

Double Jeopardy Project Summary of Focus Group Results

Introduction

In 1999, the Ohio Department of Aging developed a grant proposal in partnership with the Ohio Department of Mental Retardation and Developmental Disabilities (ODMRDD) and the Ohio Developmental Disabilities Council (ODDC) to address family support issues for families of older parents who have adult children with developmental disabilities. Funding was subsequently awarded by the Administration on Developmental Disabilities for the “Double Jeopardy” project to accomplish the goal of supporting families in planning for a secure future for their children with developmental disabilities as well as their aging parents.

One aspect of the project’s activities was to conduct focus groups for the purpose of gathering information from program administrators, staff and family members that would contribute to the design and implementation of other project activities. This component of the project was undertaken by Beverly Johnson, Executive Director of the Cerebral Palsy Association of Ohio, and Sande Johnson, Evaluation Specialist with the Ohio Department of Aging. This report constitutes a summary of the findings from these focus groups.

Methodology

A total of twelve focus groups were conducted to solicit information from older parents whose children have mental retardation or other developmental disabilities (MRDD), as well as program administrators and staff from the Aging and MRDD service systems. Four groups were held in each of the areas served by the project’s three pilot sites: one for program administrators, one for program staff, and two targeting parents whose children are 40 years of age or older. One parent focus group was held in each of the six counties represented by the County Boards of MRDD involved in the project. Focus group participants were identified by project

staff from the pilot sites. Eight to twelve individuals were invited to each group.

Questions were then constructed for each type of focus group to elicit information about the following issues:

- Barriers to planning
- Concerns of families
- Strategies for effectively educating and supporting families in planning
- Expectations professionals and families have of one another and the service system
- Available services and resources to help families plan
- Ways to locate families unknown to the system
- Components of what constitutes a comprehensive plan

A total of 102 people participated in the 12 focus groups: 22 administrators, 28 staff, 41 parents, 9 siblings and 2 other family members. Nearly 80% of the participants were women, reflecting the primary role women have as caretakers and as staff in human services. Approximately half of the participants in the focus groups for administrators and staff were from the Aging system and half from the MRDD system. The groups ranged in size from four to eleven participants.

Participants were assured of confidentiality and signed consent forms for audio-taping of the sessions. Notes were also taken during the sessions and used in conjunction with the tapes to analyze the data to produce the findings that follow.

Finally, it was decided to describe the families and their children who are the focus of the Double Jeopardy Project as families that include aging parents and their children who are adults with developmental disabilities. During the course of the focus groups and throughout this report, parents and other family members in caretaking roles were often referred to as caregivers and their children with developmental disabilities as adult children.

Findings

Results of the focus groups are categorized around four major areas: (1) Family Dynamics, (2) Planning Issues and Barriers, (3) Information and Resources, and (4) Systems Issues. Following a discussion of the findings in each of these areas, a summary of recommendations generated by the focus group participants is presented. Finally, issues identified by the facilitators for further consideration are identified.

□ **Family Dynamics**

Families spoke honestly and openly about their fear of the future. Parents reported that they know they are aging, but did not think they would outlive their children. Many were told by physicians to take their children home and love them because they would not live a full life. Others were advised to place their children in institutions and forget about them. At this point in their lives planning for their child's future is something they never thought they would have to do, and they have little or no direction on how to proceed.

The generation targeted by the project, parents over 60 years of age, is highly independent and grew up with the idea that families take care of their own. At the time their children were born it was unacceptable to have a child with a disability and help was not available for families except for institutions. As a result many families are reluctant to ask for or accept help from social service agencies or apply for benefits. In fact, some families fear that the involvement of an agency will result in institutionalization of their child.

Most families believe that caring for their children is their "burden to bear," and frequently do not expect their other children to take on this responsibility. Many parents reported that siblings have told them they would take care of their brother or sister, but parents have doubts about whether they understand what this responsibility entails.

On the other hand, staff reported that many families they've encountered believe other siblings will take on the responsibility of day-to-day care for their brother or sister with a disability. Often this expectation is not realistic because of where siblings live, other commitments they have in their lives to their own families or because some siblings do not want the responsibility.

Siblings who attended the focus groups indicated the need for information and support in order to fulfill their forthcoming responsibilities as caretakers. They will not only need information about planning, but, even

more importantly, about the full array of services and benefit programs that they have little or no experience with.

Some of these same siblings reported that other brothers and sisters in their families were very reluctant to tell their parents that they don't plan to care for their sibling with a disability on a day-to-day basis. They know that their parents have expectations of them to take on this responsibility, but don't talk about it because it will upset their parents if it is openly stated.

Some siblings, who have assumed responsibilities for their brother or sister following the death of their parents indicated that it's a challenge to take over the care of a sibling. Siblings who take on this responsibility report that relationships can be dramatically affected when they take on more of a parental role.

Some parents thought that siblings might not take over the day-to-day care of their brother or sister, but instead could take on responsibilities for monitoring their care and quality of life, stepping in as an advocate when problems arise.

Many parents mentioned other children who live in other states, some of whom have indicated an interest in caring for their brother or sister with a disability. Parents are concerned about the impact a move to another state might have on their child with a disability and wondered if the same services would be available.

Large families seem to provide parents with a built-in "buffer." Siblings are willing to share the responsibilities of caring for their family member with a disability, and plans are often not formalized. Smaller families, on the other hand, are typically more dependent on the service system for the long-term care of their son or daughter, which makes them more susceptible to external factors in making plans, especially the funding and availability of services.

Families and professionals discussed circumstances in which family members experience mutual dependence. In some families, the parents and their child with a disability have an economic interdependence. In these cases, elderly parents on fixed incomes depend on the child's disability benefits, either SSI or SSDI, to support the household. Moving the child into other living arrangements could negatively impact the ability of the parent to live independently. In other circumstances, the child is needed to help take care of the parent.

One of the biggest concerns expressed by parents is that their son or daughter maintain the same quality of life that they have today. They want their children to be well cared for, to live in a nice home, to participate in the same community activities they are involved with today and to have friends and be loved.

Furthermore, parents want an assurance that their plans will be implemented in accordance with their wishes. They are looking for a mechanism to make that happen, whether it be a legal process or whether, as some parents recommended, the state appoints a representative to monitor these situations.

Many professionals working with these families expressed frustration because they feel that they are just responding to crisis situations, instead of planning for the future because of the reluctance of the family to plan ahead. They cited cases in which parents feel they are invincible or are in denial about their mortality, and refuse to plan for a time when they will be unable to care for their child. Some professionals felt they could better work things out directly with siblings without the parents' involvement.

□ Planning Issues and Barriers

Very few parents who participated in the focus groups have made any kind of plans for their own future. Their focus on planning is centered around their children's needs in the future, not their own.

When questioned about what plans parents had made for their future, especially retirement, they indicated that retirement is very different for them. Care of their children was described as a 24 hour day, 7 days a week responsibility from which they don't retire.

Most of the parents in the focus groups are retired and have figured out how to live day-to-day. Many of them reported taking actions such as writing wills, setting up trusts, appointing a power of attorney, and, in a few cases, purchasing long-term care insurance. However, there was a high degree of uncertainty about whether their wills or trusts were properly drafted so as to protect their children's benefits. Parents found this to be very disconcerting and worrisome.

Some professionals in the MRDD system believe planning should be driven by the wishes of the adult child with a disability. Others believe the plan is driven by the parents, especially when decisions about the distribution of financial resources is involved. These conflicting viewpoints need to be

further considered before staff from both systems begin to work with families.

Professionals believe that planning for the future will provide peace of mind to families. Families who had planned and already made arrangements for out-of-home supports reported this was true. Families whose children were still living at home often negatively perceived planning as having to move their child out of their home.

Neither professionals nor families were able to identify what constitutes a comprehensive plan. Individual components, such as housing, insurance, long-term support services, guardianship, wills, trusts and burial arrangements, were mentioned, but were often not considered in any overall scheme of planning. A few family members had either developed or were working on letters of intent and thought they were very important. There is a great deal of confusion about these legal issues among both staff and families.

Families who had been advised in the past to disinherit their child with a disability in order to protect their children's eligibility for benefits, found this advice offensive, even though it is legally correct. As one parent stated, taking that action will "rip your heart out."

Both parents and professionals reported that the need for planning is often identified following a crisis, primarily illness of the caregiver or death of one parent. Many participants thought that having resources to leave also served as an impetus for planning.

Whether parents or other family members engage in planning for the future is more a function of personal style than any other characteristic. People who plan tend to plan in other aspects of their lives. They are organized and approach life in an organized fashion. Planning seems to be just as difficult for siblings to deal with as parents. CareChoice Ohio staff reported that people generally don't plan for their future, and asked why we would expect more from parents of individuals with disabilities.

Many barriers to planning were identified. These include:

- talking about planning means acknowledging loss
- many parents feel nobody will care about their children in the same way they do and struggle with having confidence in various human service agencies;

- families do not want “state or government workers” intruding into their private lives;
- some families feel their child is a stigma and that’s why they don’t ask for services
- some parents are very private, particularly with financial information
- some families are unable to communicate with one another in ways that make planning happen
- fees for professional services, such as financial planners and attorneys are prohibitive for some families;
- lack of residential supports and housing makes it difficult to make long-term plans
- the prospect of estate recovery provides a deterrent to using Medicaid services.

Families are very concerned about where their children will live, who will help them, and whether they will be safe when they are no longer able to care for them. They have heard stories about abuse and neglect of individuals with disabilities in institutions and community-based services, and fear this will happen to their child.

Some families reported that they are ready to seek a residential alternative for their child but find that none are available. At this time, nearly all placements are made for emergencies. This situation makes it nearly impossible for families to think about real planning for residential services.

Many parents believe it will be difficult for their son or daughter to move from the family’s home to a group home and would like there to be some transition. Some families believe their son or daughter would be fine in another living alternative, but don’t want them to leave. One mother wondered if she was holding her son back. Some parents believe their child won’t be able to successfully live in a group home or supported living because their needs are too great for the support provided.

Some families expressed an interest in more segregated living arrangements, where their children can live with others who have similar needs and have

round the clock assistance immediately available. Others stated they want their children to live in and participate in the community.

Families were generally concerned about the quality and stability of community services. They want to know that wherever their child lives is going to be there for them forever.

Families who had already made placement decisions were very positive about the experience. Although it was traumatic for the parents, they reported that their adult children adapted well and had developed greater independence. Parents who made these decisions reported a greater peace of mind about what would happen to their child after they're gone. They believe dealing with the loss of a parent will be difficult enough. With living arrangements already worked out their whole life won't be uprooted.

Many questions were raised about leaving the family home to the child with a disability. This is an option of great interest to families.

To assist families in planning, professionals must work with families to develop trust. Staff need to know what services are available for families and be able to link them with experts in planning. They should be honest about what they know and don't know and be willing to seek answers to questions they can't answer. Telling families what to do and not listening were identified as approaches that don't work in helping families plan for the future.

❑ Information and Resources

Those few parents who had made some kind of arrangements for the future were concerned that their plans were not done correctly. Families and professionals often do not have access to accurate, understandable information. A lack of qualified professionals, especially attorneys and financial planners, was cited as a substantial barrier to planning.

Families did not indicate any clear-cut preference for ways to receive information about planning. Various methods cited include one-to-one consultation, handouts, radio and television, general public information, support groups, seminars, videos, web sites, internet chat rooms, and at planning meetings for their children.

Community agencies such as senior citizen centers, adult day services, MRDD programs, physicians, mental health agencies and ADAMH Boards, and directories about services and supports could also be utilized to provide

information and conduct outreach to unserved individuals and their families.

Family members who will be assuming responsibility for their family member when parents are unable to do so any longer expressed great concern about their lack of knowledge. However, this concern did not focus as much on planning, as dealing with service systems, understanding complex benefit programs, providing daily care, and accessing adaptive equipment.

The Aging and MRDD systems need to come to agreement about the usage of terminology to describe the people and services they provide. Currently the two systems speak a different language. Different words are often used to refer to the same individuals and types of services. Consistency in language will aid communication between staff who work in the two systems, and is vital for effective communication with families as the systems start to work together with them.

A wide array of community agencies and resources were identified to assist families in planning. Knowledge of these resources is sporadic. They include the following:

- Community Fund Management Foundation – an agency located in Cleveland that provides trust services to people with disabilities and families to help them set aside money that won't affect entitlements.
- Frank Hickman and Janet Lowder – attorneys based in Cleveland, who have specialized in disability-related law
- Culley and Associates – financial planners based in Cleveland
- CareChoice Ohio – a service of the Area Agencies on Aging that provides consultation and information to older adults about planning for their future.
- MRDD Boards and Parent Support Groups – have often sponsored presentations by speakers on estate planning and guardianship
- Senior Centers and Adult Day Programs – may offer informative, educational programs

- Advocacy and Protective Services, Inc. – a statewide, non-profit organization that provides guardianship and trusteeship services for people with developmental disabilities who have no one else to do so
- Legal Aid Society – provides legal services for people with low incomes based on a sliding fee scale;

Other local attorneys were mentioned as local resources in some focus groups, but those in attendance had a lack of consensus about their knowledge and ability to help families in planning, so they are not mentioned by name in this report.

Families were overwhelmingly positive about the services their children receive through the County Boards of MRDD. This relationship should be used as a natural connection to provide families with information.

Families who have engaged in planning were identified as a wonderful resource for other families, and other families may be more receptive to their advice. One person said they had a parent panel discuss these issues at a parent meeting and parents were able to ask anything they wanted of the panel. This approach was very satisfying to families. Siblings who have engaged in planning could also participate in the same way.

Families need attorneys who communicate well and can explain complex legal issues in ways that are understandable. Some of the pilot areas are engaging in activities that will help identify attorneys and financial planners in their area who have an interest in working with families to plan for the future. Trumbull County, for example, has completed a survey of professionals in their county and now has a list available to give families.

Other issues to consider when determining how to provide families with information include:

- making legal services available to families who are homebound;
- addressing transportation issues so families can attend meetings with speakers, especially at night in rural area, where taxis often stop running in early evening; and,
- recognizing that some people will come to group meetings and others may not be comfortable in that setting.

❑ **Systems Issues**

Staff in the aging and staff in the MRDD system knew very little about one another's field at the time the focus groups were conducted, and lacked a basic understanding of services provided, funding streams and eligibility criteria. Both systems have functioned quite independent of one another, focusing almost exclusively on their respective target population. This has contributed to territoriality among human service agencies, which presents a barrier to working with a family as a whole unit. Professionals in the focus groups expressed a commitment to working together to help families overcome problems associated with Ohio's fragmented service delivery system.

Collaboration among human service agencies is needed to meet the needs of families. However, past attempts at collaboration have not always been successful. MRDD staff reported difficulties integrating individuals into some Senior Center programs. Other staff reported positive results for people with MRDD in working with Adult Day Care and Senior Centers. These experiences seem to be dependent on the commitment of specific individuals at local programs to integration and collaboration.

When the focus group participants were asked about their expectations of service systems, many stated that families expect the MRDD service system to be there in case something happens to the caretaker, even if they haven't made any plans for the future. Families have heard the message from MRDD professionals, "don't worry, we'll take care of everything." There is also a perception among other human service agencies that MRDD services have funds to meet all of the needs of people with MRDD. And, sometimes, there is a misperception that the MRDD system doesn't want to collaborate, even when funds are available. MRDD staff and administrators indicated that this has generally been true historically, but the commitment to the full inclusion of people with disabilities in community life has increasingly led to collaborative efforts over the last decade.

Few, if any, expectations of the Aging system were stated. Families had very little experience with or knowledge of services and resources for older adults. Staff from the Aging system reported concerns about looking at a new group of clientele, individuals with developmental disabilities, when they already have difficulty accessing certain services, especially mental health services, for people typically served by their agency.

Public policies were identified that support or impede planning for the future by families. Focus group participants identified the following policies or programs that enhance planning by families:

- CareChoice Ohio
- Service Coordination systems in both MRDD and Aging
- Long-term involvement of both service systems in the lives of the people they serve
- Commitment in both systems to providing individualized services in a person's home that meet their unique needs.

Public policies or programs that impede planning for families of older parents and their adult children with developmental disabilities include:

- Services provided under the Older Americans Act because they are restricted for citizens 60 years of age and older.
- Medicaid Waivers that have strict rules on the populations to be served based on Level of Care criteria. This criteria links eligibility for waivers with the type of long-term care facility individuals would use in the absence of the waiver. This eligibility would currently prohibit most people with developmental disabilities from being served on the same waiver as their parents;
- Lack of available services created by a lack of funding for supported living and MRDD waivers interferes with the ability and willingness of families to make plans for future living arrangements. Families can state their preferences and get on a waiting list, but have not ideas if their wishes will be or can be honored when they are no longer able to care for their son or daughter;
- Inflexibility of current funding of MRDD services makes it difficult to use funds in innovative and creative ways to support desired futures for families;
- Estate Recovery requirements under Medicaid may erode or eradicate the resources families intend to leave for their children in a trust or other mechanism, and may interfere with their willingness to access these services.

Families cited problems with the delivery of services as a barrier to planning. Many families were unfamiliar with supported living services. Staff indicated that families have a fear and mistrust of supported living because they can't look at it in the same way they can see a facility such as a group home and they are confused about who is in charge.

Problems with the consistent provision of services has eroded the trust families have in the service system. Families who receive services in their homes reported that constant staff turnover results in new staff always coming into their homes to provide services. These staff are often untrained and do not know the individuals they will be working with. This applies to home health agencies as well as residential supports for people with MRDD.

High staff turnover in case management positions also contributes to the erosion of trust between organizations and families as families are expected to repeatedly share private, personal details of their lives with new staff and build new working relationships.

Although the project examined regional characteristics that impact on planning by families, few characteristics were identified that impact on planning by families. Most notable is the isolation people in rural areas experience and the difficulties they have finding qualified experts in their communities to help them develop appropriate plans. Almost every county reported limitations on how far families were willing to drive for services or to go to meetings, which would affect access to information. Areas with high rates of poverty indicated that families would be less inclined to plan because of the lack of financial resources. Finally, some communities have more group homes developed as a result of previous deinstitutionalization efforts in the MRDD system. Staff reported that many individuals in group homes do not have involved family, and consequently they have no one outside of the service system interested in their future plans.

Recommendations

The following recommendations are based on ideas generated by focus group participants as ways to effectively support and educate families in planning for their futures and that of their children with developmental disabilities. These recommendations are organized around four major themes:

- Building trust between families and professionals

- Developing collaboration and cooperation between the Aging and MRDD systems to address the needs of families as a unit;
- Providing information and resources to families; and,
- Engaging in systems change needed to create more responsive services.

These recommendations reflect the thinking and wishes of those individuals who participated in the focus groups. There are probably others that can be added or those ideas listed below can be modified for use by the project staff. These ideas, however, provide a good starting point for thinking about issues that impact other aspects of the Double Jeopardy project's work and activities.

Build Trust Between Families and Professionals

Since assisting and supporting families in planning for the future is the major thrust of this project, it is essential that staff work diligently to develop trust with families. To accomplish this staff must address the needs of the family as a unit. Families are systems and professionals must recognize that change in one part of the system affects the other parts of it. Therefore, the impact of change for one family member must be considered in relationship to the impact on other family members.

Staff must develop and maintain open communication with families for trust to occur. This requires treating families with dignity and respect and being a good listener. Recommendations for communicating with families include:

- accepting hospitality when offered
- being honest and open with families.
- following through on promises
- consistently communicating with families in ways that they are comfortable with;
- informing families of the full range of services and options available to them
- letting families set the pace of the relationship

- being available when families need help
- respecting the choices and values of families, even when they differ from those of staff; and,
- remembering that there is no one right answer for everybody—what works well with one family may not work with others.

Staff consistently agreed that one very good mechanism for building trust is to demonstrate the ability to deliver services that provide meaningful help to families. Some counties have started by offering families services in their home while their children are still living there. Once agencies demonstrate that they can meet a family's needs, the possibilities for additional interaction and discussion about the future open up.

Other approaches that build trust and communication include:

- matching staff with families based on shared values, although this is not always possible;
- requesting only that information which is needed to provide services or support families in planning, in order to reduce intrusion into areas of people's lives that they feel are private and personal; and
- making planning as easy and convenient as possible.

□ Develop collaboration and cooperation between the Aging and MRDD service systems

Addressing the needs of family units requires a well-designed, systematic approach used by both the Aging and MRDD service systems that is based on collaboration and cooperation. These approaches need to be developed at both the local and state levels. Staff agreed consistently that the first place to start in building collaboration is to educate one another, which the project already has planned. Additional recommendations to build collaboration include:

- Defining the roles of the Aging and MRDD system in addressing the needs of families of older parents and their adult children. These roles may vary according to specific situations.

- Developing local collaborative systems between the Area Agencies on Aging, County Boards of Mental Retardation and Developmental Disabilities and other service agencies for responding to the needs of families. This includes establishing procedures for how agencies will work together and make referrals for assistance to families.
- Exchanging information on an on-going basis so staff can learn from one another about services and supports, approaches that work and don't work, and ways to work together effectively to benefit families. This could be accomplished through joint training sessions, local or regional forums, and/or individual networking. Staff consistently recommended that successful efforts be showcased in a way that they can learn from one another.

□ Provide Information and Resources

Providing meaningful information to families is essential to helping them make good decisions about planning for the future. The following recommendations provide guidance to the project in developing and designing information for families:

- Design informational materials so they are simple and easy to read. One very good example of how to do this is the Medicaid Booklet published by the Ohio Legal Rights Service.
- When discussing the importance of planning, provide examples to families that illustrate the impact planning or the lack of planning can have on families.
- Provide information to families using a variety of approaches. Match the method by which information is provided with the learning styles of individual family members. Individual family members may have different learning styles, requiring that information be presented differently to different people.
- Develop training for siblings who have or will be assuming responsibilities for their brother or sisters with developmental disabilities. Keep in mind that many of them know little or nothing about the service system, benefits, jargon, etc. They are starting from scratch and will need on-going training and support.
- Institute an information and referral service that provides families with comprehensive, up-to-date information on planning and other related issues. Widely publicize the availability of this service.

- Continue to develop and make available a list of experts and community resources that families can contact for assistance.
- To reach families and individuals who are currently unknown to service systems, develop a marketing campaign that utilizes generic community resources. This includes, but is not limited to, churches, physicians, local radio and television.

☐ **Engage in Systems Change**

The following recommendations concerning changes needed in the current systems to better support families in planning for the future are preliminary in nature. Further study of these issues is slated for the second phase of the project. However, the recommendations listed below address issues that pose significant barriers to planning in the current service delivery system.

- Expand service options for people with MRDD so they and their families can have real choice about the future.
- Redesign funding so individuals and their families can use these resources for supportive services in ways that they choose, rather than having funds tied to services in facilities.
- Explore possible changes in PASSPORT to determine if it can be used to support older adults and their children with disabilities.
- Establish a mechanism for adults similar to the children's cluster in which agencies are formally brought together to address how they will provide services and support to adults whose needs cross over into more than one service system.
- Explore the possibility of replicating services provided by the Community Fund Management Foundation in other localities in Ohio.
- Educate and inform legislators at the local, state and federal level about the benefits and outcomes of services for families of older parents and their adult children with disabilities. One suggested strategy that has been successful is to invite them to meetings, tours or open houses sponsored by agencies or advocacy organizations.
- Link with existing advocacy organizations concerned about people who are aging or who have developmental disabilities to work for needed systems changes.

Further Considerations

Several issues were identified during the course of this study that deserve further attention and consideration. This includes the following:

- Determine how the wishes of people with developmental disabilities will be incorporated into the planning process. Planning done by parents for their child's future without the involvement of the adult child flies in the face of the Ohio Department of Mental Retardation and Developmental Disabilities' commitment to the self-determination of people with MRDD. The project must consider how person-centered planning and support fit with the approaches used to help support families in planning for the future.
- Further study issues regarding the roles of siblings in helping and supporting their brothers or sisters with disabilities when their parents are unable to care for them. Tom Fish, Clinic Director at the Nisonger Center, has studied this issue and worked with siblings for many years. He has recently conducted focus groups with adult siblings in which questions have been asked about this very issue. He is highly recommended as a resource to the project on this topic.
- Gather additional information on how to best address the needs of ethnic and minority families.
 - Consider how the project can expand or shift its focus to younger families in future years so parents can have the time to sufficiently plan for their futures as well as that of their children with disabilities.