severe retardation from school to adult life. The Journal of the Association for Persons with Severe Handicaps, 13(3), '77-187.
- Hayden, M. F. (1992). Adults with mental retardation and other developmental disabilities waiting for community-based services in the U.S. Policy Research Brief, 4 (3), 1-16. Minneapolis: University of Minnesota, Center on Residential and Community Services, Institute on Community Integration.
- Heller, T. & Factor A. (1991). Permanency planning for adults with mental retardation living with family caregivers. American Journal of Mental Retardation, 96(2), 163-176.
- Heller, T. & Factor, A. (1988). Permanency planning among black and white family caregivers of older adults with mental retardation. Mental Retardation, 26(4), 203-208.
- Janicki, M., Lubin, R. & Friedman, E. (1983). Variations in characteristics and service needs of persons with autism. Journal of Autism and Developmental Disorders, 13(1), 73-85.
- Kennedy, J. F. (1963, February). Message from the President of the United States. Congressional Record, (pp. 13-14).
- Knoll, J. A. (1990). Family support: A challenge for the 1990's. Exceptional Parent, 28-34
- Krauss, M. W., Seltzer, M. M., & Goodman, S. J. (1992). Social support networks of adults with mental retardation who live at home. American Journal of Mental Retardation, 96(4), 432-441.
- Kreuger, R. A. (1988). Focus groups: A practical guide for applied research. Newbury Park: Sage
- Lakin, K. C., & Bruininks, R. H. (1985). Challenges to advocates of social integration of developmentally disabled persons. In K. D. Lakin & R. H. Bruininks (Eds.), Strategies for achieving community integration of developmentally disabled citizens (pp. 313-329). Baltimore: Brookes.

- Ohio Joint Legislative Study Committee on Community MR/DD Services (1990). Issues and funding requirements for community MR/DD residential services, support services, and quality assurance. Cleveland: Author.
- Sachs, M. L., Smull, M. W., & Bryan, B. K. (1986). Adults with mental retardation: selected demographic, functional, and service needs characteristics of respondents to the community needs survey as of July 1, 1986. Baltimore: University of Maryland, School of Medicine.
- 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., & Heller, T. (1990). Boston roundtable on research issues and application in aging and developmental disabilities. Boston: Gerontological Society of America.
- 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.
- Sherman, B. (1988). Predictors of the decision to place developmentally disabled family members in residential care. American Journal of Mental Deficiency, 92(4), 344-351.
- 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.
- Thorin, E. J., & Irvin, L. K. (1992). Family stress associated with transition to adulthood of young adults with severe disabilities. The Journal of the Association for Persons with Severe Handicaps, 13(3), 177-187.
- 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, A. P., Brotherson, M. J., & Summers, J. (1985). The impact of deinstitutionalization on families: A family systems approach. In R. H. Bruininks and K. C. Lakin (Eds.), Living and learning in the least restrictive environment (pp. 115-40). Baltimore: Paul H. Brookes.
- Ward, M. & Halloran, W. (1989). Transition to uncertainty: Status of many school leavers with severe disabilities. Career Development for Exceptional Individuals, 12(2), 26-37.
- 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: Paul H. Brookes.
- Wolfenberger, W. (1970). Counseling the parents of the retarded. In A. A. Baumeister (Ed.), Mental retardation: Appraisal, education and rehabilitation. Chicago: Aldine.

## Other Issues of Policy Research Brief

- Adults with Mental Retardation and Other Developmental Disabilities Waiting for Community-Based Services in the U.S. (August 1992)
- Positive Approaches to Managing Challenging Behavior Among Persons with Developmental Disabilities Living in the Community (May 1992)
- Financing Community Services for Persons with Disabilities: State Agency and Community Provider Perspectives (February 1992)
- Qualitative Research: Its Value and Role in Policymaking (August 1992)
- Living in the Community: Persons with Mental Retardation and Allied Medical Conditions (June 1990)
- Parent Attitudes About Their Daughter's or Son's Residential Placement Before and After Deinstitutionalization (November 1989)
- Deinstitutionalization of Persons with Mental Retardation: The Impact on Daily Living Skills (March 1989)

### Policy Research Brief

November 1992 • Vol. 4, No. 2

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 is 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 is authored by Mary F. Hayden, Paul Spicer, Paris DePaepe, and Gene Chelberg. Issue editor is Bob Prouty. Managing editor is Vicki Gaylord. 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, or the University of Minnesota.

The authors would like to thank Barb Polister, the focus group participants, and those who allowed us to interview them.

Additional copies of Policy Research Brief are available through the Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455 • (612) 624-4512.

*The University of Minnesota is an equal opportunity employer and educator.*

Center on Residential Services and Community Living  
Institute on Community Integration  
University of Minnesota  
109 Pattee Hall, 150 Pillsbury Drive SE  
Minneapolis, MN 55455

**Address Correction Requested**

Non Profit  
U.S. Postage  
PAID  
Minneapolis, MN  
Permit No. 155

CNCL. FOR EXCEPTIONAL CHIL  
(CEC)  
1920 ASSOCIATION DRIVE  
RESTON VA 22091