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CAN WE REST IN PEACE? THE ANXIETY OF ELDERLY PARENTS CARING FOR BABY BOOMERS WITH DISABILITIES

FORUM

BEFORE THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

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FORUM ON CAN WE REST IN PEACE? THE ANXIETY OF ELDERLY PARENTS CARING FOR BABY BOOMERS WITH DISABILITIES

FRIDAY, SEPTEMBER 18, 1998

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The forum convened, pursuant to notice, at 10:03 a.m., in room SH–216, Hart Senate Office Building, Jackie Golden, Joseph P. Kennedy Foundation Fellow, presiding.

OPENING STATEMENT OF JACKIE GOLDEN

Ms. GOLDEN. Good morning. We are going to go ahead and get started, and, hopefully, the seats will fill up as we go along.

First, I wanted to thank you for attending today's forum and I wish to thank the Special Committee on Aging for presenting this topic today. The title of today's forum says it all: "Can We Rest in Peace? The Anxiety of Elderly Parents Caring for Baby Boomers with Disabilities."

My name is Jackie Golden. I am a Joseph P. Kennedy Fellow and have the honor of working with the Special Committee on Aging. I am also a parent of a young man named Joshua Golden. Joshua is 17 and has Angelman's Syndrome, and Angelman's Syndrome is a deletion of chromosome 15. For the Golden family, this does not mean that we do not have dreams for our son, nor does it mean that we can provide his care alone. We need supports in the way of care, accessible housing, and school programs to make his care plan complete. We have set up Joshua's supports through the principles of self-determination, which you will learn more about from the panelists. Without these supports, I know I would not be here.

We are lucky, though. Our family is receiving supports. But let me tell you, it took a crisis for these supports to begin. We received excessive supports because of our all or nothing support system. The State of Maryland is now using the model of self-determination and now Joshua and my family are benefiting, and also the State of Maryland is benefiting because the services we truly need are cheaper.

However, as I said, we are lucky. There are hundreds of thousands of families throughout the United States that are still waiting for supports, waiting for their crisis. As our panel will describe, many of our parents are well into their 70's, 80's, and 90's, and while preparing for this forum, I did my research throughout the States. The oldest parent I found had just turned guardianship of her son over to someone else so she could go into a nursing home. This wonderful mom is 101, her son, 63. This is not uncommon, as we will hear today.

Let me review briefly what a parent goes through accessing the supports they need. Parents request supports through their State agencies. Once the request has been made, they are told there is a waiting list, that the waiting list for services and supports is long. The supports that families are looking for can take many forms, and I can tell you they are only asking for what they truly need.

Family support services can mean someone to come in and give the family a much-earned rest. It can mean financial support with supplies that are not covered by their health insurance. It might mean a day program for their son or daughter so that they will have an activity during the day so the parents can work. It could mean residential services, where the child with the disability can live an independent life.

Many staff people on the Hill, I have learned since I have been here, think that if you have a child with disabilities, you automatically receive Medicaid. This is far from true. Many families fall through the cracks and receive nothing—nothing—as the long waiting list bears out. Many families have been on waiting lists for most of their child's life and never do receive services.

My hope is that today's forum will shed some light into this dark issue and I hope some of the new innovative approaches will help with the difficult situation. The Special Committee on Aging is interested in this issue because the parents of baby boomers with disabilities are living a dual complexity, their own failing health and figuring out their own long-term care needs as well as the future of their adult child with disabilities. We would like to explore the ways the Federal Government can help solve these problems, and I am hoping this forum is just the start.

I want to introduce today our distinguished panel. We are fortunate to have with us today some of the great people working in this area. Lorraine Sheehan is from the Arc. The Arc is the country's largest volunteer organization committed to the welfare of children and adults with mental retardation and their families. Lorraine is the Chairperson of The Arc's Governmental Affairs office. She is also a parent, so she can describe the situation very well firsthand.

Mr. Cumberpatch actually is the parent I arranged to come today. As I said, the complexity of a parent in their 70's is really difficult. Mr. Cumberpatch experienced an anxiety attack on the way here. He is not going to be here. I will read his testimony.

But what I also want to share, and I asked Mr. Cumberpatch if this was OK, if I could share what brought on that anxiety attack. He said it was reliving the situation that he has lived for 35 years. He said that on the way, he just could not face it. I think that says a lot. So his absence really says more than him being here, although I will read his testimony.

Dr. Braddock we are very fortunate to have here today, and I think he will shed a lot of light on the situation. He is coauthor of *State of the States in Developmental Disabilities*. He is head of the Department of Disability at the University of Illinois at Chicago and he will actually share with us the bigger picture across the United States.

Tom Nerney is the co-director of the self determination project for the Robert Wood Johnson Foundation and he will also give us an overview of that exciting project and one I am all too familiar with as that is how my son's services were arranged.

We are also honored to have commissioner Sue Swenson here. Commissioner Swenson is the commissioner of the Administration on Developmental Disabilities. She is also a parent and we are very excited that she is here.

Diane Coughlin is the Developmental Disabilities Administration director for Maryland, and Maryland has an exciting waiting list initiative and also is using self-determination principles in their delivery system.

If I could start, I will turn the microphone over to Lorraine. Thank you.

STATEMENT OF LORRAINE SHEEHAN, CHAIRPERSON, GOVERNMENTAL AFFAIRS COMMITTEE, THE ARC

Ms. SHEEHAN. Good morning. Thank you very much for inviting The Arc to be with you today. I am a parent and I know you get special status in these forums when you are a parent. I get to speak first, after our facilitator here.

I just want to tell you what is going on as far as The Arc is concerned with this waiting list and what we consider a crisis. I am representative of hundreds of thousands of families across the country who are afraid to die because we do not know what will happen to our sons and daughters when we are no longer around to care for them. We are fearful that they will be forced to live in large congregate settings, forced to leave families and friends, or forced to live in substandard housing because there is nothing else available. The title of your forum quite clearly states that fear.

In most States, the only way to get services for people with mental retardation is at the time of severe crisis, and crisis is, indeed, spelled in capital letters. Crisis means that your caretaker is dying or dead. I have often called the waiting list the dead or dying list, because that was the only way to get services.

The services provided in that instance of crisis is always disruptive. Not only is your parent dead, you are shuttled away to a new situation to live with people you do not know, to fit into a slot that may or may not be suited to your needs. The State probably has to fund a behavior specialist because you are acting out your grief and your frustration, and it is quite evident from a common sense point of view that this is just plain wrong. From a public policy point of view, this slot is probably more expensive than would be necessary if it was provided with planning and participation of the individual and the family.

There are only three States in the country that have attacked this problem and developed 5-year plans to eliminate the waiting lists in their States. The first of these was New Jersey, under the leadership of Representative Frelinghuysen, who was a member of the New Jersey legislature at the time and is now a Member of Congress, and Governor Whitman. Maryland was the second State, under the leadership of Governor Parris Glendening, and in the last month, Governor Pataki of New York has announced his plan to eliminate the waiting list in his State.

You have in your packet a copy of The Arc's report card on waiting lists before you. This was done before New York and Maryland announced their initiatives, so the numbers are not quite correct.

Four States report no waiting lists, California, Kansas, Nevada, and Rhode Island, and I am not sure exactly the situation in the first three, but I know in Rhode Island, they have no waiting list because they have taken the savings from the closing of their institutions to fund services in the community.

Iowa, which is a very important State to this committee, Ohio, and West Virginia have not created the capacity to collect data. So while we know there are waiting lists, we do not know what the numbers are in those States.

[The report of The Arc follows:]

The Arc

a national organization on mental retardation

A STATUS REPORT TO THE NATION ON PEOPLE WITH MENTAL RETARDATION WAITING FOR COMMUNITY SERVICES

by

Sharon Davis Ph.D.
Director, The Arc's
Department of Research and Program Services

With assistance from

Alan Abeson, Ed.D., Executive Director
June C. Lloyd, Intern

November 1997

A Status Report to the Nation on People with Mental Retardation Waiting for Community Services

> *"I don't want to wait until I'm unable to take care of her. I want to be at peace with myself to be able to see she made it on her own."*
>
> *"I'm a widow age 74 and my son is 42 years old. I was in the hospital twice this summer. If I should die tomorrow, I want him to have a place to go."*
>
> *(Quotes from Massachusetts parents in Griffiths, 1997)*

Many thousands of families in the United States provide care for sons and daughters with mental retardation. Many of them depend on community supports and services to assist them in meeting the needs of their family member. Tragically, however, in most states, when these families seek services and supports, they come face to face with lengthy and sometimes unending waiting lists.

In 1987, The Arc of the United States conducted the first ever study of waiting lists for community services (Davis, 1987). We found 63,634 individuals with mental retardation waiting for residential services and 76,039 waiting for day/vocational services for a total of 139,673 services needed. Because some individuals were waiting for more than one service, the number of actual people waiting was somewhat fewer than the total number of services needed.

Ten years later, The Arc has again examined the status of waiting lists reported by states for community services across the country. We found 52,072 waiting for residential services; 64,962 waiting for day/vocational services; 35,862 waiting for either or both for a total of 152,896 services needed. In addition, in 1997 we collected data on a variety of services not strictly residential or day/vocational and found 65,290 people waiting. The total services needed by individuals in communities is 218,186 in 1997. Additionally, there are 5,376 people in state institutions waiting for community placement in 16 states that reported such data. This brings the grand total of services needed to 223,562 in the 48 states reporting waiting list information. Finally, if all 53,661 people living in state institutions are added to the waiting list, consistent with The Arc's position on "Where People Live," the waiting list for community services would grow to 271,847.

In summary, to describe the waiting list situation as a crisis for America is no exaggeration. This report makes clear that in the 10 years since The Arc first collected this information, the situation has only grown worse. Further, because of the data gathering mechanisms used by states, as described in this report, it must be acknowledged that the people waiting for 271,847 community services is probably not the true picture of need. The Arc believes it is even greater. Relieving waiting is a priority for The Arc and one which will continue to be addressed.

The Waiting List Problem

Since the early 1970s families have been encouraged to keep children with disabilities at home. Many of these children especially when young can benefit from early intervention and other services, and their families can be greatly helped by family support services, such as respite care, counseling, and cash subsidies which allow them to keep the child at home. This is where many families start to learn about waiting lists, as the service(s) they need or want may not be available to them.

As these children become adults, many still live with their families. Older families especially, who have kept an adult family member at home over the years, are greatly disturbed by the waiting list situation. Sometimes, parents in their 80s who are concerned about what will happen to their sons or daughters after they die, learn they must wait 10 or 12 years for services. Because of long waiting lists for existing residential services in particular, they have difficulty developing thoughtful future plans. They are under a tremendous amount of stress and worry. Some parents believe that the only way off the list for their adult child is for the parents to suffer serious illness or die. This was true for a New Jersey father whose child finally obtained a home in the community after he suffered a massive stroke.

This suffering is not limited only to families, but also to the thousands of individuals who are waiting and waiting! Many of them are young people leaving school only to encounter waiting lists for employment and other daytime services. They are often deprived of the opportunity to experience full life in the community. As these people age, their families cannot help them make the transition to a new living situation and ease the way to such change before the parents die. This means that when the crisis hits, the person with mental retardation loses a parent and moves out of the family home at the same time--a traumatic situation for all !

How This Study Was Conducted

Data Collection

State chapters of The Arc were contacted by mail and requested to assist in collecting information on waiting lists from the appropriate state agency or to provide a contact person who would have the waiting list information. Where additional information was needed or where there was no state chapter of The Arc, the state Developmental Disabilities Council or the state mental retardation/developmental disabilities agency was contacted. Written reports on the waiting list were obtained if available.

The following data were collected:

- Name of agency collecting and maintaining waiting list information
- Sources of waiting list data
- The frequency with which data is collected and date last collected
- Numbers of individuals waiting for each type of community service

- Whether or not numbers were an unduplicated count (meaning that no one was counted more than once)
- Numbers of individuals by age or by age of caregiver, where available
- Number of individuals residing in state institutions
- Number in state institutions on waiting list for community placement

The nature of the data varied considerably from state to state. Some states maintained detailed information on types of services requested; others did not. In general, the following descriptions explain the data in the tables:

- **Residential Services.** Requests for community-based residential placements, including group homes, supported apartments, supported living and any other community living arrangement.
- **Day/Vocational Programs.** Requests for placement in day activity centers, adult day care, work activity centers, sheltered workshops, supported employment programs, job placements and other day programs.
- **Support and Other Services.** Requests for family support services, respite care, personal assistance services, case management, early intervention services, transportation and other services not included in residential and day/employment

No attempt was made to collect data on waiting lists for transportation services. In reality, however, a lack of transportation deprives many people with disabilities from taking advantage of services which do exist.

Overview of State Data Collection Activities

Information regarding waiting lists was obtained from all states and the District of Columbia. Four states reported no waiting lists (California, Rhode Island, Nevada, Kansas). Three did not collect statewide data (Iowa, Ohio, West Virginia). Several others collected limited waiting list data (i.e. Medicaid waiver only in Idaho, family support only in Illinois). Several did not break out the list by type of service for which people were waiting.

Cautions Regarding Interpreting State Data

The Arc urges caution in interpreting the numbers of services for which people are waiting in each state. While some states are quite confident that their data collection process is at least capturing those with the most needs, some are unsure. Others are concerned that their numbers may be inflated by people placing their names on more than one community program's waiting list. Further, the data from other states is sketchy. The Arc believes that no matter the effort, most states' numbers probably underestimate the true need. Many families are managing on their own and are out of touch with the service system. Their needs only become apparent when a crisis occurs. Finally, despite these cautions the fact is that waiting lists are a serious problem for the entire nation.

The numbers collected for this report represent numbers of people waiting for a particular service category. Some people are waiting for more than one service in all but 15 states. Therefore, the total waiting list represents number of individual services needed. The number of individuals waiting for services will be somewhat fewer. In a 1991 survey of people on waiting lists, it was estimated that 19.5 percent of the reported number of people waiting for services could be attributed to duplicate counting (Hayden, 1992).

The data in this report represent the most recent numbers collected by each state at the time of reporting to The Arc during the months of July through October. In most cases, the numbers represent people on the waiting list in 1997. A few states reported 1996 data.

Data are collected by states in a variety of ways, and as indicated few states believe that they accurately identify all of the people with service needs. Most states recognize that many families may not choose to put their family member's name on a waiting list, if they believe it is unlikely to result in a service. Wisconsin notes that the 2,215 people who are on waiting lists for a place to live represent a fraction of the 7,600-plus adults with developmental disabilities who are currently living with family members (and not receiving any paid residential supports). On the other hand, there may be individuals on the waiting list who would refuse services if offered, particularly residential, as they are not ready to move from the family home at the present time. A survey of waiting list families in Massachusetts revealed 33 percent estimated they would need residential services in 2-5 years and 18 percent "in the distant future." The family's recognition of future need plus the reality of being forced to wait led them to place their family member's name on the waiting list.

In some cases, individuals whose names are on a waiting list for a particular service, may already be receiving some service. However, they desire additional services or a different type of service. A person living in a group home could be on a waiting list for a supported apartment, for example. Or, someone who was receiving supported employment services, could be on a waiting list for counseling, if counseling services were scarce. While Pennsylvania has a waiting list of 28,000, it is believed only 2,000 are not receiving any services.

Finally, in most states, these numbers waiting for services also include people with other developmental disabilities and conditions related to mental retardation. However, in a study of people receiving state supported employment services, approximately 90 percent were identified as having mental retardation (McGaughey et al, 1993). Based on this information, we estimate most people on waiting lists are people with mental retardation.

The National Waiting List

The number of community services requested by families across the country in the 48 states providing data is 223,562. This includes 5,376 people living in state institutions who have been identified as waiting for community placement. While four states reported no waiting lists, other states with no data collected acknowledge they know people need services. They simply have not created the capacity to collect the data on a statewide basis. The states falling into this category are Iowa, Ohio and West Virginia. Illinois collects data on waiting lists for its family support program only. Wyoming reports no adults waiting for residential or day/vocational programs, but 12 children are reported as waiting for services.

Table 1 displays the numbers of services requested in each state. The total number of residential services requested is 52,072. The total number of day or vocational services requested is 64,962. A third category includes services needed which could be either or both residential or day/vocational. This includes data from five states where numbers were not broken out by type of service and totals 35,862 service requests. The number of support/other services requested is 65,290. The total service requests from people living in the community is 218,186. In 1991, the University of Minnesota collected waiting list data for residential, day, vocational, support and other services and found a total of 186,272 services requested (Hayden, 1992). Thus, the increase in total requests for services in six years is 31,914. Add the 5,376 people living in state institutions who are ready to leave, and the increase becomes 37,290. If the 53,661 people in state institutions are also added to the list, as The Arc believes they should be, the waiting list for community services grows to 271,847.

The numbers represent services needed and should not be considered the total number of individuals requesting services and supports. Only 15 states indicated that the numbers reported were unduplicated numbers of individuals waiting.

State Rankings on 1997 Data

Table 2 illustrates the number of services for which people are waiting per 100,000 state population in 1997. It is based on each state's total numbers of services for which people are waiting, combining residential, day/vocational and support/other services. By examining the number of services people are waiting for as a function of a specific population figure, large and small states can be compared on an equal basis. The states with the most services needed are at the top of the list.

Louisiana heads the list with 320.3 services needed per 100,000 state population. It is followed by New York with 276 services for which people are waiting per 100,000 population; Pennsylvania with 232.1; Oregon with 226; Alaska with 209.3; and North Carolina with 171.4. Of these six, Pennsylvania's data is the most questionable. It is currently in the process of collecting more accurate data. However, Louisiana, New York, Oregon, Alaska and North

TABLE 1

Community Service Needs: Waiting List

* Data not collected ** No waiting list reported

State	Residential	Day/Voc'al	Either or Both Res/Day	Support	Total
Alabama	1,473	2,621		2,559	6,653
Alaska	353	328		594	1,275
Arizona	197			465	662
Arkansas	337	209		1,420	1,966
California **					
Colorado			1,009	173	1,182
Connecticut	1,339	365		407	2,111
D.C.	25	33			58
Delaware	428	1			429
Florida	1,765	3,462		1,289	6,516
Georgia	1,644	819		583	3,046
Hawaii	--	324		1,071	1,395
Idaho	--	--	192		192
Illinois				3,725	3,725
Indiana	2,067				2,067
Iowa *					
Kansas **					
Kentucky	900			878	1,778
Louisiana	2,587	2,296		9,075	13,958
Maine	351	605		803	1,759
Maryland	2,671	1,891		2.932	7,494
Massachusetts	2,716	471			3,187
Michigan	1,520	1,220		206	2,946
Minnesota	1,858	–		520	2,378
Mississippi	388	335		52	775
Missouri	838	936			1,774
Montana	345	410		116	871
Nebraska	1,046	951		65	2,062
Nevada **					
N. Hampshire	95	80		18	193
New Jersey	4,996	500			5,496
New Mexico	---		1,790		1,790
New York	5,513	30,080		14,632	50,225
N. Carolina	5,111	3,446		4,097	12,654
N. Dakota	39	48		50	137
Ohio *					
Oklahoma	284	445		1,306	2,035
Oregon	2,319	2,148		2,846	7,313
Pennsylvania	—		28,000		28,000
Rhode Island **					
S. Carolina	1,350	880		63	2,293
S. Dakota	14	13			27
Tennessee	876	775		1,916	3,567
Texas	2,345	2,287		6,452	11,084
Utah	1,072	836		1,179	3,087
Vermont	23	101		125	249
Virginia	—		4,871		4,871
Washington	972	4,271		1,906	7,149
West Virginia *					
Wisconsin	2,215	1,775		3,755	7,745
Wyoming				12	12
TOTAL	**52,072**	**64,962**	**35,862**	**65,290**	**218,186**

TABLE 2

State Ranking for Services Needed by People on the Waiting List per 100,000 State Population - 1997

Rank	State	Services needed per 100,000
1	Louisiana	320.3
2	New York	276.0
3	Pennsylvania	232.1
4	Oregon	226.0
5	Alaska	209.3
6	North Carolina	171.4
7	Alabama	154.6
8	Utah	152.1
9	Wisconsin	149.5
10	Maryland	147.3
11	Maine	141.7
12	Washington	127.9
13	Nebraska	123.9
14	Hawaii	117.6
15	New Mexico	103.8
16	Montana	98.5
17	Arkansas	77.8
18	Virginia	72.6
19	New Jersey	68.6
20	Tennessee	66.8
21	Connecticut	64.4
22	South Carolina	61.7
23	Oklahoma	61.4
24	Delaware	58.6
25	Texas	57.5
26	Massachusetts	52.1
27	Minnesota	50.8
28	Kentucky	45.6
29	Florida	44.3
30	Vermont	42.2
31	Georgia	41.0
32	Indiana	35.2
33	Missouri	33.0
34	Illinois	31.2
35	Colorado	30.7
36	Michigan	30.6
37	Mississippi	28.5
38	North Dakota	21.2
39	New Hampshire	16.5
40	Idaho	16.0
41	Arizona	14.7
42	DC	10.8
43	South Dakota	3.7
44	Wyoming	2.5
45	California (no waiting list)	
46	Kansas (no waiting list)	
47	Nevada (no waiting list)	
48	Rhode Island (no waiting list)	
	Iowa (data not collected)	
	Ohio (data not collected)	
	W.Virginia (data not collected)	

Carolina have data collection systems in place which provide them with data which they consider relatively accurate. It can easily be that as a function of doing the best job in collecting waiting list numbers, these states appear to be doing less to serve people on the waiting list.

At the bottom of the list are those states reporting no waiting lists: California, Kansas, Nevada and Rhode Island (listed in alphabetical order).

The states reporting the fewest services needed per 100,000 state population are Wyoming (2.5); South Dakota (3.7); District of Columbia (10.8); Arizona (14.7); Idaho (16.0) and New Hampshire (16.5). In Arizona, the numbers for people waiting for day/vocational services were not available in time to include them. Idaho only maintained a waiting list for people waiting for Medicaid Home and Community Based waiver services. The other states are small and rural. We've noted in past reports on community services that they often seem to be able to identify people and provide services to those who need them more easily than larger states.

Each state needs to weigh the value of the information in Table 2 based on what is known within the state about the waiting list and the state's effort to alleviate the waiting for families and individuals. The data should be used cautiously unless the state has confidence in its own data. Comparisons with other states is not recommended because of the variations in the way data is collected by individual states and the concern it may not accurately represent the state.

Discussion

The effort a state puts into gathering and maintaining waiting list information is a dramatic indicator of the importance and value a state places on supporting persons with mental retardation. In those states where data is maintained, legislators, governors, policy makers, service providers - and even the general public - are more aware of the phenomenon of service waiting lists and how they affect the status and welfare of consumers of services and supports for people with mental retardation as well as their families.

States choose not to maintain waiting lists for several reasons. If an entitlement to services exists in a state, the existence of a waiting list can be cause for litigation. Such litigation was successful in California some years ago. A few states do not collect data out of concern that the visibility of a waiting list will bring too much attention to a problem they already know exists. Other states worry that if families know about the waiting list and the effort to provide services to those on the list, more families will make themselves known to the service system. (New Jersey has found its waiting list growing as more and more families have become familiar with that state's success in obtaining funds for individuals on the waiting list.) A few other states simply have not created the capacity to collect and report aggregate data on waiting lists from local programs across the state. However, The Arc notes that a number of states have created that capacity since 1987 when waiting list data was first collected, including Texas and Connecticut. Other states have upgraded their systems for data collection (i.e. North Carolina).

Waiting lists are a critical public policy issue in almost every state. However, to date, advocates in many states have failed to communicate successfully the immediacy of family and consumer needs to legislators and others. A large number of families and individuals with disabilities on the waiting list need services now, not some time in the future. A survey of families on the waiting list for residential services in Massachusetts found 40 percent needing services immediately or within a year. The caregivers were in poorer health; their sons and daughters had significantly more behavior problems, and fewer had estate plans or designated guardians in their wills than the 60 percent who needed services later. It is possible that some of the families who did not indicate an immediate need may end up requiring services sooner than they anticipate. What is clear is that all will eventually need residential services for their family members (Griffiths, 1997). Many states have a high percentage of people on the waiting list classified as in a crisis or high need situation. In Utah, one such family has been on the waiting list for 18 years and classified as "critically in need of services" for 10 years. Once again, the only sure way for an individual to receive services in many states is for the caretaker to die.

Another issue that goes largely unrecognized is the number of families unknown to the service system. Pennsylvania recently reviewed applications for nursing home placement by aging people with mental retardation and found the majority had never before made contact with the mental retardation service system. These people were never on waiting lists. This is a problem that will likely grow, as families recognize the uselessness in many instances of trying to obtain services. There are also some families who choose not to seek services for their family member with mental retardation while they are living and can provide care. They may suddenly become known to the system only when a crisis occurs.

A major concern of families is how the state deals with individuals moving out of state institutions when many families have been waiting years or are in critical need of services. The population in large state institutions is declining at a rate of about six percent annually. They point out that they have saved the state a considerable amount of money, and now they are waiting for community services and frequently will only be served after people waiting to leave institutions.

Detrimental Effects on Individuals and Families

The unavailability of community services and supports can have detrimental effects on individuals and their families. The following examples are outlined in The Arc's position statement on "Availability of Community Services and Supports."

- Infants who cannot access early intervention services may have greater developmental delays. Early intervention must begin by the time children with disabilities are 2-3 years of age to capitalize on the developing brain's capacity to be sculpted (Thompson, 1997).

- The lack of supports for individuals and families results in emotional and financial hardships. One mother caring for her five-feet-seven-inches tall daughter with severe disabilities reported having back surgery from the heavy lifting. She still continues to care for and diaper her daughter who is 26 years old (Seymour, 1996).
- Inadequate services upon exiting school results in loss of learned abilities, productivity, self-esteem, and the ability to live a more normal lifestyle and, in addition, increases stress on the individual and family. If a community program is not available for the exiting student, when both parents are wage earners, one may have to quit working to stay home to care for the family member.
- Insufficient community housing often results in placing families in a perpetual caregiver situation and keeps the individual in a dependent situation. This is especially critical to elderly families who are literally afraid to die. Several states maintain data on the ages of family caregivers of people on the waiting list. In Maryland, for example, 40 percent of family caregivers are over age 60 and 13 percent over 80.
- The lack of access to transportation results in an inability to access employment and routine community life, thus resulting in social isolation and lost opportunities. In Illinois, the Home-Based Support Services Program has 1700 adults on its waiting list. These support funds could be used to purchase transportation services, but those on the waiting list needing these services remain isolated.

Action Is Needed to Solve the Waiting List Problem

> *Government at all levels must devote more financial resources to eliminating the waiting lists and other barriers to community services and supports. In addition to increased funding, creative usage of existing resources, including generic services, must also be explored to its fullest. Individuals with mental retardation and their families should drive the design of services and supports to assure consumer empowerment, choice and inclusion (The Arc, 1993.)*

The Arc believes eliminating the waiting list to be very difficult, but not an insolvable problem. Solutions lie in society's recognition of the severity of the situation for many families. More effort is urgently needed for solutions to meet families' needs. Described below are some of the efforts already undertaken to find solutions.

We recognize that many states are very concerned about how to offer more services when budgets are strained and competition for existing funds is intense. Some states have increased funding for family support programs, recognizing that for many families, a little support will help them care for their family member at home a little longer. In a number of states, these supports can be used for adults as well as children.

Many states use the Medicaid Home and Community-Based Waiver, which allows Medicaid to pay for community options for people who are in an institution or at risk of going to one. The waiver can be used to move people out of institutions. It can also be used to provide community residential services to people on the waiting list, particularly those with urgent needs. Waiver services typically cost considerably less than institutional services, allowing a state to serve more individuals.

Several states have closed institutions or are in the process of closing institutions which enables them to serve more people on the waiting list. State leaders point out that institutional services are extremely costly. By closing institutions, many more people can be served. Oregon just announced the closing of the Fairview Developmental Center by the year 2000. The state estimates $1.4 million in savings in 1998, $6.6 million in 1999 and $14 million thereafter can be used to serve people from the waiting list. Currently the cost of care at Fairview is about $212,000 per resident, per year and consumes 30 percent of the state agency's program budget, while Fairview serves only 3 percent of the population with mental retardation receiving services. In Wisconsin, 50 percent of the state's funds support 4 percent of the people in institutions.

Several chapters of The Arc and other advocacy organizations have been actively involved in seeking solutions to the waiting list problem. Some solutions result in increased funds devoted to serving the waiting list. The Arc of New Jersey launched a media campaign to help the public and legislators understand the needs of families on the waiting list titled "A Key of Our Own." As a result, the voters passed a bond issue to finance the construction of community residences. The Arc then advocated for the legislature to allocate operational funds and was successful.

The Arc of New Hampshire reports success in obtaining passage by the state legislature of two bills related to waiting lists in 1997. One urged "the preservation and continued development of community services to people with developmental disabilities and their families" and the other called for "full funding for services for persons with developmental disabilities."

In Nevada, advocates, including members of The Arc, succeeded in convincing legislators to fully fund the residential and day services waiting list in 1997 with funds for two years of growth in day services. An increase in family support funds was allocated to help any families entering the residential waiting list in the next two years.

Arc Massachusetts was instrumental in bringing together a coalition of three statewide family-based groups to create solutions to the waiting list for residential and day services. The collaboration, referred to as Family to Family, unites families in a statewide information network devoted to the waiting list. They are connected with other families in similar circumstances to share experiences and work together on common concerns. Families have been surveyed regarding their needs, assisted in voicing their needs to the state legislature and guided in pursuing creative service options in partnership with other families, private organizations or government agencies. Their efforts did not go unnoticed. The legislature increased funds for students leaving school, family support, direct support staff, and for the first time, included a separate line item in the budget for the waiting list.

The Arc of Maryland recently launched a campaign to reduce the waiting list in Maryland based largely on The Arc of New Jersey's experience. The "Key Campaign: Unlock the Waiting List" kicked off with a conference where families on the waiting list learned about successful strategies used by The Arc of New Jersey and Arc Massachusetts. The conference was designed to empower families to take specific action - media, town meetings, legislator contacts - in the effort to meaningfully address services to people on the waiting list.

The Arc of Utah has been engaged in a three-year campaign to educate legislators about the personal stories of people on the waiting list. Many people have been willing to have their stories made public. The Arc of Utah contends that maintaining the waiting list implies that there will be services available, but some people classified as having "critical needs" have been waiting 10 years. This year The Arc is sending legislators a monthly update on the waiting list with personal stories and current waiting list statistics.

Finally, The Arc believes the voices of families are key to solving the waiting list crisis. Families within The Arc are speaking out on their concerns. Their voices, heard by legislators across the country, will help make a difference. The following quotes from family interviews in Massachusetts express the sentiments of families across the country (Griffiths, 1997):

> *"It does not seem right that family members who were put in institutions at an early age are the first ones to get residential services at 22. Parents who kept their child at home have been abandoned by the system. Something is wrong with this."*
>
> *"I am so discouraged by the 'waiting list.' It seems that I don't know who to speak to or what to say to improve the chances of getting services. I would mostly hope that I could find a safe, family-like situation for my [daughter]. At best, she could continue to thrive in her life without me always there."*
>
> *"...he is very anxious that he is still at home--he sees that move as a goal which indicates being an ADULT and more control over his life. He is so frustrated to still be home with parents."*
>
> *"We want to be involved in his transition to a new home and a new life."*
>
> *"He can't wait much longer. I don't want to drop dead in front of him."*

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APPENDIX

People in State Institutions Waiting for Community Placement

State	Institutional Population	No. Waiting for Community Placement
Alabama	721	0
Alaska	8	8
Arizona *	114	N/A
Arkansas	1,243	N/A
California	4,000	N/A
Colorado *	219	N/A
Connecticut	1,106	N/A
Delaware	278	150
D.C.	0	
Florida	1,585	N/A
Georgia	1,994	N/A
Hawaii	29	29
Idaho *	123	N/A
Illinois	3,496	N/A
Indiana	1,261	N/A
Iowa *	687	N/A
Kansas *	693	N/A
Kentucky *	644	N/A
Louisiana	2,000	206
Maine	0	0
Maryland	740	0
Massachusetts	1,550	770
Michigan	316	N/A
Minnesota	268	72
Mississippi	1,424	130
Missouri	1,494	N/A
Montana	142	79
Nebraska	395	N/A
Nevada	181	N/A
N. Hampshire	0	
New Jersey	4,056	1,600
New Mexico	0	
New York *	3,768	N/A
N. Carolina	2,400	96
N. Dakota *	147	N/A
Ohio *	2,087	N/A
Oklahoma	455	0
Oregon	378	307
Pennsylvania *	3,272	N/A
Rhode Island	0	
S. Carolina	1,388	N/A
S. Dakota	229	62
Tennessee	1,438	800
Texas	2,400	N/A
Utah	289	N/A
Vermont	0	
Virginia	1,966	1,000
Washington	1,307	N/A
West Virginia	52	52
Wisconsin	1,179	N/A
Wyoming *	139	15
TOTAL	53,661	5,376

*** Data from Prouty & Lakin, 1997**

**** N/A = Not available**

Ms. SHEEHAN. Once The Arc issued the report card of the waiting lists, it was evident that we had to do more. The Arc of United States has launched a waiting list campaign. We have held four regional conferences this summer and are providing information and technical assistance to State Arcs and their partners who want to launch a campaign in their own States.

In Maryland, 40 percent of those on the waiting lists have caregivers who are over the age of 60, and I have to tell you, the day I woke up and had my 60th birthday, that came to mind, that I was now one of the 40 percent and maybe I had better get busy here and figure out what the heck we were going to do with John.

Interestingly enough, we are finding that families, especially those that are elderly, are not necessarily wanting a full-blown set of services. Families are satisfied with in-home supports that assist them in the day-to-day caregiving. Often, aging services are matched with disability services to provide services to both people in the home. Families are pleased to be able to plan supports for a time when they cannot provide the caregiving. Sometimes these plans include leaving the family home to the individual. Other times, they are involved in the search for a compatible housemate and appropriate housing.

All families, obviously, and individuals are not alike and there are many situations when our sons and daughters want to move out and have a life of their own. In all of these situations, when an individual and a family can be involved in planning, a majority of the time, as Jackie stated, the services cost less than they would if we had waited for a crisis.

I want to tell you a little bit about my own situation. Everybody likes to talk about their kids. My son, John, is very successful. He is 32 years old and he has mental retardation. He does not speak very well, but he has great communication skills in his own way. He works every day in a variety of recycling jobs, collecting trash and recyclables. It is just his thing. He puts the trash out for five or six neighbors on trash night. He walks the neighbor's dog every day and is often hired by neighbors to help with a variety of chores. In his spare time, he patrols the local shopping center and the gas station, picking up recyclables.

The highlight of his week is Saturday morning. That is tomorrow morning, he has already reminded me. I prepare a deposit slip, or sometimes a withdrawal slip, so that he can go to the bank, and from the bank he goes to the local Giant supermarket to shop and he hangs out in what he calls the break room for a couple hours, and the staff, including the manager, come in and out and chat with John and buy him doughnuts and drinks and it is great.

After he finishes with the Giant, he stops to greet the people at the gas station, the local Ledo's restaurant, although he does not like pizza—I think I fed him too much pizza when he was a kid—and he ends up at the liquor store to buy his six-pack of O'Doul's. After he puts his groceries away, he visits with our neighbor Charlie.

John is happy. He is accepted as a participating member of our community. I do not worry about his safety or mistakes because someone would let me know if something went wrong. Would it make any sense to move him out of that community, away from everything he loves, when I die?

We have made provisions to leave our home to John and move support services in as he needs them. He needs a great deal of support, but not as much as if he had to move away from his familiar surroundings. This arrangement is good for John, it is good for our family because we know John will continue to be happy, and it is good for taxpayers because John will be receiving the supports he needs, no more and no less.

While we had this plan in mind before the waiting list initiative, I am relieved to know that the plan can be implemented when it is needed. John would have to be in severe crisis to receive services and the time of severe crisis is no time to implement an innovative plan. Transitioning dependency from me to others is also part of this plan and we hope to be able to get some individual supports so that John can hang out and do things with other people besides his mom.

In each State that has an initiative, the Federal partnership is a key element to creating solutions to this very serious problem. There are many issues to be addressed by Congress to facilitate the elimination of the waiting lists. We families who have sons and daughters with mental retardation are looking to you for help, and I am just going to mention a couple of them, because we do not want to be here all day.

The most important issue in my mind is Medicaid. All three States who have waiting list initiatives are using the Medicaid waiver to help fund community services. It would not work without it. Yet, Medicaid funding is very biased toward institutions, in spite of the fact that there is little or no demand for institutional placements. Nobody is waiting for institutional placement.

We have a situation in this country with haves and have nots. We have people in very expensive institutional settings with costs as high as $250,000. Probably the mid-level is more around $100,000. I will leave that to Dr. Braddock to address. Then, on the other hand, we have people who have no services at all, and I want to point out and I want to make very clear that the people who live in institutions and people who live in the community have similar disabilities. There is not anything about the disability that says that they need to be in an institution to get care. I mean, there could be some debate on that, but if there is a debate, we are talking about 3 to 5 percent, and we could leave those 3 to 5 percent for now. The majority of folks can live in the community, I think all of them.

We would like to see changes that favor supports that are driven by individual desires for freedom and responsibility. HCFA has recently written to Medicaid directors advising them of court decisions that have determined that the Americans with Disabilities Act prohibit ongoing institutionalization if professionals have determined the resident can be served in the community. I believe that we will see a number of States taking those decisions very seriously and use it as an opportunity to downsize and close institutions. These decisions, as I understand it, affect nursing homes, mental health hospitals, as well as facilities for people with mental retardation. A review of this bias to large congregate settings is way overdue.

Another very important issue and one that parents have not paid a lot of attention to, except in the last couple of years, is housing. Because of their disability, the vast majority of individuals on the waiting lists are very, very poor. The unemployment rate for people with disabilities is 60, 70, and again, I will leave that to someone who knows.

Most people with mental retardation are either unemployed or work part-time in very minimum wage jobs or substandard subwage jobs. Their SSI and SSDI benefits are not enough to rent at market rates. HUD recently released a report to Congress called, "Rental Housing Assistance: The Crisis Continues." The report estimates the number of people with disabilities, and this is all disabilities, with worst case housing needs may well have grown to 1.4 million people across the country.

The housing appropriations bills coming out of the House and the Senate include additional funding for Section 8 tenant-based rental assistance specifically for people in disabilities, increases the Section 811 program, and a recommendation that nonprofits become eligible applicants for tenant-based rental assistance funded with Section 811.

As we look at self-determination and look at people being more involved in the community, if we do not do this housing piece, it is just not going to work.

We also would like to see support for a requirement that ensures funds from HOME and CDBG are targeted to people with mental retardation and other disabilities. I work sometimes for an agency that serves people in Prince George's and Charles County, Maryland, here, that using HOME money has assisted people to purchase their own homes. They are actually homeowners in the community, and this only worked because we had some downpayment and closing costs with HOME funds.

Other issues are the SSI and Social Security disability policies. Current policies do not encourage or support persons with disabilities to work and live independently and need substantial reform. As I said, the vast majority of people with disabilities want to work but are unable to make the leap from SSI/SSDI benefits and health coverage to sufficient wages to afford independence and health coverage. A person has to choose to stay poor with SSI/SSDI and health coverage or get a part-time, low-paying job without benefits and be very poor—not a very good choice.

Other issues, job training, family supports, opening access to generic programs are all things we could talk about, but we will leave that, not to mention health care and transportation, of course. That is also quite important.

In 1987, The Arc conducted the first study ever on the waiting lists, and at the time, we found a total of 152,896 services needed. Ten years later, that number had jumped to 218,000 services. And we did not include in that waiting list people who want to leave institutions and move into the community.

To describe the waiting list situation as a crisis in America is no exaggeration. And further, because of the data gathering mechanism in the States, as described in the report, The Arc truly believes that the picture of the need is understated.

I know of a situation in Prince George's County, MD, here where a person who works in Adult Protective Services told me that at least once a month, they call on a home where mom, usually mom, has had a stroke or died, a heart attack, or something, and they find a person with mental retardation that nobody knew was there, and this is happening in that one county once a month. So as you multiply that, you will know that there are a lot more folks out there than we have counted.

We believe that the Senate Special Committee on Aging can play a unique role in raising the awareness of this issue. It is an issue in 50 States. This is not targeted.

You can help parents find hope and peace of mind by taking the leadership to start the process of finding a solution to this vexing problem. Thank you.

[The prepared statement of Ms. Sheehan follows:]

Can We Rest in Peace? The Anxiety of Elderly Parents Caring for Baby Boomers with Disabilities?
Forum - Senate Special Committee on Aging
Lorraine Sheehan Presenting for The Arc of the United States

I am representative of the hundreds of thousands of families across this country who are afraid to die because we don't know what will happen to our sons and daughters when we are no longer around to care for them. We are fearful that they will be forced to live in large congregate settings, forced to leave their families and friends or forced to live in substandard housing because there is nothing else available. The title of your forum clearly states that fear.

In most states, the only way to get services for persons with mental retardation is at the time of severe crisis. Crisis is spelt in capital letters. Crisis means your caretaker is dead or dying. The service provided in that instance is disruptive. Not only is your parent dead, you are shuttled away to a new situation to live with people you do not know to fit into a "slot" that may or may not be suited to your needs. The state probably has to fund a "behavior specialist" because you are "acting out" your grief and frustration. It is quite evident from a common sense point of view that this is just plain wrong! From a public policy point of view, this "slot" is probably more expensive than would be necessary if it was provided with planning and participation of the individual and his/her family.

There are only three states that have attacked this problem and developed 5 year plans to eliminate the Waiting List in their states. The first of these is New Jersey under the leadership of Representative Frelinghuysen (a member of the NJ legislature at the time) and Governor Whitman. Maryland was the second state under the leadership of Governor Parris Glendening. I am biased being from Maryland but I think we have the best approach, we are implementing the Waiting List Initiative using principles of self-determination. In the last few weeks Governor Pataki of New York announced his plan to eliminate the Waiting List in his state.

You have a copy of The Arc's Report Card on Waiting List before you. Obviously, it was issued before Maryland and New York announced their Initiatives. Four states reported no waiting lists, California, Kansas, Nevada and Rhode Island. Rhode Island has no Waiting List because they have used the savings from closure of their institution to fund services in the community. Iowa, Ohio and West Virginia have not created the capacity to collect data.

Once The Arc had issued the Report Card on the Waiting List, it became evident that we could not stop there. The Arc of the United States has launched a Waiting List Campaign. We have held four regional conferences around the country and are providing information and technical assistance to state Arcs and their partners to launch a campaign in their own states.

In Maryland, 40% of those on the Waiting List have caregivers over the age of 60. Yet, interestingly enough we are finding that families especially those who are elderly are not necessarily wanting a full blown set of services. Families are satisfied with in-home supports that assist them in the day to day caregiving. Often, Aging services for the caregiver have been combined with support services from the disability agency. They are pleased to be able to plan supports for a time when they cannot provide the caregiving. Sometimes these plans include leaving the family home to the individual. Other times they are involved in the search for compatible housemates and appropriate housing.

All families and individuals are not alike and there are many situations where our sons and daughters want to move out of the family home and get a life of their own. In all of these situations, when an individual and family can be involved in planning, a majority of the time, the services cost less than they would have if waiting for a crisis.

I want to tell you a little bit about my own situation. My son John is 32 years old and has mental retardation. He does not speak very well, but he has great communication skills in his own way. He works every day on a variety of recycling jobs. Collecting trash and recyclables is his thing. He puts out the trash for five or six neighbors, walks the neighbor's dog every day and is often hired by neighbors to help with a variety of chores. In his spare time, he patrols the local shopping center and gas station picking up recyclables.

The highlight of the week is Saturday morning. I prepare a deposit slip for his check so he may go to the bank. From the bank, he goes to the local Giant Supermarket to shop and hangs out in the breakroom for a couple of hours. As the staff, including the manager, take breaks, they sit and chat with John buy him donuts and drinks. After he finishes at the Giant, he stops to great the people at the gas station, the local Lido's Restaurant (although he doesn't like pizza) and ends up at the liquor store to buy a six pack of O'Douls. After putting his groceries away, he visits with our neighbor Charlie. John is happy, is accepted as a participating member of the community. I don't worry about his safety or mistakes, because someone would let me know. Would it make any sense to move him out of that community away from everything he loves when I die?

We have made provisions to leave our home to John and move support services in as he needs them. He will need a good deal of support but not as much as moving him away to an unknown setting. This arrangement is good for John, it is good for our family because we know John will continue to be happy and good for the taxpayers because John will be receiving the supports he needs, no more or no less. While we had this plan for John in mind before the Waiting List Initiative, I am very relieved to know that the plan can be implemented when it is needed. John would have to be in severe crisis to receive services and time of severe crisis is no time to implement an innovative plan.

In each of the states that has an Initiative, the federal partnership is a key element in creating solutions to this very serious problem. There are many issues to be addressed by Congress to facilitate the elimination of these Waiting Lists. We families who have sons and daughters with mental retardation are looking to you for help.

The Individuals with Disabilities Education Act (IDEA) has had a tremendous impact on the lives of kids with disabilities and their families. Since children are educated in our communities, the expectation of these adults and their families will be community supports.

Critical Issues

Medicaid -The most important factor in the three states with Waiting List Initiatives is Medicaid. All three states are using the Medicaid Waiver to help fund the community services. Yet Medicaid funding is very biased towards institutions. in spite of the fact that there is no or very little demand for institutional placements. We have a situation in this country with "haves and have nots". We have people in very expensive institutional settings with costs as high as $250,000 a year per individual and people who have no services at all. I would like to point out that persons with very similar disabilities are being served in the community at much lower cost. We would like to see that change to favor supports that are driven by individual desires for freedom and responsibility.

HCFA has recently written to state Medicaid Directors advising them of court decisions that have determined that the American with Disabilities Act prohibit ongoing institutionalization if professionals have determined the resident can be served in the community. I believe we will see a number of states taking those decisions very seriously and use the opportunity to downsize and close institutions. These decisions affect nursing homes and mental health hospitals as well as any state funded facility for people with disabilities. A review of this bias to large congregate settings is way overdue.

Housing - Another very important issue to solving the Waiting List problem is housing. Because of their disability, the vast majority of individuals on the Waiting List are very, very poor. The unemployment rate for people with disabilities is 60% or more. Most people with mental retardation are either unemployed or work part time in minimum wage jobs. Their SSI or SSDI benefits are not enough to rent at market rates. HUD recently released a report to the Congress, "Rental Housing Assistance - The Crisis Continues. The report estimates the the number of people with disabilities with worst case housing needs may well have grown to 1.1 to 1.4 million people. Households with worst case needs are defined as unassisted renters with incomes below 50 percent of the local median who pay more than one half of their income for rent or live in substandard housing.

The Housing Appropriations bills coming out of the House and the Senate include an additional funding for Section 8 tenant based rental assistance specifically for people with disabilities, increases for the Section 811 program and a recommendation that nonprofits become eligible applicants for tenant based rental assistance funded with Section 811. (Only Housing Authorities are eligible at this time.)

We would also like to see support for requirements that ensure that funds from both the HOME and CDBG programs are targeted to people with mental retardation and other disabilities. Melwood, an agency serving persons in Prince George's and Charles Counties, assisted 22 people to purchase their own homes in the community with the help of HOME funds. These folks had stable jobs and SSI or SSDI benefits. They qualified for a purchase of a home because Prince George's County and the state or Maryland granted Melwood funding to assist these purchasers with downpayment and closing costs.

SSI and Social Security Disability Policies -
The House passed HR 3433 earlier this year. This bill entitled "Ticket to Work and Self Sufficiency Act of 1998" reforms and improves the Supplemental Security Income (SSI) and the Social Security Disability Insurance (SSDI) work incentives program to assist people with disabilities overcome the barriers to work. Senators Jeffords and Kennedy have introduced their own bill that simplifies provisions from the House version.

Current policies to encourage and support persons with disabilities to work and live independently need substantial reform. The vast majority of persons with disabilities want to work (including people with mental retardation) but are unable to make the leap from SSI/SSDI benefits and health coverage to sufficient wages to afford independence and health coverage. A person has to choose to stay poor with SSI/SSDI and health coverage or get a part time, low paying job without benefits and be very poor. Not a very good choice.

With a gradual reduction in benefits, a person with mental retardation can at least have a minimum wage job and maintain some degree of independence. This is crucial to eliminating the Waiting List. It is awfully hard to live on your own without resources of some kind!

Other Issues

1. Expansion and improvement of transition, job training and employment
2. Reauthorization and funding of Family Support Program
3. Opening access to generic programs such as rental and homeownership; job training and employment; access to health care and transportation.

In 1987, The Arc conducted the first ever study of waiting list. At the time we found a total of 152,896 services needed. Ten years later, the number has jumped to 218,186 services. Additionally, there are people in institutions waiting to move to the community. To describe the waiting list situation as a crisis for America is no exaggeration. Further, because of the data gathering mechanisms used by states, as described in the report, The Arc believes the true picture of need is understated. We believe that the Senate Special Committee on Aging can play a unique role in raising the awareness of this issue. The Waiting List is an issue in each of the 50 states. You can help aging parents find hope and peace by taking the leadership to start the process of finding a solution to this vexing problem

Ms. GOLDEN. Thank you, Lorraine.

STATEMENT OF JAMES CUMBERPATCH, PARENT, KENSINGTON, MD

Ms. GOLDEN. As I said, I will read Mr. Cumberpatch's statement. His story is very compelling.

Mr. Cumberpatch, Joseph Cumberpatch, the younger son, is 35 years old and is mentally retarded and deals with Down's Syndrome. His wife and he had seven children, six boys and one girl. When Joseph was born in 1962, Mr. Cumberpatch was in the Air Force. He was working long hours at the Pentagon in the Air Force office as a Congressional liaison. This put a heavy burden on his wife, who did a fantastic job of taking care of Joe and her other children. She was even able to inspire in the older children, ages 16, 13, and 10, a desire to help take care of Joe and teach him many things.

Three years later, in 1965, Mr. Cumberpatch's oldest son was killed in Vietnam. After this, he realized that he could not give his wife the support she deserved to take care of Joe and also pursue a military career involving long working hours and separations, so he therefore was forced to retire from the Air Force. He founded a small corporation in Kensington, MD, which he operated as president until he retired in 1997 at age 75.

When Joe was 9 years old, he entered Concord School in Potomac, MD, a public elementary school for retarded children. This was a wonderful school with small classes, a great deal of individual attention, but his wife continued to give Joseph continuous instruction and encouragement and living skills. They also took Joseph to the Special Olympic activities for which he was eligible, and between school and his wife's teaching, Joe developed fairly well living with Down's Syndrome.

During the years, his wife spent tremendous amounts of time teaching and caring for Joe, plus trying to spend adequate time with her other children.

In 1983, Joseph started working in the Centers for the Handicapped, now known as CHI Centers, Inc., in Silver Spring, MD. This agency supports a large number of seriously retarded and physically impaired clients, and the center provides meaningful and satisfying work for its clients, such as their self esteem and happiness are greatly enhanced. It is a wonderful place and Joe still works there.

Even though they have these issues, Mr. Cumberpatch says, "We have been fortunate that Joseph has had someplace to go during business hours on Mondays through Fridays. However, someone always had to be with him in the evenings and on weekends."

They did not have any trouble obtaining medical services for Joseph. The State of Maryland did have a medical assistance program that provides for all of his medical and dental needs. It was a user-friendly program.

Their next-to-youngest child, Mark, graduated from college and left home in 1982. Whereas most couples have earned full freedom after all their children have been raised and left home, they would have to take care of Joseph for the rest of their lives. This was going to be a big job, because Joseph is, in most ways, the equivalent of a 3- to a 6-year-old.

I am sure that such a situation could put a terrible strain on many marriages. However, his wife was wonderful, considerate, a generous person, and never once complained about Joe. She considered Joe a little angel and that she had been entrusted to care for him.

So from 1982 to 1988, they took care of Joseph. Fortunately, Mr. Cumberpatch's grown children also helped. For example, his wife and he finally could take a trip in 1986 to celebrate their 40th wedding anniversary. Mr. Cumberpatch's daughter and son-in-law, Robert Durbin, took Joe for 10 days. In those days, they could not leave Joe even overnight. "This trip to Hawaii was the longest time that my wife and I," and I am reading it in his words, "had been away alone together since Joseph was born."

In 1988, Mrs. Cumberpatch was diagnosed with cancer and died a few years later. She was 64 years of age.

After this, Joseph and Mr. Cumberpatch continued to live in their house in Kensington. Joe continued to work at CHI and Mr. Cumberpatch ran his business from his basement so that he could be there when Joe returned from work. When he traveled on business, Joe would stay at his daughter's house and his son-in-law often would take Joe to play basketball or sports events. His sons Thomas and Michael, who live in Annapolis, often took Joseph, as well, to the mall and cookouts at their homes. Mark, who lives in Baltimore, takes Joseph to Orioles games and Joseph is a big Orioles fan.

Although Mr. Cumberpatch would be with Joseph in the evenings and on weekends, he worried about spending so much time alone, Joseph's time alone in front of the television set. During the mid–1990's, it seemed that either Mr. Cumberpatch was working or taking care of Joe. He was unable to develop a social life. In 1995, Mr. Cumberpatch was diagnosed with a manic-depression condition, which actually took him from being here today, and put a heavy burden on him and also he was having to take medication for this condition. Phasing down Mr. Cumberpatch's business was also depressing for him. He knew he had to retire soon, and he was 73 at the time.

In 1983, his wife had put Joseph on the State of Maryland waiting list for residential services. There were many people on the list and they did not think that they had a chance to get help. However, in 1997, The Arc of Maryland started a program called a waiting list initiative that would provide services for an increased number of retarded citizens. This was good news because it meant that Joe might be able to have a home of his own and companionable roommates. The Governor of Maryland budgeted a large sum of money for this program and the legislature passed it unanimously in early 1998.

In May 1998, Joe was selected by The Arc of Montgomery County to move into one of their new residential homes for retarded citizens. Joe moved into this new home on August 21, 1998. Joe loves his new home. He has two roommates who also work with him at the CHI Centers. They are good friends. He now has great companionship, friends to talk to. He has a good staff caregiver and sits down at meals with his friends in the dining room. The benefits to Joe are tremendous. He brags to everyone that he now has his own home, just like his brothers. It is a great source of pride to him.

The funds provided by the Maryland Governor and legislature will benefit a large number of retarded citizens and their families. This is a highly cost-effective program. Most of these citizens receive a monthly SSI check for about $450 and earn about $100 per month. Except for a personal allowance of about $120, this money is used to help defray the room and board costs of the home, so the program is practically self-funded, so every group home gives great benefit to three families, parents, and siblings and three citizens with retardation. This is why I say it is a high cost-effective program.

"In the meantime, I seem to have recovered from my manic-depression and no longer take medication. Also, I have a sense of freedom that I have not had for many years. I am sorry that my wife did not live to feel the same freedom with me and to see Joe so well situated and happy. Finally, I no longer have to worry about what would happen to Joseph if I were to get sick or die. I am always afraid that my children might inherit this responsibility. They have spouses and small children of their own, and such a thing would be an unfair and heavy burden."

However, the greatest beneficiaries of this wonderful program are the retarded citizens that it serves. It puts them in the mainstream of life, provides them with a happy and healthy home of their own, just like their brothers and sisters.

Ms. Golden I also wanted to add, too, in speaking with Mr. Cumberpatch, I asked him the question, what has it done for him and his family and what does he feel about Joe not being there anymore, and he said, "Well, it is sort of like I have been in jail and I have gotten a pardon, an early pardon that was unexpected."

It is an amazing story and Mr. Cumberpatch is an amazing man. I only wish you all could have met him in person, but his story says it all. Thank you.

[The prepared statement of Mr. Cumberpatch follows:]

Statement of James R. Cumberpatch

September 18, 1998

My name is James R. Cumberpatch.

My youngest son is Joseph Cumberpatch. He is 35 years old and is mentally retarded with Down's Syndrome.

My wife and I had seven children, six boys and one girl. When Joseph was born in 1962, I was in the Air Force. I was working long hours at the Pentagon in the Air Force Office of Congressional Liaison. This put a heavy burden on my wife who did a fantastic job of taking care of Joseph and the other children. She was even able to inspire in the older children (ages 16, 13 and 10) a desire to help take care of Joseph and teach him many things.

Three years later, in 1965, our oldest son was killed in Vietnam. After this, I realized that I could not give my wife the support she deserved to help take care of Joseph and also pursue a military career involving long working hours and separations. I therefore retired from the Air Force.

I founded a small corporation in Kingsington, Maryland, which I operated as president until I retired again in 1997 at 75 years of age.

When Joseph as about nine years old he entered Concord School, in Potomac, MD, a public elementary school for retarded children. This was a wonderful school with small classes and a great deal of individual attention. My wife continued to give Joseph continuous instruction and encouragement in living skills. We also took him to all the Special Olympics activities for which he was eligible. Between Concord School and my wife's teaching, Joseph developed fairly well for a Down Syndrome child.

During these years my wife spent tremendous amounts of time teaching and caring for Joseph plus trying to spend adequate time with the other children.

In 1983, Joseph started working at the Centers for the Handicapped, now known as CHI Centers, Inc., in Silver spring, Md. This agency supports a large number of seriously retarded and physically impaired clients. The Center provides meaningful and satisfying work for its clients such that their self-esteem and happiness are greatly enhanced. It is a wonderful place. Joseph still works there.

We have bene fortunate that for many years Joseph has had someplace to go during business hours on Mondays thru Fridays. However, someone always had to be with him in the evenings and on weekends.

We did not have any trouble obtaining medical services for Joseph. The state of Maryland has a Medical Assistance Program that provides for al of his medical and dental needs. It is a very user-friendly program.

Our next-to youngest child, Mark, graduated from college and left home in 1982. Whereas most couples have earned full freedom after all of their children have been raised and left home, we would have to take care of Joseph for the rest of our lives. This was going to be a big job because Joseph is, in most ways, the equivalent of a three- to six-year old.

I am sure that such a situation could put a terrible strain on many marriages. However, my wife was a wonderfully considerate and generous person and never once complained about Joseph. She considered Joseph to be a little angel that she had bene entrusted to care for.

So, from 1982 to 1988, we took care o Joseph. Fortunately, our grown children also helped. For example, my wife and I finally took a trip to Hawaii in 1986 to celebrate our 40th wedding anniversary. Our daughter and son-in-law, Robert Durbin, took are of Joseph for ten days. In those days we could not leave Joseph alone overnight. This trip to Hawaii was the longest time that my wife and I had bee away alone together since Joseph was born.

In 1988, my wife was diagnosed with cancer and died a few months later. She was 64 years of age.

After this, Joseph and I continued to live in our house in Kinsington. Joseph continued to work at the CHI, Inc., and I ran my business from my basement so that I would be there when Joseph returned from work. When I traveled on business, Joseph would stay at my daughter's house. Y son-in-law often takes Joseph to play basketball or to sports events. My sons, Thomas and Michael who live in Annapolis, often take Joseph to the Mall and to cook-outs at their homes. My son Mark, who lives in Baltimore, takes Joseph to Orioles games. Joseph is a rabid Orioles fan.

Although I would be with Joseph in the evenings and on weekends, I worried about him spending so much time alone in front of a television set.

During the mid-90's, it seemed that I was either working or taking care of Joseph. I seemed unable to develop a social life. In 1995 I was diagnosed with a manic-depression condition and put on fairly heavy medication. Phasing down my business was also very depressing to me, but I knew I had to retire soon. I was now 73 years of age.

In 1983, my wife and I had put Joseph on the State of Maryland "waiting list' for residential services for Joseph. There were many people on the list and we did not think that we had a chance to for help. However, in 19997-1998, the ARC of Maryland started a program called with "Waiting List Initiative" that would provide services for an increased number of retarded citizens. This was good news because it meant that Joseph might be able to have a home of his own with companionable roommates.

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However, the greatest beneficiaries of this wonderful program are the retarded citizens that it serves. It puts them into the mainstream of life and provides them with a happy and healthy home of their own, "just like their brothers (or sisters)!"

Ms. GOLDEN. Now I want to present Dr. Braddock.

STATEMENT OF DAVID BRADDOCK, PH.D., PROFESSOR OF HUMAN DEVELOPMENT AND HEAD, DEPARTMENT OF DISABILITY AND HUMAN DEVELOPMENT, UNIVERSITY OF ILLINOIS AT CHICAGO, CHICAGO, IL

Mr. BRADDOCK. May I encourage you to move closer to the front if you would like to see the overheads a little better, or you can follow along in the written testimony.

It is always a challenge to follow stories that touch the human heart. I am not going to apologize for primarily preventing facts. There are such powerful and moving human stories that do undergird many of the needs that we have in the field of developmental disabilities. When the two are brought together, that is to say, the heart and the mind, we have the best chance to try to make decent public policy for America's citizens with developmental disabilities.

So I am going to present some empirical information to you today, but I do not want any of us to lose sight of the central reason that we are here today, and that is really to try to address the human needs expressed in the moving stories that we have heard described so well this morning.

Very often, in serious social problems, you will find bright spots, and one of the very bright spots of the human story that was just read to us is the fact that Joe is living long enough to present this support problem, because in the 1920's, he would have died perhaps at about age nine. As late as the 1960's, he might have lived to age 30. Today, the average lifespan of an individual born with Down's Syndrome is about 55 years, and the average age or death in the United States today, is about 70.4 years. So even individuals with Down's Syndrome are beginning to approach normal life spans and individuals with mental retardation and closely related developmental disabilities who do not have Down's Syndrome or related organic conditions are living to be about 66 years of age.

I think that most of the growth in our service delivery systems over the past 20 years, and the growth has been rather significant in terms of numbers of people served, about 36 percent, can be attributed to the increasing life span of individuals with mental retardation and closely related developmental disabilities.

Let me present a portrait of what the United States looked like 20 years ago in terms of the structure of services that we provided and we will see if you can see the information very well. I brought this laser pointer to assist, and I am going to need to talk into this microphone, I guess, is that right?

In short, 20 years ago, 86 percent of all individuals with mental retardation resided in large congregate care settings. Only 20,000 individuals in the entire country lived in settings for six or fewer individuals. We were truly a congregate care society. We essentially had one solution to fit almost all. That solution was institutional settings, and only 14 percent of the pie chart here that you see that is settings for 15 or fewer persons, and just as this even smaller slice here for 20,000 people out of the total of 290,000 was for industrial in one- to six-person settings.

Things have changed quite a bit. First, the system expanded 36 percent. It now serves 394,000 people. However, the U.S. population grew 22 percent across this period, so we have really only had about an average of 1 percent of growth per year in terms of the number of people served, and as I mentioned just a moment ago, that is substantially reflected in terms of the aging of people with intellectual disabilities in the sense that if you live longer, you require services and supports for a longer period of time.

Today, we have roughly 51 percent of the total number of individuals in this country who are in formal out-of-home placements 394,000 persons, living in settings for one to six persons. We still have substantial numbers in large congregate care settings, however, as represented by just under 60,000 in State institutions, nearly 40,000 in nursing homes, 31,000 in large privately operated intermediate care facilities for 16 or more persons. We still have 10,000 facilities that are not certified as ICFs/MR but are operated privately. And we have 55,000 individuals in settings for 7 to 15 individuals. About 200,000 individuals of the 394,000 are now in the one- to six-person settings.

So we have placed great emphasis upon the individualization of services, smaller-scale services, more family scale services, expanding the service system, providing more resources for the service system in general, but in terms of the numbers of individuals served, it has actually grown relatively modestly when compared to the general growth in the U.S. population and the fact that individuals with intellectual disabilities and related developmental disabilities are also living longer.

The specific question we want to address today in this forum is, to what extent are family caregivers supporting people with developmental disabilities at home, and to what extent are these families aging? National data have not been developed that are particularly rigorous in this regard, and we have worked on that in relation to this forum. The results are truly provactive.

The prevalence of developmental disabilities, that is to say, mental retardation, cerebral palsy, autism, epilepsy, and other childhood disabilities that originate prior to age 22, is about 1.2 percent, which would suggest that about 3.17 million American citizens have significant conditions of this type. But recall just a moment ago I characterized for you the size of our formal out-of-home service delivery system as 394,000 individuals, so there are 2.7 million people who are not being supported residentially in the formal out-of-home service delivery systems operated or financial by the States in partnership with the Federal Government.

Sixty percent of these 2.7 million individuals who are not in the formal out-of-home placements, that is to say, 1.89 million persons are living with family caregivers. That is this portion of the graphic that I am pointing to at the moment. This part here, 12 percent, refers to those in formal out-of-home placements that I just showed you the previous graphic, the 394,000 individuals.

So you see we have been getting very excited in our field these last 20 years about growing the size of our service delivery system to serve essentially 12 percent of the population of individuals with developmental disabilities, when, in effect, what has been happening is that families have been the informal backbone of our "service delivery system" all along and we are only now coming to recognize it, and we are coming to recognize it, unfortunately, because of the tremendous pressures that are being applied to these families, as Lorraine has so aptly noted today.

That pressure is a consequence of the aging of the families in significant measure, it is a consequence of the longevity increases of individuals with developmental disabilities, and it is a product of the fact that in many States, we have simply not developed much infrastructure for community services. So these forces acting together in synergy are creating the kinds of pressures that we see nationally and that have resulted in this hearing today.

Now, we have identified the number of aging caregivers supporting people with developmental disabilities. How many of these caregivers are over age 60? Twenty-five percent of the 60 percent, that is to say, 25 percent of the 1.89 million person, is represented here in the graphic as this slice right here, and it is about 480,000 people.

Equally of concern for us is who is in the pipeline. How many families who are in middle age or advanced middle age and how large is that cohort? Well, that cohort is 40 percent larger than the current age 60-plus cohort of family caregivers. It is about 663,000 individuals. In the next 18 years, all of those individuals will move into the age 60-plus cohort and, thus, we will have an increase of roughly 40–50 percent in the size of the aging family caregiver cohort. So the pressures will intensify, and, of course, the thing that is pushing this along is the growth of the baby boom group.

The number of baby boomers in our society those born between 1946–64 will double between now and the year 2030. They will increase by 50 percent between now and the year 2020. This is illustrated in the graphic in the testimony and here on the charts. You can see, we have 26 million individuals over age 65 in 1980, an increase to 31 million in 1990, 35 million in the year 2000, which is roughly today. It is going to double to 70 million by the year 2030, and between 2000 and 2010, we get an increase of 5 million to 40 million. Then the big jump comes between 2010 and 2020, when it increases from 40 to 53 million.

In short, there are moderately large stairsteps and then a dramatic increase in the size of our aging population in the United States, in general. The numbers of aging caregivers with disabled relatives at home will grow correspondingly larger and larger.

We are not alone among modern societies in terms of having to deal with the aging issue in our society. Frankly, it could be much worse. We could be in Germany or Japan, where in the year 2040, it is projected that 33 percent of their populations will be age 65-plus. We are going to peak between 2020 and 2030 at about 22 percent of the U.S. population over age 65. Compared to most members of the OECD we are actually among the younger nations. But, nonetheless, our changing society is aging significantly.

Longevity for individuals with intellectual disabilities, not Down's Syndrome but just intellectual disabilities in general, was about 18 years in the 1930's. In the 1970's, it increased to 59, and today it is 66 years only 4 years less than the average age at death. The trend, given the improvements in health care, the emphasis on inclusion in the community, employment opportunities, healthy living, and healthy lifestyles, suggests that there is every likelihood that most individuals with developmental disabilities will be able to live lives that will be as long as the normal population, with the exception of individuals who have truly severe and very multiple, complicated medical conditions that go along with the intellectual disability; that, fortunately, is a very small percentage of individuals. So, increasing longevity is a powerful impact.

We have been able to develop estimates of individuals with developmental disabilities living with aging family caregivers for each of the American States. This is the first time such estimates have been made available. They are contained in the written testimony I supplied for the forum today. My graphic will be too small for you to see them, suffice it to say that we identified some 6,000 aging family caregivers in the State of Iowa Chairman Grassley's home and a total of 480,000 nationally.

It may surprise some of you to realize that there is great variation State to State in the number of older people. Florida has 110 percent more old people, if you define old as 65 than Utah. Iowa, in fact, is 19 percent older than the average U.S. State. So we have a lot to learn about aging and the way it affects the demography of our States and of our nation.

One of the things we have not done a very good job of in terms of planning at the national level or at the State level is to take a very careful look at and an objective look at how this changing demography is going to affect our service delivery systems in the States. We have looked at waiting lists, but we have not looked at causal aspects of it, and that is to say, what is causing the waiting list problem?

One of the causal factors is the aging of our country, and this shows significant variation State to State. You can consult the table for your State in the written testimony.

Maryland is an excellent illustration of a State that is grappling with both waiting lists and aging family caregivers, because there is a close relationship between the two, quite naturally. Sometime within the past year or so, the Maryland Developmental Disabilities Administration supplied waiting list data to the Baltimore Sun. This was published in an excellent series of articles that were published in March 1997, and the portrait of the waiting list in Maryland identified 4,682 people waiting for services, some 39 percent of which were individuals who were currently living with aging caregivers age 60-plus.

Fifteen percent were age 60 to 69. Another 10 percent were age 70 to 79. And 14 percent were age 80-plus. I repeat, a total of 39 percent of the 4,682 persons on the waiting list were age 60 and over. But given the power of the demographic trends that I have described today, that is to say the increasing longevity of people with developmental disabilities, coupled with the aging of our society, should we be surprised at the close correlation between the waiting list statistics and aging family caregivers in Maryland?

Now, Maryland has, I believe, over five million people. It is not a small State in population terms. I do not think Maryland is unrepresentative of the Nation as a whole, but we are going to have to do more and better individual State studies to be sure. I think Maryland is relatively representative.

Reference has been made to the initiatives on waiting lists that are being undertaken in Maryland and in New Jersey. There are other initiatives in a few other States, as well. New Hampshire has creatively adopted a policy in which a waiting list report and how the State is addressing the waiting list is required to be furnished to the Governor, I believe, on an annual basis now, and they have appropriated some funds to address this issue.

The New Jersey initiative is a $30 million a year initiative. Their waiting list is quite substantial in size and growing rapidly, but I should hasten to add that New Jersey is one of the States that waited the longest to begin to address seriously the development of community alternatives to institutions. I would also place the State of Illinois in this group. Quite a number of other laggards nationally on community services development reside in the American South, but New Jersey and Illinois are wayward souls in this regard and they are a little bit behind the national pattern.

So it is quite wonderful to see New Jersey beginning to address this issue, but it is overdue. It is also overdue in Illinois, and as I pointed out in my testimony, Illinois does not have anybody on the waiting list. Again, some States feel that it is unwise to furnish statistics that suggest they ought to be perhaps raising taxes, providing more services, and so forth.

In many cases, new resources are not what is required, but it is, rather, an internal reallocation of resources from one part of the system to another part of the system that is called for, and I have outlined some ideas for doing this in my testimony, but they include the closure and consolidations of institutions. We have seven States and the District of Columbia that are now institution-free. We have roughly 20 American States with fewer than 400 individuals living in publicly operated State institutions.

I think within the next 20 years, virtually every American State, with perhaps a few holdovers, will be institution-free. We are rapidly, inexorably moving in this direction and have every year beginning in 1968. The population of our State operated institutions in this country has declined every year since 1968 by between 3 and 6 percent per year. It is not so much a question of if closures and consolidating of state operated institutions will occur but rather a question of when. There still is a financial bias in the Medicaid Program towards supporting individuals in these large institutional settings but the HCBS Medicaid waiver program, has helped remedy this by facilitating a dramatic expansion in community services throughout the country. This expansion in the community will need to be given the demographic imperatives that are underlying changes in the aging of our society and the family caregiver issues.

There are a number of other strategies to consider implementing besides simply growing the waiver program and closing and consolidating institutions and reallocating resources internally. They include expanding family supports and cash subsidy payments to prevent or delay the need for placement. The State of Michigan has been exemplary in this regard. It has currently 4,000 individuals families receiving cash subsidy payments.

However, we have about $23 billion in the developmental disabilities field on a national basis today and only about 3 percent of those resources are directly associated with family support activity, another 4 percent with what you might call individualized services in terms of supported employment, supported living, and personal assistance. So a total of about 7 percent of our system is orientated toward family support and individual support. The remaining 93 percent tends to be associated with the support of facilities. So we need to find ways to enhance the flexibility of how we fund our individuals in our service systems.

In closing, we should support the Medicaid Community Attendant Services Act. We should encourage States to adopt waiting list reduction initiatives, such as those we see now in New Jersey, New Hampshire, and Maryland. We should encourage DD planning councils to fund special studies and demonstrations of models pertaining to serving aging caregivers and waiting lists in the States. We should support the pending special appropriation in the DD Act for family support. We need to stress greater administrative and fiscal coordination between the aging networks and the MRDD networks. We certainly need to work with Medicaid leadership in Washington and in the states to provide greater flexibility through the HCBS waiver program and other Medicaid waivers and, as I know Tom Nerney will describe later, to build in self-determination in this regard.

Thank you, Mr. Chairman.

[The prepared statement of Mr. Braddock follows:]

Aging and Developmental Disabilities: Demographic and Policy Issues Affecting American Families

Statement Before
The Senate Special Committee on Aging
Hart Senate Office Building
Washington, DC

Presented by David Braddock, Ph.D.
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September 18, 1998

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Presentation of David Braddock, Ph.D.
On Aging and Developmental Disabilities
Senate Special Committee on Aging

Thank you Mr. Chairman for the opportunity to present at this Committee-sponsored inquiry on the issues pertaining to aging and the growing number of persons with developmental disabilities awaiting services in the states. For the record, I am David Braddock, Professor and Head of the Department of Disability and Human Development at the University of Illinois at Chicago. For the past 10 years I have also served as the director of our Department's research and public service Institute concerned with developmental disabilities, the Institute on Disability and Human Development. This Institute serves as the "university affiliated program in developmental disabilities" for the State of Illinois. It is authorized under the Federal Developmental Disabilities Act, as amended, which is administered by the Administration on Developmental Disabilities in the U.S. Department of Health and Human Services.

Our Institute is also fortunate to have the nation's only Federally-designated Rehabilitation Research and Training Center on Aging with Mental Retardation. I serve as the co-principal investigator of this Center (Dr. Tamar Heller is the Principal Investigator) which is funded by the U.S. Department of Education's National Institute on Disability and Rehabilitation Research. I have been active in the field of developmental disabilities for 30 years and I am a former President of the American Association on Mental Retardation.

My presentation today will provide empirical information for the Committee to assist your deliberations on the increasing service and support needs of individuals with developmental disabilities who live in families with aging parents or other caregivers.

The aging of our society, coupled with the increasing longevity of persons with developmental disabilities, will be the primary focus of my remarks today. These two key forces are working in a powerful synergy that is stretching state service delivery systems well beyond their capacities to meet current and projected demands for residential, vocational, and family support services for individuals with developmental disabilities. Large and growing waiting lists are very common in the states today.

My presentation is structured to address five general questions:

I. Structure of Residential Care

- What is the general structure of the long-term care service system for persons with developmental disabilities in the United States today, and how is it changing?

II. Aging Family Caregivers

- What is the scope of the role played by family caregivers in the long-term care system? Specifically,
    - ➢ How large a demographic subset is the group of family caregivers aged 60 years and older?
    - ➢ Can we estimate the size of the aging family caregiver cohort in each of the 50 states and can we determine how dynamic its growth pattern may be in future years as the baby boom generation ages?

III. Increasing Longevity

- To what extent has longevity improved for persons with developmental disabilities over the past half century?

IV. Waiting Lists

- How large are waiting lists in the states and can we expect them to continue to grow? and, in conclusion,

V. Policy Considerations and Recommendations

- What recommendations can be offered to address the limitations noted in service system capacity in the states?

I. STRUCTURE OF RESIDENTIAL CARE IN THE UNITED STATES

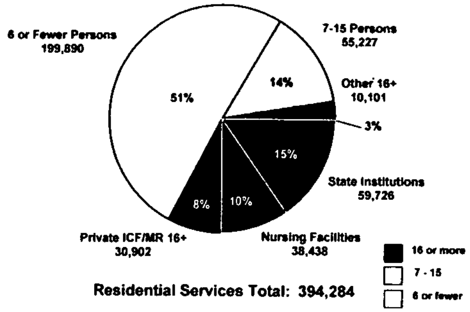
Formal, supervised out-of-home residential services were being provided to 394,284 persons in the states in 1996, according to a national study completed this past year at the University of Illinois at Chicago (Braddock, Hemp, Parish, & Westrich, 1998). Fifty-one percent of the individuals (about 200,000 persons) lived in 1-6 person settings such as small group homes, supervised apartments, foster care, and supported living placements. The vast majority of these settings are operated by private, non-profit service providers. An additional 55,227 persons resided in facilities for 7-15 persons; 100,729 individuals were living in large public or private institutions for 16 or more persons, and 38,438 persons lived in nursing homes (see Figure 1).

The structure of the residential care system has changed markedly over the past 20 years as state-operated residential institutions reduced their census by two-thirds from 150,000 to under 60,000 persons. Concurrently, the number of persons residing in 1-6 person settings expanded ten-fold--from about 20,000 individuals in 1977 to the present figure of just under 200,000 persons. Over-all system capacity, however, grew by only 36% over the 20-year period, an average growth rate of just 2% per year. Given that the U.S. general population increased by 22% during the past 20 years, the entire system of residential care grew at a very modest pace. This is remarkable in light of the fact that public funding for residential and community services expanded from $3.5 billion in 1977 to $22.8 billion in 1996, a growth rate of 167% after adjusting for inflation.

Figure 1

UNITED STATES

Out-of-Home MR/DD Residential Placements by Setting: 1996



Residential Services Total: 394,284

Source: Department of Disability and Human Development, University of Illinois at Chicago, 1998

The Medicaid program was the principal catalyst of system expansion, both in terms of persons served and resources allocated (Braddock & Hemp, 1996). In 1996, 71% of all public resources in the nation's MR/DD service system was associated with the federal-state Medicaid program through the Intermediate Care Facility for the Mentally Retarded (ICF/MR) authority or the Home and Community Based Services (HCBS) Waiver program. The ICF/MR program has been instrumental in the financing of large public and private institutions; the HCBS Waiver program supports a wide array of community services and supports for people with developmental disabilities and their families. The dominant national trend today is clearly toward implementing more family and community supports in the states, while closing and consolidating state-operated institutions (Braddock & Hemp, 1997).

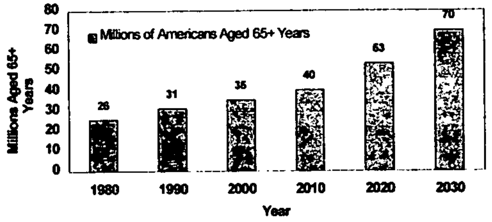
II. AGING CAREGIVERS AND THE GROWING DEMAND FOR SERVICES

The aging of our society directly influences demand for developmental disabilities services. This occurs because the majority of people with developmental disabilities in the United States currently reside with family caregivers. As these caregivers age beyond their care-giving capacity, formal supervised living arrangements must be established to support their disabled relatives. It is logical to assume that the size of the cohorts of people with developmental disabilities living with aging family caregivers in each state would correspond closely to the size of waiting lists for residential services in those states.

The aging of our society is a product of several forces, primary among them the size of the baby boom generation (persons born during 1946-64), declining fertility rates, and increased longevity. Baby boomers will begin to reach age 65 in about 11 years--in 2010. The number of persons in our society aged 65+ years is projected by the U.S. Bureau of the Census to be 35 million persons in the year 2000; the number will double by the year 2030 to 70 million (see Figure 2) due to the aging of the baby boom cohort (U.S. Bureau of the Census, 1996). Currently, 12.8% of the U.S. general population is aged 65+ years. Census Bureau demographers anticipate that this percentage will grow steadily for the next three decades, finally leveling off at 22% of the U.S. population in 2030. Problems loom even larger in countries such as Japan and Germany, where the 65+ cohort is projected to approximate one-third of their general populations by the year 2040 (U.S. Bureau of the Census, 1997).

Figure 2

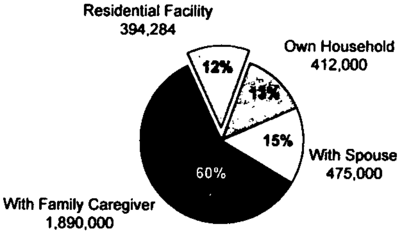
Growing Numbers of Americans Aged 65+ Years: 1980-2030



Understanding the impact of aging on the increased demand for developmental disabilities services in the states requires an appreciation of the prevalence of developmental disabilities in our society. Fujiura (in press) recommends using a prevalence rate of 1.2% based on the Survey of Income and Program Participation (SIPP) (U.S. Bureau of the Census, 1992), which collected survey data from 91,000 U.S. households. The 1.2% rate includes persons with mental retardation, cerebral palsy, autism, epilepsy, and other childhood disabilities originating prior to 22 years of age. Fujiura's (in press) analysis indicated that, in 1991, 60% of persons with developmental disabilities in the U.S. resided with family caregivers, as opposed to living on their own or within the formal out-of-home supervised residential care system in the states.

I updated Fujiura's 1991 data based on the more current Braddock et al. (1998) study of the formal out-of-home residential system, and on U.S. population growth through 1996. The results are presented in Figure 3, which indicates that 1.89 million of the 3.17 million persons with developmental disabilities in the U.S. population in 1996 were receiving residential care from family caregivers. This "informal" system of residential care served about ***five times*** the numbers served by the formal residential care system (394,284 persons).

Figure 3
Distribution of Individuals with a Developmental Disability by Living Arrangement, 1996

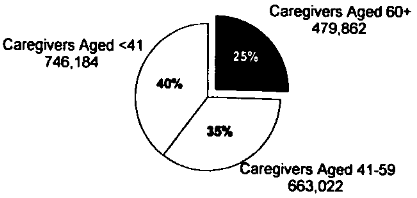


Total Estimated Population with a Developmental Disability: 3.17 Million

Source: Adapted from Braddock et al. (1998) & Fujiura (in press).

Fujiura's 1991 data, based on the SIPP, indicated that 25% of individuals with developmental disabilities across the U.S. lived with family caregivers aged 60+ years, and an additional 35% were "in the households of middle-aged caretakers for whom transition issues are near-term considerations." In Figure 4, I reconfigured Figure 3 to draw specific attention to the size of the aging family caregiver cohort (479,862 persons in 1996).

Figure 4
Distribution of Individuals with a Developmental Disability Living With Family Caregivers, 1996



Total Estimated Population of Persons with a Developmental Disability Living at Home: 1.89 Million

Source: Braddock (1998), adapted from Fujiura (in press).

How large is the aging caregiver cohort in each of the states? State-by-state estimates can be generated by taking into account differences both in terms of states' utilization of out-of-home placements and in terms of differences in the size of states' cohorts over age 60+ years. For example, 10% of persons with developmental disabilities in

Michigan live in out-of-home settings while the figure is 27% in North Dakota (Braddock et al., 1998). Also, the percentage of older individuals in the general population in the "oldest" state, Florida (18.5%), is three times the percentage of older individuals in the youngest state, Alaska (5.2%) (U.S. Department of Commerce, 1997). State-by-state estimates of individuals with developmental disabilities living with older (60+ years) caregivers appear in Table 1.

III. INCREASED LONGEVITY OF PERSONS WITH DEVELOPMENTAL DISABILITIES

A second factor impinging on the growing demand for MR/DD services has to do with increases in the life-span of individuals with developmental disabilities. The mean age at death for persons with mental retardation was 66.2 years in 1993--up from 18.5 years in the 1930s and 59.1 years in the 1970s. The mean age at death for the general population is 70.4 years (Janicki, 1996). Janicki, a noted authority on aging and mental retardation affiliated with UIC"s Rehabilitation Research and Training Center on Aging with Mental Retardation, has observed that, with continued improvement in their health status, individuals with mental retardation--particularly those without severe impairment--can be expected to have a life span equal to that of the general population. Longevity has increased dramatically for persons with significant developmental problems such as Down Syndrome. Average age at death in the 1920s was 9 years for this group; it rose to 30.5 years in the 1960s and to 55.8 years in 1993 (Janicki, Dalton, Henderson, & Davidson, in press).

As persons with developmental disabilities live longer, they require long-term care for longer periods of time. This directly impacts on the finite capacities of service delivery systems in the states. The increased life expectancy of persons with developmental disabilities between 1970 and the present accounts for a significant percentage, perhaps as much as 20% or more, of the long term care resources now being consumed by such persons in the formal out-of-home long term care service system.

The likelihood of older persons with developmental disabilities living into their own retirement and outliving their family caregivers has increased substantially in recent years. This has in turn stimulated a growing need for more services and supports. The need to provide these services is frequently unanticipated by Federal, state, and local agencies, often resulting in a crisis situation for families in the most extreme cases of need. It is unfortunately not an exaggeration to note that many family caregivers must die before the disabled relative they are caring for receives appropriate residential and community services from the state system.

TABLE 1: Individuals with Developmental Disabilities Living in Households with Caregivers Aged 60+ Years, 1996

State	Est. Individuals/Households
ALABAMA	8,362
ALASKA	402
ARIZONA	8,898
ARKANSAS	4,694
CALIFORNIA	49,374
COLORADO	5,611
CONNECTICUT	6,378
DELAWARE	1,345
DISTRICT OF COLUMBIA	1,017
FLORIDA	40,145
GEORGIA	10,949
HAWAII	2,209
IDAHO	1,764
ILLINOIS	20,602
INDIANA	10,208
IOWA	5,631
KANSAS	5,019
KENTUCKY	7,325
LOUISIANA	6,808
MAINE	2,270
MARYLAND	8,526
MASSACHUSETTS	11,745
MICHIGAN	17,453
MINNESOTA	7,283
MISSISSIPPI	4,777
MISSOURI	10,378
MONTANA	1,580
NEBRASKA	3,048
NEVADA	2,787
NEW HAMPSHIRE	1,985
NEW JERSEY	15,789
NEW MEXICO	2,630
NEW YORK	32,391
NORTH CAROLINA	13,483
NORTH DAKOTA	1,110
OHIO	21,109
OKLAHOMA	6,235
OREGON	6,150
PENNSYLVANIA	27,115
RHODE ISLAND	2,219
SOUTH CAROLINA	6,432
SOUTH DAKOTA	1,291
TENNESSEE	9,766
TEXAS	29,129
UTAH	2,547
VERMONT	1,011
VIRGINIA	11,115
WASHINGTON	8,747
WEST VIRGINIA	3,760
WISCONSIN	8,572
WYOMING	691
UNITED STATES	479,862

Source: Braddock, D. (1998). Department of Disability and Human Development.

University of Illinois at Chicago. Revision of September 22, 1998.

IV. WAITING LISTS IN THE STATES

The size of the state cohorts of individuals with developmental disabilities living with aging family caregivers (Table 1) correlates strongly with the size of waiting lists reported by the states (r = .649; p < .01). According to data collected by the University of Minnesota in 1997, an estimated nationwide total of 83,101 persons with developmental disabilities are on formal state waiting lists for residential services (Prouty & Lakin, 1998). This figure is nearly equivalent to the total service system expansion during the previous 20 years (104,000 persons). A second recent survey conducted by the Arc/United States (Davis, 1997) confirms the magnitude of waiting lists in the states today. Thus, demographic trends clearly suggest that waiting lists will accelerate markedly in the states as baby boomers age, unless a concerted state-federal effort is mounted to address this issue.

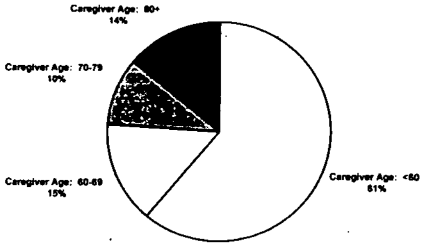
Some states keep detailed waiting lists on service needs for persons with developmental disabilities. Some do not keep "official" lists although state officials informally acknowledge that significant demand for needed services exists. Prouty & Lakin's 1997 survey of waiting lists in the states noted a 38% increase in persons requesting residential services (Prouty & Lakin, 1998) compared to a survey done five years earlier in 1992 by Hayden & DePaepe (1994). Eleven states did not furnish waiting list data in the 1997 survey (California, Iowa, Kansas, Maine, Maryland, Michigan, Mississippi, Ohio, Texas, Virginia, and West Virginia) and five states indicated that the waiting list was zero (District of Columbia, Hawaii, Illinois, North Dakota, and Rhode Island). One of the states indicating zero persons awaiting services was Illinois, which is remarkable since the state has long lagged behind most other states in the development of family-scale residential alternatives. We need more accurate waiting list data from states such as Illinois. States should not cover up this problem. They should conduct rigorous needs assessments for services and develop plans to serve the burgeoning number of families awaiting services in the states.

The close connection between aging caregivers and growing waiting lists in the states can be illustrated in the vivid example of Maryland. Maryland's Developmental Disabilities Administration provided residential waiting list data to the Baltimore Sun (March 23, 1997). The Sun reported 4,682 persons waiting for services in 1997. Thirty-nine percent of these individuals were living with caregivers aged 60+ years (see Figure 5). Twenty-four percent of the 4,682 persons waiting for services had caregivers aged 70+ years, and 14% were aged 80+ years. It is not likely that Maryland represents an aberration among the states. Because of the state's fairly large general population, its percentage of aging caregivers on the waiting list (39%) may well approximate the pattern in most states. There is no doubt that aging family caregivers are extremely oversubscribed on state waiting lists and that the Maryland data are indicative of a serious national problem requiring this Committee's concerted attention.

STATE INITIATIVES TO ADDRESS WAITING LISTS

Several states have begun initiatives to address waiting lists. New Jersey, for example, appropriated $30 million in FY 1999 to reduce its waiting list for community residential services. Between 1986-96, the New Jersey waiting list increased from 767 to 4,600 persons. The "urgent" category in 1996 consisted of 2,286 persons. The New Jersey Department of Human Services, Division of Developmental Disabilities, projects the need for a 10-year waiting list reduction initiative with appropriations of $30 million per year through the Year 2008. New Hampshire has enacted a special appropriation to address the waiting list and is requiring an annual status report to the Governor regarding progress in addressing the waiting list. Connecticut, Texas, Massachusetts, and Oregon have also commenced waiting list initiatives. Lakin (1998) has noted that waiting list initiatives in the states generally involved re-allocating resources in the following ways:

Figure 5
MARYLAND
Caregiver Age for Developmentally Disabled Adults on Residential Waiting Lists: 1997



Clients on Waiting List: 4,682

Source: Baltimore Sun, March 23rd, 1997 (compiled from waiting lists of the Maryland Developmental Disabilities Administration)

- The closure/consolidation of institutions;
- The conversion of ICFs/MR to HCBS programs;
- Capping reimbursement for existing programs;
- Augmenting state funding with Medicaid funding;
- Expanding family support and subsidies to prevent or delay the need for placement; and,
- Promoting flexibility in residential and day programs for persons leaving high cost programs.

V. POLICY CONSIDERATIONS AND RECOMMENDATIONS

Aging of the nation's population, marked improvement in the life-span of persons with developmental disabilities, and our country's traditional reliance on families to provide most developmental disabilities long-term care are currently having profound impacts in the states and

these impacts will increase dramatically in the years ahead. We can anticipate increased pressures on family caregivers, especially in states with a large percentage of older citizens, and also in those many states that have yet to develop an extensive array of community services and supports. A major problem is the fact that only three percent of the total funding base of $22.8 billion in the developmental disabilities field is currently targeted toward family support services. A similar miniscule percentage of total funding (4%) is allocated for consolidated activity in supported living, personal assistance, and supported employment. The remaining 93% of the field's funding base finances residential and vocational facilities including large public and private institutions, sheltered workshops, and other primarily facility-based services.

The Federal Government should encourage greater flexibility in resource allocation through use of the HCBS Waiver and other Medicaid Waivers. In-home support programs and cash subsidies frequently prevent more costly placements in institutions, nursing homes, and other residential settings where costs often exceed $100,000 per year. States and community providers need greater flexibility to access HCBS Waiver funds for families and consumers on waiting lists. The Medicaid state plan amendment process is cumbersome in many respects. The Federal Government should provide additional incentives to states to reallocate Medicaid ICF/MR funding to community and family support objectives that address waiting list and aging caregiver issues. Personal assistance legislation (MICASA, the Medicaid Community Attendant Services Act, H.R. 2020) should be supported. Improved coordination between Older Americans Act services and the MR/DD service system should be stressed.

The states should also be encouraged to adopt waiting list reduction initiatives and to conduct independent special studies of the number of persons awaiting various developmental services in the states. The state developmental disabilities planning councils and university affiliated programs should assist in carrying out such studies. A special initiative for family support appropriations is currently pending in the Developmental Disabilities Act appropriation bill before Congress. This special appropriation should be supported. A portion of these DD Act funds might be targeted for developing models in the states for serving aging caregivers and for carrying out carefully designed waiting list studies to inform the state planning process required under the Developmental Disabilities Act.

Thank you, Mr. Chairman, for the opportunity to present this statement to the Committee today.

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Ms. GOLDEN. Thank you, Dr. Braddock. That was most enlightening.

Now I wish to present Tom Nerney who is co-director of the Robert Wood Johnson Self-Determination Project. Mr. Nerney.

STATEMENT OF THOMAS NERNEY, CO-DIRECTOR, NATIONAL PROGRAM OFFICE ON SELF-DETERMINATION, INSTITUTE ON DISABILITY, UNIVERSITY OF NEW HAMPSHIRE, CONCORD, NH

Mr. NERNEY. Thank you. I think the topic this morning goes right to the heart of the question of equity, or what I would call the lack of equity in the present system. We have an incredible unequal distribution of the existing funds within the present human service system for folks with developmental disabilities.

When I talk about self-determination and go back to the early 1990's when we first started this, we came to the conclusion the challenge for us, based on demographics and the little bit that we knew then about what was going to happen with the population of this country, that we had to think about designing a long-term care system based on American values that went right to the heart of the basic freedoms that all people in America take for granted but that folks with developmental disabilities have to give up in return for support.

We wanted to design a system that addresses the issue of quality while honoring exactly how people wanted to live, where they wanted to live, with whom they wanted to live. So we organized a self-determination initiative, not around a program or a model. We organized it around a set of principles.

What I want to do this morning very quickly, and you will see all of this in the written testimony and some of the other attachments, the monographs and the newsletter that are available for those who are interested in reading some more, I want to tell you very quickly what self-determination means, give you some examples, I think, of the potential for both enhanced quality and reduced average cost, I mention what structural requirements we think it is going to take in order for the promise of self-determination to become a reality for people, and then I have just a few recommendations.

Self-determination is organized conceptually around four very simple principles. The first one is freedom, what people with developmental disabilities have to give up in exchange for support in the present system, the same kind of freedom that we take for granted.

Authority over resources, we talk seriously about moving control of the dollars directly to individuals and families and friends and social networks via the development of an individual budget that is frequently developed below current service costs, and I will get to that issue.

The third principle is one of support. Everybody ought to have the ability to be able to design their supports that are unique for them. What we are talking about here is arranging the kinds of resources that an individual needs and paying only for what you get instead of being offered, as the present system does for so many folks with disabilities, a program slot or an opening or a bed in a group home.

The fourth principle is simply that of responsibility, and responsibility means not only the wise use of public dollars and the efficient use of public dollars, but the ordinary acts of citizenship that folks with developmental disabilities are completely capable of contributing within their communities if they were, indeed, allowed to gain supports from the system that encouraged that.

What have we learned so far? We have projects now, small and large, in 29 States around the country, and I cannot go into very much of it, but with regard to the waiting list and to the cost of current supports, let me mention just a few things.

When we started a pilot to demonstrate that this could be an effective way for people in the current system, we did it in the early 1990's in the New Hampshire area, Keene, NH. We selected 45 individuals whose average cost was between $60,000 and $90,000. They were, on average, more significantly disabled than anyone else. There is no institution in New Hampshire, has not been for 10 years, so everybody lives in the community.

We found out in less than 3 years, by organizing supports for individuals around these principles, that through an independent analysis by Conroy Outcome Analysis, their lives had improved dramatically. The qualitative differences, you could record, you could see. And in addition to that, we found out those 45 individuals saved $300,000 of public dollars over those 3 years on an annual basis. That is $300,000 on an annual basis.

Two States then started piloting these principles for folks on the waiting list, and I want to mention Connecticut was one of the first to do it. The legislature appropriated about half a million dollars and told the department, there are no strings attached to you. How would you use it more effectively? And so they went to the waiting list and they made available to families an average of $20,000. If those folks had come off the waiting list into the system in Connecticut, the average cost would be anywhere from $60,000 to $120,000. The families, to a person, said they thought they had won the lottery, and 17 of the first 20 families chose in-home supports.

When New Hampshire did the same thing with their waiting list, the data, interestingly enough, is almost exactly the same. The average cost under the Medicaid waiver in New Hampshire for a person served 24 hours is about $43,000. They gave priority to self-determination for people on the waiting list and the average plan there is under $22,000, using, again, the principles of self-determination.

So we are looking at enormous potential and an issue where we can, if we are willing to take the time and restructure the present system, where we actually could do more with the same resources and serve more people.

The structural requirements that we think have to be in place are very simple. People have to have an individual budget and they have to have access, independent of existing service provision, to information and ongoing information, and we call that independent brokering. And then the money itself has to be logged somewhere where there is no conflict of interest. We call that a fiscal intermediary. So the functions of having a fiscal intermediary and having independent brokering available to individuals and families is absolutely essential to the success of this.

The implications. As our projects unfold, and that is probably the best word to use, we are gaining more information all the time and starting new discussions. People are now talking seriously about the inherent conflicts of interest in the present system and why it is so expensive.

The present system is based, to a large degree, on a facility or a congregate care mentality. There are huge sunken costs in property and buildings, and these consign individuals to these places because that is the only way these mortgages and capital debt can be reduced. So, in fact, folks with disabilities are being held hostage, literally, to investments in buildings and places.

Current expenditures are provider-driven and they reflect the ordinary increased costs associated with providing traditional services. Self-determination challenges this method of contracting and says very clearly that the contracting authority ought to be between the funding source, the State, county, or local government, and the person with the disability and family, and that is ultimately the most important arrangement that has to be in place legally.

Public dollars are now seen as investments in organizations and buildings. Self-determination insists that public dollars be seen as an investment in the lives of people with disabilities and in families. Public dollars need to be used strategically to support existing family and community relationships, and where those do not exist, and they do not in the present human service system for many people, they need to be created.

Along with the basic lack of freedoms, we have to address the question of the almost total personal impoverishment of folks with developmental disabilities in the present system.

Some of the recommendations that I would make, by way of summary, we have found that the Health Care Financing Administration, the Federal Medicaid statute is not the problem at all, that almost all the problems with changing the system are self-imposed by the States by the way they wrote their current Medicaid waiver. If we were able to put into the Federal Medicaid statute permissive language encouraging States to adopt principles like this and give them permission a priori to adopt them without having to create the incredible amount of paperwork associated with either an experimental waiver, like an 1115, or just a modification to their waiver, I think we could go a long way toward helping and assisting States in redesigning their systems.

I think the Federal Medicaid statute should be amended to allow for the individual development accounts, so that folks with disabilities can protect savings and even have them matched for buying a home, for education, for training, and for developing small businesses, just as we have designed it into the Federal welfare reform statute. And I think there are other uses, technology especially and some other things, that folks with disabilities need to be able to put money aside for.

I think this approach may very well be appropriate for all individuals with disabilities, but I think at some point, we are going to have to struggle with putting in these principles, if they do make sense to people, into Federal statute, one way or another, and I think, as I look at the field of aging, I wonder why the promise of the area agencies on aging could not possibly be fulfilled if they had an interest in working with folks who were elderly with disabilities and families, as well, and looking at those structural transformations that we need, the fiscal intermediary and the independent brokering, for a lot of other folks, as well. My recommendation would be that we would look closely at all of those.

[The prepared statement of Mr. Nerney follows:]

SELF-DETERMINATION FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

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September 18, 1998

TESTIMONY BEFORE THE SENATE SPECIAL COMMITTEE ON AGING

DOING MORE WITH LESS: RETHINKING LONG TERM CARE

My name is Tom Nerney and I am Co-Director of The National Program Office on Self-Determination funded by the Robert Wood Johnson Foundation and located at the Institute on Disability at the University of New Hampshire. I am pleased to be able to testify at this forum on "The Anxiety of Elderly Parents Caring for Baby Boomers with Disabilities" and thank Senator Grassley and members of this committee for the invitation.

Our efforts to redefine and reshape the system of long term care for individuals with developmental disabilities impacts directly on this topic, and, furthermore, may have enormous implications for all individuals with disabilities. Elderly family caregivers are an important constituency who are part of a growing body of family caregivers including middle age families caring for elderly parents. Their anxiety about lack of services or supports is exacerbated by the limited choices available in the present human service system, Medicaid eligibility problems and lack of direction over these services or supports.

Within the field of developmental disabilities we have witnessed growing waiting lists in state after state for supports and long term care. The present system has become enormously expensive, frequently does not furnish the types of support that individuals and families desire and severely limits the freedom to design supports in keeping with the express wishes of those with disabilities and their family and close friends. One of the reasons for this is the complex, clinically oriented, regulation dominated, Medicaid program whose original design was meant to treat individuals with disabilities like patients. While much has been accomplished to address this issue in new and improved state waivers under Medicaid, there remains much more that needs to be done.

The challenge for all of us is simply this: *can we design a system of long term care that values the freedoms that all Americans take for granted and be cost effective? Can we design a system of supports that addresses the issue of quality while honoring the desires of individuals in need of support to live where they want and with whom they choose?*

This morning I would simply like to tell you what self determination means, give you some examples of the potential for both enhanced quality and reduced average costs, mention the new structural requirements for implementing this approach and discuss the implications of self-determination for all individuals with disabilities or chronic health conditions who warrant our support. Some recommendations then follow.

WHAT IS SELF-DETERMINATION

Self-determination is a national movement to redesign long term care for individuals with developmental disabilities that eschews traditional program model and facility placement approaches. Rather, self-determination is based on a set of fundamental American principles developed to guide our efforts in re-thinking our system of long term care and re-thinking how public dollars are apportioned and utilized. These principles are Freedom, Authority over Resources, Support and Responsibility.

Freedom in this context simply means that individuals with disabilities have the freedom to choose where they live, with whom they live and how they spend their time. This is done with the assistance of freely chosen family, friends and professionals.

Authority over Resources means that these social networks of individuals with disabilities and their allies control the budgeting of some targeted amount of resources and choose who provides any particular support as well as direct changes to the budget based on changing circumstances.

Support means that these individuals and family and friends can organize the unique supports that an individual may need and desire rather than have to fill a bed or a program slot in a typical provider arrangement.

Responsibility means that individuals with disabilities will carefully purchase only what they need, husband scarce public resources and contribute to their communities.

In early 1993 we designed a pilot to test this approach with 45 individuals in Southwestern New Hampshire with assistance from the Robert Wood Johnson Foundation. We took the then radical path of asking individuals and families what supports they valued, how they would like to see them developed and implemented and gave them the freedom to prioritize these supports as well as change them when they felt they were not working. These were all individuals served on a 24 hour basis within the current Medicaid waiver.

An independently funded evaluation by Conroy Outcome Analysis found greatly enhanced quality of life among the participants at the end of this demonstration. Not to be undervalued was the secondary finding: these individuals had enjoyed an increased quality of life while saving $300,000—a reduction in average cost of from 12 to 15 percent.

As a result of this effort the Robert Wood Johnson Foundation moved to set in motion a series of demonstrations around the country. Today, there are small and large efforts in 29 states that are geared to pioneer self-determination and provide us with the information we need on the myriad ways that these principles can be implemented. In well over 100 communities thousands of individuals are working on transferring resources directly to individuals with disabilities and their family and close friends.

WHAT WE ARE LEARNING: THE POTENTIAL

Throughout the field of long term care state officials, advocates and individuals with disabilities as well as close family and friends are coming to some rather common sense conclusions. States are faced with a growing population of elderly individuals many of whom will need support. Demographics alone are cause for a fundamental re-evaluation of current expenditures as policy makers weigh the influx of an increasingly aging population on their Medicaid budgets. Just as nursing home placements represent the least desirable choice for elderly people nursing homes also represent the least desirable choice for cost conscious state officials. Even if enough "beds" could be built it is fantasy to believe that state Medicaid budgets could absorb these increased costs.

So too in the field of developmental disabilities. Many states have been moving away from the traditional institutional settings of yesteryear and exploring new ways to reinvest public dollars in order to serve more individuals in cost effective ways in our communities. Reallocating existing resources is the first step in this process. Moving from large congregate facility approaches to highly unique individual budgets designed by individuals with disabilities and their family and friends appears to be a logical next step in the re-design of our current system.

The self-determination movement has given state officials a new set of tools to both increase the efficiency of the present system and meet the aspirations of people with disabilities. Two states have recently generated data that gives a glimmer of how costs could be contained without denying needed benefits to individuals and families. Both New Hampshire and Connecticut developed strategies that brought a targeted amount of resources directly to family caregivers and individuals with disabilities instead of taking individuals into the system in the old way.

In Connecticut, an average amount of $20,000 was made available to a small number of families through a special appropriation from the State Legislature that emphasized self-determination. This was welcomed by these families on the waiting list and utilized in novel and ordinary ways. The twenty four hour cost of bringing any one of those individuals into the old system would have topped $60,000 per person annually. In New Hampshire the average expenditure for those served under the Medicaid waiver is $44,425 in the traditional system. Utilizing the principles of self-determination state officials gave priority to any waiting list plan that reflected the principles of self-determination.. This strategy emphasized non-traditional and lower cost alternatives. The average expenditure under this approach was $22,314.

We know quite a bit about the costs associated with congregate settings. We know very little about costs associated with supporting individuals in ways that meet their unique desires. Not every person is going to cost less than the present system. However, all of the preliminary evidence points to average reductions in public outlays under a self-determined system—a new way to think about serving more individuals with the same resources. This appears to be true for those currently served as well as those on existing waiting lists.

THE NEW STRUCTURAL AND SYSTEM REQUIRMENTS

Self-determination appears to require that we rethink almost all of our current assumptions about long term care and carefully develop the appropriate structural conditions to assure that real freedom is the hallmark of the new system and that quality and the wise, efficient use of resources undergirds the new system.

Individual budgets are developed by persons with disabilities and their allies based on a targeted amount of dollars usually set somewhere below current traditional costs. This is the first step in this structural reform. Two resources appear to be necessary in order for this to work properly.

First, the dollars themselves have to be physically located so that they can be drawn down in conformance with an approved budget. We refer to this as a fiscal intermediary and see it as essential to success. Currently state and county contracts are with provider agencies who budget their dollars on a set amount per person times the number of individuals in their contracts. In this way the dollars are subsumed in the agency contract and the individual never has control of them. Fiscal intermediaries are independent of service providers and also responsible for insuring the proper payment of taxes, withholding and understanding when individuals providing support are employees, independent contractors, homemakers or companions.

Second, the resources available to individuals must be understood and the information and planning necessary to utilize both traditional and community supports must be available to individuals with disabilities and families. This we call independent brokering—the presence of individuals or agencies whose sole loyalty is to the person with a disability.

In many of our project sites around the country state and county authorities are testing new approaches to both of these structural requirements. In one county in Minnesota a local bank has agreed to act as a fiscal intermediary and has issued checkbooks to individuals with disabilities who draw down the county money upon completion of an approved budget. The county provides the necessary information and planning expertise that an individual or family may desire. In other places the county or regional authority may act as the fiscal intermediary. Some states are planning or already implementing independent brokering agencies where individuals with disabilities and families can go for partial or total assistance in developing and implementing individual budgets. Oregon has already created one such agency which incidentally is run by an independent board with a majority of consumers. Maryland is planning an even more ambitious effort. The Governor of Hawaii just signed ground-breaking legislation that places the person with a disability and social network in charge of both the plan and the resources. Minnesota and Wisconsin have added "self-determination" to their state waiver plans and state long term care strategies.

In many project sites traditional case managers are being trained and retrained to take on the role of independent broker. In many instances family members or close friends are allowed to carry out this function. The planning process itself is changing as only those in close and trusted relationships with the person with a disability assist that person in planning. Provider agencies roles change considerably under self-determination. They are now required to enter a new marketplace where individuals and families can choose them, reject them or simply contract for a type of assistance that the agency has a proven track record in providing. The new contracting authority is between the funding source—state, county or local-- and the individual with a disability.

Individuals with disabilities and families ask only for what they want and, now, will pay only for what they get. We are learning daily about the cost efficiencies inherent in this arrangement. We are also learning constantly about new and more effective ways to organize long term care that meets both individual and public policy expectations. We envision these projects as laboratories that will constantly bring us more information and improved ways of assisting individuals to live full and meaningful lives in their communities.

THE IMPLICATIONS

The implications of self-determination which apply in particular to the population of folks with developmental disabilities seem congruous for any person with a disability of any age.

- The present system of long term care is based on a facility or congregate care mentality. Huge sunken costs in property and buildings consign individuals to these places in order to pay off mortgages or reduce capital debt. Self-determination is challenging this mentality and raising questions about holding persons with disabilities hostage to these investments.
- Current expenditures are provider driven and reflect increasing costs associated with organizational needs. Self-determination challenges this method of contracting that almost always results in loss of freedom for the individual and cost increases annually.

It simply does not allow for determining what a person wants and allow public dollars to be used in innovative ways to achieve these highly personal goals.

- Public dollars are now seen as an investment in organizations and buildings. Self-determination insists that public dollars be seen as an investment in the lives of people with disabilities. Public dollars need to be used strategically to support existing family and community relationships as well as help create them where they do not now exist.
- There are not current fiscal incentives for many stakeholders to change and help make this system more cost effective as well as honor the basic rights that all Americans take for granted. Self-determination can, over time, assist us in restructuring the fiscal incentives so that everyone has a reason to be more cost effective.
- Along with basic lack of freedoms, personal impoverishment characterizes the situation of most people with disabilities in the current system.

RECOMMENDATIONS

The Federal Medicaid statute should be amended to give permissive, a priori, authority to states that opt for including self-determination in their state plans. By encouraging this approach and making it easy for states to implement these principles, The Health Care Financing Administration can become a partner with the states in insuring quality while demonstrating cost effectiveness.

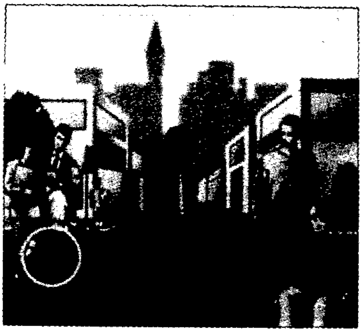
The Federal Medicaid statute should be amended to allow individuals with disabilities to utilize individual development accounts that would enable them (without losing Medicaid eligibility) to save and invest in home ownership, education and training, small business development, necessary communications and mobility technology and other items that hold out the promise of increasing disposable income, paying taxes like ordinary citizens and potentially lessening the costs associated with SSI/SSDI and even Medicaid itself.

This approach should be encouraged for all populations of individuals with disabilities, especially those with various physical and psychiatric disabilities.

In the field of aging it might make particular sense to examine the capacity of the Area Agencies on Aging to determine if they could play a significant role in implementing these principles for older Americans in need of long term support.

BEYOND MANAGED CARE:

SELF-DETERMINATION FOR PEOPLE WITH DISABILITIES



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WRITTEN BY:

THOMAS NERNEY AND DONALD SHUMWAY

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BEYOND MANAGED CARE:

SELF-DETERMINATION
FOR PEOPLE WITH DISABILITIES

By Thomas Nerney and Donald Shumway

INTRODUCTION

Persons with developmental disabilities often receive services or supports from a variety of human service agencies under contract to a public funding source. This "third party" payment method is the preferred way to operate under current Medicaid and most state regulations. Human service agency budgets usually get constructed or built from the average payments made by these funding sources multiplied by the number of people served by that agency. These annual payments are frequently based on rate setting and purport to represent what a person with a certain level of disability will cost in public care. Of course, the type of service offered has much to do with this cost, e.g., group home, sheltered workshop or supported employment. Other factors may also influence these costs. When a vacancy occurs, human service agencies move quickly to fill this "slot" because their overall budget is usually dependent on serving the same or more individuals referred to them by the funding source.

Although current Medicaid statutes allow individuals with developmental disabilities to "choose" or change providers if they are not satisfied, the reality in most states is that individuals are not always allowed these choices because of the closed market that the very method of state and county contracting procedures have created over the years in response to traditional program budgeting and other State and Medicaid regulations.

Contemporary political discussions of long-term care center mainly around issues relating to the cost of this system for persons with disabilities. Congressional and Administration attempts to slow the growth in Medicaid spending for acute health care costs impact directly on Medicaid funding for long-term care. Acute and long-term care share the same budget as well as the same federal oversight and bureaucracy. Indeed, it can be argued that one of the reasons for the current high per capita costs associated with the system of long-term care for persons with developmental disabilities emanates directly from the clinical and medical orientation and regulation associated with Medicaid and the Health Care Financing Administration.

The irony that should not be lost on anyone is the almost total impoverishment of the majority of people with developmental disabilities in the richest and most costly system of care in this country.

There is almost universal consensus that Medicaid spending will be slowed. Primary among these reasons is the inability of state budgets to keep up with these spiraling costs. The looming federal deficit shrouds any discussion of alternatives. Long waiting lists of eligible persons in many states contribute to the pressure to reduce costs. Given the exigencies of the present system, however, most states have not been able to lower individual costs appreciably. Many states have leveraged the vast majority of their state funds in order to meet the match requirements of the Medicaid program. Demographics, however, may be the most salient reason to question the viability of our present, expensive system of long-term care. The burgeoning population of elderly people who will come to rely on a dwindling supply of federal and state dollars, as well as a decreasing supply of caregivers who will be available as a labor supply, may be the most important reasons to create significant changes in the system. **The present crisis presents an opportunity to re-examine our present assumptions regarding long-term care with an eye toward making it more cost-effective, as well as bringing it into line with the aspirations of people with disabilities and families.**

Aside from high per person costs, there are two important problems with the present system. First, individuals or consumers frequently have no choice over which agencies will provide their services or supports and, more importantly, have no control over the quality or nature of the services or supports rendered. Second, because of the way many states have organized their systems of services, individuals with a disability have no choice other than to utilize the services of "qualified" human service agencies–those agencies certified and organized to provide highly regulated programs. This has the effect of limiting choices to current service providers and barring more informal supports.

How, then, can the individual or the family truly control the nature and quality of supports that may be required? Put another way, how can the "consumer" become a real consumer and, within a competitive marketplace of options, become the actual employer (if desired) for personnel hired for various tasks? For states and localities, the question becomes "How can we put structures into place that will enable people with disabilities and families to truly control resources?" Of all the questions that arise in conjunction with self-determination or consumer controlled supports, this is the question that raises the most complex issues. The bottom line issue, however, is whether a professionally structured system of services is ready to relinquish control. Other issues range from interpreting current Medicaid regulations (which specifically prohibit giving cash to individuals or families in order to arrange their own supports) to issues surrounding the applicability of IRS and Department of Labor regulations.

This paper, then, deals with options or choices that individuals with disabilities or families can make today under current regulations and laws in order to achieve self-determination. It explores both the requirements that must be met and the organizational mechanisms that might prove to be good choices. The purpose is to call for a recognition of the options that extend beyond current service delivery methods and to challenge the assumption that the sterile solution of managed care is the only or the preferred next step in this vital support system. We start with the basic principles of self-determination and then take a closer look at three organizational or reengineering issues:

- Fiscal Intermediaries or controlling dollars without dealing with cash;
- Independent brokering of supports that an individual or family may desire; and
- Organizing a coherent response in a managed care culture.

PRINCIPLES OF SELF-DETERMINATION

The following principles are meant to provide a philosophical foundation for substantive system change that incorporates the values deeply held by persons with disabilities, families and friends and advocates:

FREEDOM

The ability for individuals with freely chosen family and or friends to plan a life with necessary support rather than purchase a program;

AUTHORITY

The ability for a person with a disability (with a social support network or circle if needed) to control a certain sum of dollars in order to purchase these supports;

SUPPORT

The arranging of resources and personnel--both formal and informal--that will assist an individual with a disability to live a life in the community rich in community association and contribution; and

RESPONSIBILITY

The acceptance of a valued role in a person's community through competitive employment, organizational affiliations, spiritual development and general caring for others in the community, as well as accountability for spending public dollars in ways that are life-enhancing for persons with disabilities.

A new way of organizing and delivering supports must be found. These four principles simply describe the conceptual basis for this approach. Each principle has important operational dimensions which should be observed without unduly restricting the forms in which these new ways of delivering supports may grow. For example, each state is organized in different ways and needs to make its own assessment of how to operationalize these principles.

Freedom in this context means that people with disabilities will have the option of utilizing public dollars to build a life rather than purchase a pre-determined program. Freedom means that individuals with disabilities, within some rational and cost-efficient system, will be able to control resources via individual budgets in order to gain the necessary experience in living and to move the dollars when their life choices change.

Authority means that individuals with disabilities really do have meaningful control over some limited amount of dollars. While many persons with developmental disabilities will need assistance in controlling dollars and planning their lives, those chosen by the person with a disability should be ever mindful of the need to ascertain the real desires and aspirations of the person who chose them to assist.

Support is the opposite of "programming." Assisting a person with a disability to nurture informal family and friends as part of a support network is key for those who have these natural resources in place. For those who do not, creating this informal network is important and hard work. Support includes the notion of participating in the rich associational life of the person's community. One of the underlying assumptions of this principle is simply that ordinary community members, under more natural circumstances and environments, will welcome and support people with disabilities. It is important for us to remember that we have allowed public dollars to become an instrument of isolation and an artificial barrier between the person with a disability and the wider community.

Responsibility, like freedom, is a new word in our vocabulary. Both words belong in the same sentence. People with disabilities should assume responsibility for giving back to their communities, for seeking employment whenever possible, for developing their unique gifts and talents. For too long, individuals with disabilities have been seen and treated as dependent and incapable of being contributing members of our communities. The intense over-regulation of programs and the setting of goals and objectives to meet the needs of the human service system more than the aspirations of people with disabilities, have conspired to prevent people with disabilities from truly contributing to the associational life of their communities, the spiritual life of our churches and synagogues, and the cultural and artistic life of our cities and towns.

These basic principles confirm the necessity for creating structures to support their implementation. They exclude the status quo fee for service payment and program model, as well as the managed care models that rely on networked service delivery with utilization controls. These structures must include the development of an individual budget based on a capped amount of dollars that can be used to build the supports a person needs by purchasing only what is needed and paying only for what is received. Caring social networks will become important for most individuals with disabilities, as well as the presence of independent brokerage in order to assist in both identifying and arranging necessary supports. Dollars spent can then be both invested in building a future and invested close to where the person lives.

Self-determination is not person-centered planning, although person-centered planning is a clear prerequisite for implementing these principles. Self-determination is an attempt to fundamentally reform both financing mechanisms and basic structural aspects of the current service delivery system.

INDIVIDUAL BUDGETS AND FISCAL INTERMEDIARIES

Even if giving cash were an option under current regulations, it is a path fraught with danger: tax filings, unemployment insurance, complex forms to fill in and deadlines to meet--let alone the intricacies of these systems. This is not to say that cash is a bad idea for those who might desire to do this work if it ever becomes possible to use it under the federal Medicaid statute. In fact, even under a cash payment system, individuals might want to consider following the same course as those who opt for control of resources without physically receiving cash. So, under the present system, how can individuals or families gain control over dollars but not become saddled with these legal and regulatory requirements?

The first answer is to allow individuals with the help of freely chosen friends and family (and professionals they trust) to construct a highly individualized budget plan usually based on some percentage of current service costs or other capitation method. Individual budgets separated from existing congregate budgets provide real freedom for individuals and families to both purchase what they truly need and pay only for what they get. Self-determination requires the human service system to transfer total individual resources--individually negotiated depending on current need–in order for real control over the long-term to rest with individuals with disabilities. Under this arrangement individuals with disabilities can then organize the supports they need to live and work effectively in their own communities. They can build on already present informal supports or with assistance if necessary create informal support networks--sometimes called *circles*. When these circles are free to plan to assist an individual to create a life, these individuals can purchase only what is desired and necessary. Certain economic efficiencies may then materialize–especially if informal supports are the backbone of the life plan. When individuals are free to develop a plan for a life rather than required to purchase a program from an agency, they can gain the experience and, hopefully, the relationships necessary for future decision-making that will be based on these experiences. The hallmarks of individually controlled budgets are freedom and responsibility. Each year or as often as necessary individual annual plans can be constructed based on a predetermined set of dollars and past experience of what works and doesn't work. (It is wise to create a "risk pool" of some of the dollars saved in order to provide a certain amount of insurance for these individuals.)

The second part of the answer (which also appears in an obscure part of the Internal Revenue Service code) is called "Fiscal Intermediaries." This organizational/intermediary function allows individuals with disabilities (or families) to serve as the employer of record (or this other intermediary) individual or organization can become the employer of record) for any staff hired to provide supports and allows this other organization or individual to manage all tax filings and payments to these staff. Fiscal intermediaries simply provide technical and fiscal supports without usurping the primacy of the individual with a disability, family and friends. It is important to maintain the integrity of self-determination when another individual or organization becomes the employer of record. However, there is no reason to assume a priori that the integrity of self-determination cannot be maintained under these circumstances. For example, when a local or regional funding source becomes the fiscal intermediary, it is important that steps are taken to insure that the authority for purchasing supports does not revert to the fiscal intermediary--although this arrangement can help insure that individual budgets are constructed in practical and life affirming ways.

Fiscal intermediaries may also assume functions associated with brokering that relate to assisting individuals in designing support plans and purchasing supports. These supportive functions can include various quality assurance measures (determined for the first time by individuals with disabilities), recruitment and training issues and monitoring.

There are reasons why the Internal Revenue Service would welcome the use of fiscal intermediaries. One of the most pressing is the temptation for individuals acting as employers to pay support staff as private contractors rather than as employees and, in this process avoid paying taxes that are due. (In many cases staff should be considered employees rather than private contractors.) Conversely, there are many instances when payments for certain types of support can be paid under the rules of contracting rather than formal employer/employee relationships. Skilled fiscal intermediaries can assist in making these kinds of determinations. Utilizing a fiscal intermediary then allows for a form of *dual employment* : the individual hired is an employee of an organization that will provide all of the paperwork necessary to meet federal and state requirements, but the person with a disability (with assistance when necessary) will actually hire and manage these individuals.

The very structure of the work to be performed by employees, consultants and companions emanates from the desires and plans of the individual with a disability.

What organizations can be a fiscal intermediary? State and local agencies may become fiscal intermediaries. Counties or even individuals may become fiscal intermediaries as well. This designation, however, should only be incorporated into a system that preserves all of the principles of self-determination.

What can fiscal intermediaries do? These organizations or individuals can assume a variety of tasks from simply filing the proper taxes and paying employees (like a payroll company or a bank) to assisting with some of the functions of independent brokering such as staff recruitment and training. Ideally, brokering responsibilities should be separate from service provision. However, it is not impossible to imagine a local or regional/county funding source incorporating both fiscal intermediary status and some brokering functions. Much will depend on the real independence and authority of the brokering agent.
We need to gain far more experience in how these functions can best be carried out without compromising the independence of those served by these structural reforms.

In contemplating the functions of a fiscal intermediary it might be helpful to understand the requirements that must be met for all employees:

Employment Taxes

Income taxes, Social Security taxes, federal and state unemployment insurance, worker's compensation

All of the payments listed above must be paid for anyone considered an employee rather than an independent contractor.

Minimum Wage and Overtime

As a general rule all employees must be paid minimum wages or higher if an individual state has a minimum wage law that exceeds the federal minimum. While fiscal intermediaries have no say in these issues, they can be valuable in assisting individuals and circles in understanding the sometimes complex and subjective rules that apply to workers in one's own home, for example. The Fair Labor Standards Act which governs federal minimum wage and overtime provisions is easily as complex as the Internal Revenue Code. What makes these labor laws particularly complex is the interaction between the federal Fair Labor Standards Act and the labor laws of a particular state. One example may suffice. If an individual with a disability hires someone to provide personal assistance and that person lives in the home, then room and board may be or may be not considered income for purposes of remuneration. This all depends on whether the live-in situation is primarily for the convenience of the person with a disability or for the worker.

This situation gets even more complex when a determination must be made concerning whether the worker is a "companion" under the Fair Labor Standards Act. In some cases companions do not have to be paid minimum wage. There are important fiscal savings if you are able to hire someone in a "companion" role rather than as a typical employee. The federal labor laws may exempt these individuals from the overtime provisions of the federal statutes. A good fiscal intermediary would be able to provide needed advice in these areas. These issues can best be sorted out by an individual or organization familiar with these regulations.

Personal Injury and General Liability

Issues of personal liability need to be addressed in a manner that will put individuals with disabilities and families at ease. While Workmen's Compensation will provide coverage for injuries on the job, other legal matters may get raised ranging from disputes over employment practices and wages to differences that may get created over issues of negligence or acts that are deemed harmful to another. This area of personal liability is one that can in most cases be adequately covered by typical agency insurance and is one of the best reasons for considering the use of a properly insured fiscal intermediary.

Medicaid Regulations

While typical arrangements for "services" or supports to individuals are usually done through contracts between human service agencies and state, county or local funding sources, there exists the possibility for these funding sources to move decision-making control of individually designed and approved budgets directly to individuals and families. Depending on how a state's Medicaid waiver is written, authority for doing this may be possible under current regulations. A local or regional funding source may also serve as the fiscal intermediary or some other arrangement may be created. While Medicaid regulations appear to prohibit any system that does not provide direct payment to qualified providers of service, this can be addressed by having the fiscal intermediaries become the billing agents for Medicaid dollars. Recent communications from the Secretary of the Department of Health and Human Services indicate a real willingness on the part of the federal government to support self-determination. Potential providers of services or supports can also voluntarily assign their reimbursement to these fiscal intermediaries under a more restrictive interpretation of the Medicaid regulations.

For example, a regional authority like a county or a not-for-profit organization that distributes funds to human service agencies could change their contracting authority and create individual budgets for those served by these agencies. Individuals and families would then be free to create life plans of their own and purchase supports from existing agencies, new agencies or from ordinary community members--or some combination of these. Either the funding source or, perhaps, a consumer-directed organization, could then serve as the fiscal intermediary. It is wise to separate the functions of a fiscal intermediary from the direct provision of service or support. Requiring the dual signatures of both the person with a disability and the fiscal intermediary in order to approve fund dispersal would be one way of implementing self-determination under current Medicaid regulations.

INDEPENDENT BROKERING

It is important to note here that "brokering" functions, i.e., arranging for the series of supports a person may need, or management functions, i.e., day-to-day supervision of these supports, may also be contracted out by the individual with a disability or family. Both brokering and management functions can become functions that human service agencies willing to re-tool for the future might consider in lieu of providing more traditional services.

Brokering responsibilities become an important linchpin in a fundamentally reformed system. While we need to gain much more experience in how this function can best be provided--through "case management" systems, individuals or agencies, there is some agreement on the role that brokers should perform. Service or support brokers or brokerage agencies become the mediating arm between the person with a disability and the provision of necessary supports. Individuals who perform these functions arrange with others to carry out the plans developed by the person with a disability or family and arrange for all necessary supports. They do not provide these supports. They become "personal agents" for the person with a disability and that person's circle or social support network. Of all the roles a broker may assume there are several that seem to fit well with this function:

- Assisting in defining support needs and life dreams;
- Assisting in providing information and resources;

- Assisting in identifying potential formal and informal service providers and supports;
- Assisting in arranging/contracting for services and/or supports; and
- Assisting in ongoing evaluation and other consultations.

One of the primary skills necessary to perform this function is the ability to build on informal supports that may already be present in a person's life or assist the person to help create these informal supports over time. A primary goal could be understood as assisting the person to become connected or reconnected to their community. Skills in bartering or exchange would also be helpful in this role.

Experience needs to be gained in determining how best to provide these functions. Newly created consumer controlled organizations might be one method. Independent Living Organizations might also prove to be valuable. Existing case management systems could be re-tooled to provide these functions under some circumstances. No matter what method is chosen, it is imperative that everyone recognize the authority of these individuals and that these individual brokers represent the interests of the person with a disability. For all of these reasons, utilizing a fiscal intermediary and incorporating the functions of an independent support broker has many advantages. Even when professional or clinical services are needed and a fee negotiated with a particular individual or organization, it is helpful to have an individual broker or agency broker--one without a conflict of interest--function on behalf of an individual with a disability. What is important to incorporate in any of these arrangements is the shift in real control of these monetary resources directly to individuals with disabilities, their families where appropriate, and social support networks or circles. All of this can be accomplished under current federal statutes and regulations. Exceptions might occur in particular states where regulations, laws or even Medicaid waivers might have to be modified.

Because it is likely that fiscal intermediaries and independent brokerage will be the desired method in most instances, it is important that the integrity of the self-determination process be protected at every stage. It is wise to consider the brokering role as separate from any individual or agency that might provide services. However the restructuring takes place, two important elements should dominate. First, it will often be necessary to put into place independent brokers or personal agents, who, for a fee if necessary, assist in planning and contracting based on an individual plan and budget. Part of this responsibility might be to assist with ongoing quality assurance and advocacy. Second, it is important that new structures only be created when absolutely necessary. Otherwise, a growing percentage of available dollars will be siphoned off for expenses connected with these organizational structures. Converting existing organizations into new roles may be more cost-effective.

Certain training needs will become self-evident. While much attention has been spent on the re-design of personal plans based on consumer preferences, little attention has been paid to the need to train people on the imaginative use of resources, the utilization of ordinary community members and organizations and the creative use of traditional Medicaid monies previously used to purchase pre-arranged programs. In fact, the retraining of support personnel used to the program requirements and narrow focus of Medicaid regulations may be the largest training need that will develop.

What must be kept in mind, no matter how this new system is constructed, is the primary goal of individual and family decision-making (depending on the age of the individual) together with the social goal of maintaining or instituting real connections to the person's community and associational life.

Some examples may illustrate these arrangements. Mary was on a waiting list for services for several years. Mary's family was very involved in providing support for her in their own home. Rather than have Mary and her family wait for years in order to take her into the human services system at a cost that might exceed $50,000, Mary and her family were given an individual budget of $15,000 that they were free to use to hire assistants at appropriate times to support Mary in pursuing her life ambitions. Mary and her family had complete authority to recruit and hire some part-time individuals to provide this assistance. The regional funding authority maintained a relationship with the family and supported their choices for various staff functions by providing all payroll and tax filing requirements. If Mary and her family decided to replace a particular worker, their decision was always honored. Mary and/or her family or friend could provide the brokering function themselves if they felt comfortable. An independent individual or agency could also provide this brokering function. The broker could be paid as a result of a contract with the funding source or from the individual budget allocated to Mary.

John, who lived in a group home for many years, decided that he wanted to live a shared life with another person without a disability. In the past, John might have been "placed" in a family home. Today, with an individual budget, John can rent his own home, condo or apartment and interview friends and interested strangers who might want to share a home and give some support to John in return for free or reduced rent. Depending on John's needs, a fee for extra support might also be paid to this person and/or to another. The house is John's. With enough assistance, John and, hopefully, friends and family, can evaluate the effectiveness of these supports. When changes need to be made, John doesn't have to move. Others move. Again, John may need the assistance of a broker, perhaps an agency to help manage staff, and certainly a fiscal intermediary which will pay John's bills at his behest.

In a typical case managed system a number of choices exist in order to make this possible. Case managers could assume the role of "personal agents" or brokers who not only assist John in setting up his home but also assist in monitoring the quality of what John is purchasing. John could have his individual budget physically reside with a county funding source and, upon John's and his personal agent's recommendation, a system for approving payments could be set up. John might also have a friend or relative who would fulfill some of these brokering or monitoring functions.

The ways and methods to reorganize the present system are many and varied. A lot will depend on the present structures that are in place and an evaluation of how these structures can be modified or replaced with others.

CHANGE IN A MANAGED CARE CULTURE

As the rush to managed care that we have seen in acute health care has become a harbinger for long-term care, self-determination strategies can be offered as a more appropriate alternative to meet the states' needs to control costs. As Ashbaugh and Smith have reminded us, person-centered managed care concepts can incorporate self-determination strategies. Offering these strategies may be a way for states to answer the managed care movement where it has already surfaced and as a way to surpass it where it does not presently loom. If the goal of managed care is to control costs, self-determination may be a way to demonstrate "how more can be done with less." Some examples may be helpful by comparing just three common managed care strategies to self-determination:

- **CAPITATION** replaces typical fee for services by identifying groups of individuals with similar average costs. Payment is then made based on the average cost of all care and supports for the individuals within the group, setting an overall cap on the number of dollars that can be spent. These capitation "costs" are usually derived from estimating that purports to represent what groups with certain levels of disability will cost–sometimes based on standardized assessment tools. Capitation amounts can be good or bad--depending on how they are shaped. They are fraught with danger and confusion for individuals and their families.

From one perspective, capitation will almost certainly keep individual costs arbitrarily high because it is difficult to capture the value of informal supports under managed care conditions that do not allow for maximum freedom (with increased resources during emergencies) and promote informal supports. On the other hand this payment methodology is susceptible to arbitrary budget cutting and profit taking. These forces in combination may mean that individuals will not get the support they need, efficiently and responsively delivered, when capitation exists independent of the principles and values of self-determination.

Self-determination begins with financial planning structured and allotted for assuring that natural supports are the foundation for an individual life plan. Additional formal services can be arranged but only as needed. Self-determination is then in a position to viably cap the individual cost somewhere below (sometimes between 10 and 25 percent below) current service costs. This creates an insurance pool for those who need more time to develop informal supports, provides "risk management" for those who may seek increased support from time to time, as well as assisting individuals who will contract only for those supports they actually need. Over time it has the potential to free some existing resources for those not now receiving any support. Self-determination strategies also match managed care strategies in melding funding sources into one coherent stream.

- UTILIZATION MANAGEMENT is a managed care concept that shifts the decision-making for needed assistance away from the service delivery level to a management level. Frequently, standardized "practice guidelines" are used to establish limits on volume and type of services. Self-determination moves control away from remote middle management and into the most decentralized levels of ourselves, our families, and our local communities. This builds local capacity and self-reliance. It creates an opportunity for investment in lifelong relationships and opportunities.

- RESTRICTING CHOICE OF PROVIDERS is a managed care strategy that limits providers to those who agree to abide by program specific cost limits imposed by the managed care company. This restricts such needed access to special supports. Self-determination actually reverses this strategy by <u>increasing</u> the options available to individuals by allowing persons with disabilities to begin with the purchase of supports from generic community groups and ordinary community members, family and friends, and with provider agencies as necessary.

THE CHALLENGE OF THE FUTURE

Self-determination will involve profound changes in how the present system is organized and financed. It will require provider agencies to re-think their roles, substantial re-training of many in the service system and a fundamental commitment to honoring the aspirations of those with disabilities and families and friends. Quality assurance will gain new meaning in a system based on the principles of self-determination. We may wonder years from now how we thought we could measure quality assurance in a system devoid of freedom.

Given the current climate of fiscal retrenchment the options are few. We can stand still or offer a new vision for the future– a vision that is both fiscally conservative and truly responsive, finally, to those we profess to serve. We need to both work together and learn together in order for the four principles of self-determination to have real meaning in the lives of those with developmental disabilities and their families and friends.

Freedom

Authority

Support

Responsibility

THE IMPORTANCE OF INCOME

THE POVERTY OF HUMAN SERVICES: AN INTRODUCTION
BY THOMAS NERNEY

CHOICE AND CONTROL OF EMPLOYMENT FOR PEOPLE WITH DISABILITIES
BY MICHAEL CALLAHAN, PH.D. AND DAVID MANK, PH.D.

FREEDOM

SUPPORT

AUTHORITY

RESPONSIBILITY

Edited by Thomas Nerney and Donald Shumway
Self-Determination for Persons with Developmental Disabilities

July, 1998

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THE POVERTY OF HUMAN SERVICES:

AN INTRODUCTION

by

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THE POVERTY OF HUMAN SERVICES

INTRODUCTION

Self-determination addresses the stunning lack of freedom experienced by individuals with disabilities and their attendant poverty in the present human services system.

One of the great ironies of our human service approach to supports for people with developmental disabilities is the near absolute impoverishment of individuals *within the most costly system of "care" in the world*—a system that spends twenty-five billion dollars annually, averages almost $90,000 a year for those in institutions, and often exceeds this per person amount in many public and private congregate care facilities. This situation persists in the face of tens of thousands of individuals with disabilities who receive no supports from this human service system.

For persons with developmental disabilities, their lack of disposable income is directly related to their continued isolation from our communities and their overwhelming lack of true friendships and relationships. Their shocking lack of control over the resources spent to support them contributes to their isolation and loneliness amid untold expenditures presumably made in their name. It supplies an added wrinkle to our notion of poverty in this country: wealth, without the means to spend it in ways that meet any personal desires or dreams. Enormous amounts of money are spent annually to bolster a system that individuals with disabilities did not design.

ENFORCED POVERTY

While the self-determination movement cannot solve the problem of poverty in any traditional way, it does address the pernicious effects of that poverty by speaking to some of the most intractable problems in the field of disability: *isolation from the community, lack of real friendships and relationships*, and *lack of disposable income; i.e., income that all Americans use to enhance the quality of their lives.* It places these problems within the service system's enforced poverty of individuals with disabilities. Self-determination requires that we confront the enormous disparities between the dreams of individuals with disabilities and the expenditures made on their behalf.

Self-determination also demands that we address questions of equity like we have never had to before, including the growing number of "have nots" waiting for supports. As more and more individuals and families begin to understand that similarly situated persons with disabilities both within a state and across states are given very unequal amounts of resources, an accounting will have to take place.

As knowledge of current expenditures seeps closer and closer to folks with disabilities--family members and even direct support staff and service or support coordinators--there will emerge a preliminary evaluation of the worth of these expenditures—their cost-effectiveness, if you will. This may startle policy makers in the field of developmental disabilities. As the resources being utilized become clearer, more and more questions will emerge concerning one hundred thousand dollar to ten thousand dollar expenditures for similarly disabled individuals or expenditures between five thousand dollars and twenty thousand dollars so that an individual with a disability can "earn" ten dollars to thirty dollars a week. In resource rich systems, expenditures over one hundred thousand dollars per person are not uncommon.

We have created a situation where we know a lot about facility and program costs but very little about the costs associated with supporting individuals with disabilities based on their desires and wishes. As individuals and families gain experience in self-determination, and as those without these resources begin to understand, this tension will only heighten. It is important that this discussion and any resolution be carried out by those committed to individuals with disabilities. Others may not take the time to insure that better alternatives are created.

CURRENT MYTHOLOGY

The problem of the loneliness of individuals with disabilities is not simply a result of lack of friends, relationships and community memberships. It is, rather, a result of pervasive poverty, human service configurations and congregate settings that isolate individuals from the community, as well as misplaced priorities for spending public dollars. It is also a result of a wider cultural failure that places little value on the gifts that we can all contribute. We wrongly place the blame for this situation on the person's cognitive disability and, sometimes, charge direct support workers with solving it, failing to understand that their role in the system may be as much of a barrier to the wider community as a bridge to it.

POVERTY

Seldom do we see the link between the poverty of people with developmental disabilities and their lack of community and personal relationships. We forget just how much ordinary community members rely on money to cement their ties both to communities and to other individuals. Instead, we have ignored this central truth and rely, instead, on a shallow concept of "informal supports" and "unpaid friends"– noble goals, but, for some unfathomable reason, often out of the reach of folks with cognitive disabilities. This is especially true of those who receive 24-hour supports.

But this kind of human service poverty has a secondary and equally toxic consequence. Others control the sometimes enormous resources that get distributed in typical human service environments. The person with a disability is bereft of basic human freedom in exchange for other-directed human supports/services. This stunning lack of freedom is a high price to pay for having all of one's "needs" met--with the exception of the satisfaction of those needs universal to us all that make life worth living: the contemplation and then the quest for a meaningful life suffused with relationships and membership in one's community.

HUMAN SERVICES VS COMMUNITY

This issue, the deep, personal, poverty of so many individuals with disabilities, gets ignored as a central problem, precisely because we do not recognize the role of money in our own relationships and community connections. As a field and to a person, we commit ourselves to the idea of community and relationships, but never acknowledge the reality that individuals with disabilities, just like everyone else, need cash or disposable income to navigate their communities in successful ways and need cash to carry out the simple rituals and rites associated with friendships and relationships. The entire idea of contribution on the part of people with disabilities gets lost irrevocably because they are so frequently placed in situations where they are perceived as *taking*, not *giving*.

This kind of powerlessness and poverty will do that to you. Reciprocity is the hallmark of both good relationships and meaningful community ties. Money is not the only path to reciprocity, but disposable income may be one of the fundamental social ways that reciprocity can best be expressed and implemented. Simple acts of buying coffee or dinner for a friend, purchasing a present for a relative, or preparing a home-cooked meal for a co-worker are frequently beyond the reach of many individuals with disabilities in this system.

RECIPROCITY

Central to any notion of friendship and community association is this concept of reciprocity. Both friendships and communities are two-way streets. Some individuals overcome the odds in this equation by the simple force of their personalities or their volunteering activities. However, even here the controlling environments of our human service structures place so many restrictions on the movement and choices of individuals, let alone the experiences necessary for reciprocity, that people with disabilities are not only seen as dependent but actually become so in many cases. If we are to be successful in addressing the twin problems of loneliness and poverty, then we are going to have to re-examine the role money plays in the current system and re-think money as an investment in people's lives, not as a source of productive employment for us.

MISPLACED PRIORITIES

Simply put, when everything and everyone in the present system is paid for, there is no more money left for the individual with a disability. Poverty has become a residual entitlement as well as a precondition for receiving support. We have a distinct predilection in human supports/services for solving every other problem with money, more money preferably. When an individual presents a challenge to the present system, we hire someone, also, ironically, at close to poverty wages, to help control the problem. Until we learn to think differently about money and how it is used, we will neither alleviate the loneliness of so many nor adequately address the issue of poverty.

THE DESIGN OF THE HUMAN SERVICE SYSTEM

On a more complex level, there are structural reasons why individuals remain so poor: the income limitation related to program eligibility is just one of these. The paternalistic organization of services is another. We have concentrated on organizing "models" of service instead of allowing and encouraging supports for living. All of the money in the present system gets used by those of us who work in the system.

SELF-DETERMINATION AS A SOLUTION

Control of human service dollars for supports required in all dimensions of one's life, combined with real, remunerative employment and the production of income, provide what may be the two most important answers for both the poverty of individuals served by the present system and the lack of meaningful relationships and community associations.

THE PRINCIPLES

Self-determination rests on four basic principles:

1. **Freedom to develop a personal life plan**
   The work of those committed to persons with disabilities is simply to assist in operationalizing freedom for those who may need assistance in exercising this basic American right.
2. **Authority to control a targeted sum of resources**
   Systems committed to persons with disabilities have to first isolate the dollars available, no matter whether capitation strategies are utilized, and insist that the dollars be under the control of individuals and freely chosen family and friends. This means that the dollars are also free. They can be re-configured, priorities can be changed and the dollars can follow the individual.

3. **Support to obtain personal goals**
   Those caring individuals who are committed to individuals with disabilities have to also be free to provide assistance both within and without existing systems to achieve the type and intensity of supports that an individual may desire.
4. **Responsibility for contributing to one's community and using public dollars wisely**
   Individuals with disabilities and those close to them have the ordinary obligations associated with freedom in America. These are obligations of citizenship and include the obligation to spend public dollars in ways that are life-enhancing and cost-effective. This obligation includes engaging other social, business and religious organizations in ways that help re-define and build community for all of us.

This new way of doing business is vastly different from traditional provider agency contracts and moves the field of developmental disabilities solidly into consumer and/or family control of resources depending on the age of the person. Individuals only pay for supports they actually obtain and only use public dollars to the extent they are needed. Traditional provider agency contracts tend to remain in force over extended periods of time whether or not the individual obtains any or sufficient employment, and whether the individual is satisfied with the outcomes of the funder/provider agency contract. Under this new scenario, people with disabilities and/or families and friends seek only what they need and pay only for what they get.

STRATEGIES FOR CHANGE

Human Service Systems

MEDICAID

Eligible individuals with disabilities generate state and federal dollars based on their personal circumstances and disability. The dollars are generated in their names. This benefit or "entitlement" is originally an individual one. This individual benefit or entitlement is then lost amid the state's contracting and regulatory mechanisms. It becomes a provider or corporate entitlement and the individual must accept what the provider offers. Individuals with disabilities become commodities in this system. We need to revisit the nature of the original entitlement and insure that it remains an individual one, especially in the field of long-term care.

In return for attempting to lower the average cost of many in the present system, and in return for addressing the unequal distribution of resources in the present system, the <u>system</u> obligation, as part of this new agreement, becomes one of promoting responsible freedom and insuring maximum flexibility and control of resources by those who need them. This new "bargain" with public funding authorities becomes a demonstration of how individuals and families can make the system more efficient and equitable in return for freedom and flexibility.

While there are many dimensions to the present human service system, there are several areas that need to be addressed simultaneously. State Medicaid waiver programs frequently need to be changed, not only to concretely support self-determination, but also to make it clear that the present human service system is moving inexorably toward personal control of resources. States like Minnesota and Michigan have set the pace for including these features in already approved waiver amendments or in anticipation of new waivers that will meld current dollars, remove incentives for congregating people with disabilities and give individuals control over their own budgets.

Medicaid eligibility provisions can also be addressed in state waiver plans. However, the combination of Medicaid eligibility standards and SSI and SSDI eligibility criteria have sown the seeds of enforced poverty, and this will require both state and federal action. The Medicaid waiver rejection of room and board costs, rational only under the presumption that individuals can never achieve meaningful or "substantial" income from work, needs to be re-examined as do present formulas that decrease SSI and SSDI payments even as relatively small amounts of personal income increase. Tens of thousands of individuals with developmental disabilities remain unemployed or under-employed at tremendous cost to the present human services system and at tremendous personal cost to the individuals simply because we have failed to develop rational and cost-effective solutions to these barriers.

INDIVIDUAL PLANNING AND BUDGETING

RETHINKING MONEY

Re-thinking money, the role that public dollars play in the present system, offers one way to begin a more powerful analysis of these issues.

Self-determination explicitly requires that individuals with a disability have some targeted sum of dollars that they are free to use in ways that help them obtain the supports that they need. Often with the help of family members, friends and/or selected staff, individuals with disabilities will be able to formulate life goals including where and with whom they would like to live, how they would like to be connected to their communities based on their interests, as well as obtaining remunerative employment and career development.

Two of the most powerful changes that occur at the individual level under self-determination are freedom for those invited to assist someone in planning a life (rather than purchasing a program or slot) and the electricity that individual budgets inject into the planning and budgeting process. Person-centered planning takes on new meaning when individuals know how much they can spend, are free to prioritize budgets and can purchase wherever the dollars will bring the most value.

THE RECOGNITION OF CONFLICT OF INTEREST

The real failure of contemporary person-centered planning is rooted in the unwillingness of those who currently assist people plan to acknowledge clear conflicts of interest. They do not articulate their conflicts or address them in any adequate fashion. This conflict of interest concerns itself mostly with control of the dollars. In the existing system, the majority of those who come to the traditional planning table have imposed on them conflicts of interest over their present employment status or represent agencies with conflicts of interest over their current contracts. Sometimes agency-owned property is involved. Untold billions of dollars in property costs literally mortgage individuals with disabilities to the present system arrangements. The person with a disability remains a commodity and person-centered planning under this regimen leads inexorably to buying back what those at this planning table have been selling.

Within this context, person-centered planning becomes cruel and unusual punishment for the person with a disability. They are assisted to dream, form life goals and then are not free to pursue them in any meaningful way except under the strictures of the present system. It is for this reason that only those invited by the person with a disability should be able to assist in planning and budgeting. Those with current conflicts should be required to eschew them in a new relationship of trust with those who invited them. This is the major reason why independent brokering and fiscal intermediaries are so important to self-determination.

PLANNING PRINCIPLES

In many states personal planning and budgeting are assuming for the first time that every person with a disability can live in their own place and can earn money in productive ways. Just as the human service system must address certain issues, this personal planning and budgeting process enables individuals and those freely chosen to assist them to address (among other things) the following issues: Moving from human service planning and human service "needs" to planning around human needs and human desires. This means that the first priority for planning addresses those needs that are universal. This process explicitly eschews traditional human service "needs" and "responses." Under self-determination, planning moves from supervision and staffing, incompatible with freedom, to support and companionship, the community membership approach. Individual budgets get developed that include domains that all community members understand:

- Moving from 24-hour supervision to a home with support and companionship including resources for transportation.
- Moving from budgeting food, fuel, and clothing as a simple maintenance expense to creating food and clothing budgets that recognize the social role of mealtimes and the expression of personality in selecting wardrobes.
- Moving from low paying work or quasi work situations directly to real jobs and income-producing activities. Individual budgets give persons with disabilities the freedom to contract directly with employers, utilize friends and family, support their own wages, pay co-workers directly and create business opportunities for themselves. When assistance is needed in arranging these activities, fees can be budgeted for these supports.
- Moving from human service arrangements to community relationships. This means that individuals can now budget for the costs of community memberships, the reciprocity attendant on relationships, and the contribution expected of all community members.
- Moving to individual budgets which allow for the possibility of one-time investments. The cost of support is frequently related to the inability of individuals to purchase both mobility and communications technology , create the resources for a down payment on a home, and purchase business-related, income-producing equipment and property.
- Moving to individual budgets that now allow for fees to be included so that any and all of the resources needed can be arranged and managed. This means that provider agencies who share these values can re-tool and become expert at assisting individuals to obtain these supports, help them manage the supports and assist in other ways that would enable the person to live the life desired. They could assist the planning circle, independent broker and others for fees that would be negotiated on the person's behalf. The dollars for support, however, remain under the individual's control and are drawn down on a regular basis according to a negotiated plan.

FROM CASE MANAGEMENT TO INDIVIDUAL REPRESENTATION

Traditional case managers and case management agencies are beginning to convert to independent brokering or to support the creation of independent brokering agencies. These individuals will have the authority to assist individuals and families in planning and arranging the resources needed. Working in conjunction with fiscal intermediaries, these new personal agents will finally represent the desires and dreams of individuals rather than support the limited range of current services and enforce human service regulations.

The self-determination movement has posited the necessity for both independent brokering and fiscal intermediaries. Independent brokering assures that individuals and families can have access to assistance with planning and implementing individual dreams, as well as in monitoring the configuring of resources independently of present service provision. Fiscal intermediaries are, among other things, repositories of the dollars that will be utilized by an individual with a disability or a family. The State of Oregon has created an independent brokerage house where individuals and families can go to obtain just enough assistance with planning and implementing a life with needed supports. Other states like Maryland are moving in the same direction with even bolder proposals that would eventually place all of the system's resources within consumer run, resource and brokering agencies.

STATE AND PROVIDER AGENCIES

Most current human service contracts limit creativity, keep the power away from individuals with disabilities and families, and allow a monopoly to determine just what folks with disabilities "need." States are complicit in this pre-determined assumption of human service "needs." They reinforce and nurture specific funding streams often tied to slots and programs in human service industries and environments. Too often provider agencies believe they have ownership of beds and slots, which they then believe government has an obligation to help them "fill."

Everyone pays a high price for this. The obligation of states ought to rest on a different assumption: the money does not belong to those who operate the present system but to those who are supposed to be served by it. Those responsible for the system at the policy level become guardians or trustees of the money together with individuals with disabilities and families. This means that state, county and local officials will have to move the contracting authority in such a way that individuals and families actually get to control the resources.

This change will require fundamental alteration in the structure of provider agencies. At the very least, provider agencies must compete, and, instead of offering slots and programs, offer support in implementing the individual's life dream. Provider agencies in a number of states are beginning to experiment with a variety of ways that they can change their culture; their congregate, slot-based service system; and their hierarchical structures. Those who value the principles of self-determination will, in exchange for fees, support the implementation of a desired life for a person with a disability without attempting to control the resources necessary to support that life.

A NEW QUALITY ASSURANCE

It is inconceivable that the human service system could pretend for so long that it had designed complex systems of "quality assurance" without guaranteeing basic American freedoms. *Where there is no freedom there is no quality.* Self-determination posits the necessity for basic freedom before we can even begin to determine quality. People with disabilities, families and friends will now be able to set qualitative goals that will determine the nature of quality assurance. The present system measures liability assurance. It focuses on safety and professional responsibility/liability at the expense of individual hopes, dreams and aspirations. The future system can now begin to re-think the nature of "quality" and listen to the voices of those it presumably serves to start this process. In re-defining quality, we must now look at measuring the degree of freedom a person with a disability possesses as well as the plenitude of an individual budget that ameliorates the insidious consequences of personal poverty.

THE IMPORTANCE OF INCOME

Almost 75% of people with disabilities remain unemployed today in an economy that has seen unemployment plummet for all other workers. The situation is so bad that these individuals do not even get counted in the unemployment statistics released by the US Labor Department. Of those who do work, their hours and employment opportunities are significantly constricted by various aspects of present program eligibility guidelines, income limitations, asset limitations and human service configurations. The situation is even more drastic for individuals with developmental disabilities.

The specter of unemployment and underemployment for individuals with disabilities has remained intractable for the last decade in spite of important successes with various approaches to supported employment. The evidence that virtually all individuals with disabilities could work if support and environmental changes were provided has not led to the increases in employment that should have been achieved.

SELF-DETERMINATION CAN OFFER A REVOLUTION IN EMPLOYMENT

Once personal career goals are established, the individual, with control over an individual budget and with independent assistance, is then free to contract directly with new provider agencies who share these values, with an employer for support which can vary from wage supplementation for training periods to co-worker support and even transportation. The individual may also desire to contract with an experienced job developer or someone to assist in identifying potential jobs and in negotiating a fruitful arrangement with an employer. Fees can be paid for these supports/services out of the individual budget.

These possibilities should bring us to re-examine the assumptions we have made about the systemic problems and, perhaps, force us to shine a brighter light on structural problems that we have not previously addressed. Are we prepared to finally remove the structural barriers that have created these enormous disincentives to work? Are we prepared to re-examine what passes for day and vocational programs?

Across the range of disability conditions, Medicaid medical insurance has posed a stark dilemma for many individuals who want to work. Because of income limitations set into the eligibility requirements for Medicaid, many individuals have been caught in a Catch-22 situation: if they earn even barely enough to survive, they remain in danger of losing their medical insurance. This problem is exacerbated for those individuals who also rely on Medicaid to supply their resources for long-term support. The penalties for working have been built into a complex multi-jurisdictional set of eligibility criteria. For persons with developmental disabilities supported in living arrangements, the loss of SSI income, even when Medicaid is not lost, means that almost 100% of their earnings have to go toward room and board—providing a further rationale for not earning any substantial wages.

The willingness of the present Medicaid program to pay for activities that do not result in meaningful income is a source of rising concern. A rational approach to removing the barriers to income production could go a long way in helping states achieve a better balance in their Medicaid program and reap a better investment from their state tax dollars.

Just as individual budgets can become better understood as vehicles for a tremendous increase in employment for individuals with disabilities, we must look to the current assumptions that under-gird the present attempt at obtaining meaningful employment for persons with disabilities. Foremost among these previous assumptions is the goal of "jobs, work or employment" within the present system of disincentives. What if we were to change the goal? How much further could self-determination revolutionize the world of work for all individuals with disabilities no matter how significant those disabilities?

A NEW GOAL: THE PRODUCTION OF INCOME

If we were to substitute the goal of income production for jobs and work we could make real earnings possible for any individual with a disability. While there is nothing wrong with fast food restaurants and cleaning jobs, what if the person with a disability were the owner or part owner of a business (e.g., hot dog stand or cleaning business) either alone or in partnership with community members? If public dollars are now to be thought of as an investment in the lives of people with disabilities, then we must take the next step and think seriously of some of these dollars as capital or investments in the person's small business community. Even those without the ability to perform physical tasks associated with a certain kind of work could employ others. Some individuals could simply be the instruments of passive income from community business ventures where they gain socially as well as monetarily. Others might buy or rent equipment necessary for the performance of certain jobs. Still others might buy small franchises either alone or in conjunction with community members.

All of these activities could change the fundamental relationship that individuals with disabilities now have with their communities. The world of small business has great potential for assisting individuals with disabilities to become integral parts of their communities. The concept of supported entrepreneurial employment, via the development of individual budgets, could revolutionize the world of work provided that we make available the technical resources as well as the limited capital they would need.

We would have to develop this technical capacity utilizing community members with skills in small business development. We would have to learn to embrace local financial institutions both as fiscal intermediaries and as sources of capital. We would have to gradually shift the focus, legally especially, away from the welfare culture associated with Medicaid and income and asset limitations—at least for as long as it takes individuals to become successful. We would have to learn how not to put all of a person's money at risk. These are the new challenges of a new era when folks with disabilities and families finally have the opportunity to see public dollars spent more efficiently and as investments in the life of a person with a disability.

The development of individual budgets and the freedom that self-determination offers finally make possible the assumption of valued community roles and responsibility for citizenship. The income earned from regular jobs, those subsidized by individual budgets and those that result from entrepreneurial activities, return to the person with a disability with no strings attached. Of all sources of income in a person's budget, income from work, no matter how it is obtained, is free to address those dreams and aspirations in ways that other sources of public revenue never could. They allow for the budgeting of those items not usually reimbursed by traditional state and federal programs like Medicaid.

INTEGRITY

The notion of integrity is essential to self-determination. Understanding conflicts of interest and insuring that freedom becomes a reality for all individuals with disabilities requires that we address the issue of integrity with some passion. Writing about values in America, Stephen L. Carter (*Integrity*, 1996) articulates three components of integrity:

1. Discernment of what is right and what is wrong—serious moral reflection;
2. Acting, even at personal cost, on what one has discerned; and

3. Saying openly that one is acting on one's understanding.

Carter applies these principles to both political and personal life. They seem to have especially important meaning for self-determination. We have allowed the present human service system to force individuals with disabilities to trade their basic American freedoms for other-directed services and supports. We have minimized the conflicts of interest in the present system. We have kept individuals with disabilities poor and powerless. Only personal and group acts of integrity will lead us to reverse this course, examine all of our present assumptions and do the hard work associated with this movement.

Carter, S. (1996). Integrity. Harper Collins Basic Books.

Choice and Control of Employment for People with Disabilities
A White Paper

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CHOICE AND CONTROL OF EMPLOYMENT FOR PEOPLE WITH DISABILITIES

INTRODUCTION

Get a job. Get a career. Get a life. Adults at every rung of the socio-economic ladder in our society invest a working lifetime in their choice of jobs that lead to careers. Past generations imagined a series of job types across decades of employment -- typically all with the same employer. The current and emerging economy, with the constant restructuring of market forces and businesses, requires a more flexible employee who must expect to change both jobs and employers with some frequency. Labor statistics now show that the typical American worker will change careers three to five times over a lifetime. As employment has become less secure, employees are learning that it is necessary to take control of their careers and to negotiate, to personalize and to carve out working conditions which meet the needs and preferences of both the employer and the individual.

This changing pattern of employment means that people in the work force must make choices about jobs and about how those jobs become careers. At the heart of getting a job and changing jobs are questions about choice. What employment choices can be made? How are possibilities pursued and understood? Who decides? How are such decisions made? Can employer requirements and expectations be negotiated?

People with disabilities and their supporters are asking these same questions about employment. They are asking these questions not only in the context of a new economic environment but, more importantly, in the context of a social service system that has typically limited choices in employment or imposed a structure of employment services on people with disabilities. That structure has, by and large, controlled the types of jobs and the types of work environments available for people with significant disabilities. The last fifteen years has brought a much broader range of employment possibilities for people with disabilities. The restricted opportunities of sheltered workshops or activity programs have given way to the broader possibilities of real choice in individualized jobs in the community.

However, it is also clear that people with disabilities have not, by and large, had free choice of employment and employment services, nor have they had control of the processes or the resources invested in their employment. While on the surface choice may seem to be a relatively simple matter, in reality it is complex and confusing. Are people with disabilities encouraged to make choices in jobs? Is information about possibilities and opportunities available and understood? What resources are available to support someone's employment and will the available providers be willing to work for people with disabilities? Who controls the resources? Is choice in employment a free choice of many options, including those identified by the customer, or is it a forced choice among limited options? Who decides what is acceptable and meaningful and what is not? Who holds the trump cards and has the final word?

The answers to these questions challenge the traditional basis of employment services for persons with disabilities. In order to answer them in a manner most likely to favor the individual, it is necessary to embrace the value of person control and choice as one of the most defining aspects of employment. Choice in employment is as complex as it is important.

- True choice in employment depends on having preferences, information, options and control. It also requires willing supporters or providers to accept the challenge of meeting someone's choices.
- Having an employment preference depends on having considered at least several possibilities in order to develop a preference for one kind of work over another.
- Experiencing possibilities for various kinds of work depends on either knowing one's preference, having opportunity to experience different options or having the information necessary to consider a likely preference. It is also possible for others to look closely at a person's life for indicators of possible work preferences.
- The opportunity to experience possibilities depends upon a context in which exploration is valued and encouraged.
- Informed choice results from a complex interaction of information, advice, options and supports. Although these factors can be easily perverted to favor the system or other stakeholders other than the person of concern, they also can be utilized to assure that choices made by the customer reflect the individual's true preference.
- After the experiences, the options, the advice and the information have been considered by the person and a choice is made, the final litmus test for success

> depends on the willingness and capacity of those who are called on to provide services, representation and support for employment. Choice is a hollow promise if the necessary supports for employment are not available.

For people with more significant disabilities, the possibility of choice in jobs and support services expanded with the emergence of supported employment. Because supported employment means jobs in the community, the range and variety of jobs available for people with significant disabilities expanded. *However, people with disabilities and advocates clearly point out that the options made available, and control of the resources for the services, have continued to rest in the hands of professionals and our bureaucracies and defined by arbitrary assumptions about the labor market.*

Questions about choice, control of resources and self-determination are now being asked by people with disabilities about where they live and with whom they live, about family support and access to neighborhood schools. Questions are now raised about informed choice in the decision-making process and who controls the process. Questions are now posed about the available financial resources for community services and who controls and makes the decisions about how those resources are spent.

Choice and control in many aspects and decisions about employment are also now clearly a part of the Vocational Rehabilitation Act and the Americans with Disabilities Act. Yet real choices in daily life and in employment have been more rhetoric than reality. However, the U.S. Congress was sufficiently concerned about the issue to direct the Rehabilitation Services Administration to fund pilot projects to demonstrate real choice in employment parallel to the existing Vocational Rehabilitation system, as a part of the 1992 re-authorization of the Rehabilitation Act. Seven projects were funded for a five-year effort to examine the feasibility of offering choice and personal budgets to persons with disabilities traditionally served by Vocational Rehabilitation, including persons with significant disabilities. Three of the projects were within state rehabilitation agencies and the remaining four were managed by private, non-profit organizations.

Conventional wisdom about employment services has assumed it was best to fund programs for services that are then offered to consumers in the role of service recipients. Selection of the options to offer, the process for making decisions and the control of resources has rested with the system, not the person to be employed. The only choice available was to accept the program or to not accept it. Real choice means that the options, the process of decision-making and the control of the resources move from the system's control to the person's control.

This shift in control has profound implications on employment services for people with disabilities. Those implications affect the heart of the relationship between support personnel and people with disabilities on a day-to-day basis, the configuration of services in the community and the broader system of funding and regulating government programs.

FEATURES OR INDICATORS OF INDIVIDUALIZED CHOICE IN EMPLOYMENT SERVICES

Any discussion of choice in employment must recognize that this is a concept which needs to be perceived from two different, but critically important, perspectives: factors relating to the individual's journey towards employment and factors relating to the system's implementation of a choice effort. There are a number of indicators which relate to the individual perspective of choice.

1. Acceptance of the individual as the starting point and driving force in all services and supports

Traditionally, employment for persons with disabilities has been more about the arbitrary services available from a provider or the perceived needs of the labor market than the needs, conditions, preferences and contributions of the applicant. A commitment to choice requires that funders and providers alike embrace the commitment to choice. The individual should be the focal point of the planning, job matching, job development and task restructuring activities which are used in the process of employment. Indeed, more than a focal point, the applicant must be the guiding force for all the decisions and strategies which affect the job. Indications of this commitment to choice involve:

- informing all applicants of the shift,
- starting all planning and interactions with a "blank slate" agenda that is free from system and program assumptions,
- implementing an information-gathering process which develops an optimistic and descriptive picture of the person,
- developing a personalized employment plan which describes the applicant's conditions, preferences, and potential contributions, as well as a prospective list of potential employers for job development,
- representing the person in job development in a manner which connects the planning process to employers' needs through the use of job restructuring techniques, and

- providing naturally-referenced job analysis and job site support strategies which allow the applicant to successfully meet the demands of the work place.

2. Control of Money

A sub-set of choice, as well as an indicator that it is available, occurs when the individual controls the money which has been set aside for employment services. While it is possible to offer significant choice to customers without placing them in control of their resources, whenever someone does have that control, they almost certainly have choice. Placing the control of resources in the hands of the ultimate consumer creates a number of challenges to individuals with disabilities. Often, this represents the first time they actually become monied customers, buying employment supports, rather than "consumers" in name only as service recipients. This status places the applicant in the same position as all of us in society who experience difficulty in dealing with the interaction between a seller and a buyer. We know this to be among the most frustrating and confusing of life's challenges.

3. Consumer Empowerment

Empowerment is one of the trickier words in human service jargon. On its face, many providers, advocates and bureaucrats embrace empowerment as an ideal outcome and indicator of quality services. However, when persons with disabilities are truly empowered, professionals seem to begin to lose sight of the higher aspects of this value and begin to cautiously urge system-friendly values such as fiscal responsibility, safety, quality service provision and the need to assure a source of support for those who will need it. Indeed, empowerment and these system values are not incompatible. In fact, consumers are best empowered when all of these factors are considered. The real issue in empowerment, choice, self-determination -- whatever the name we give to prerogative and control -- is determining who owns the solution to the problem.

Traditionally, human issues have been solved through the ownership and direction of the system designed to respond to those issues. People with disabilities are somewhat like residents of public housing in a local community. The people have the need for housing, but the system owns the structures, the land, and the prerogative. Empowerment is like the homeowners in a community. Sure, the bank may own the mortgage, but the homeowners own the structure, the land, and almost all the decisions concerning what goes on about the house.

Empowerment requires systems and professionals to embrace a fundamental power shift rather than simply adopting an attractive new value. Empowered consumers can say "no," "when," "how," "where," and "yes" when they choose. For this reason, a new relationship between providers and consumers must be defined, new roles must be identified and new rules must be accepted. And since power is not easily shared or relinquished, providers must carefully consider the depth of responsibility that comes with embracing empowerment for persons with disabilities. It is critical that empowerment not become yet another hollow promise diluted by providers in their effort to maintain control and prerogative.

4. Role of Advice

The ownership of the process, the essence of choice, empowerment, and self-determination, rely on people with disabilities making informed decisions about their goals and service needs. Good advice is an individualized blend of **information, opinion** and workable **options** offered to a customer in a manner which can be understood and utilized. Information and advice have been fundamental aspects of the provider/consumer relationship. The provider has been responsible for virtually all aspects of employment for persons with disabilities, including the provision of advice. Provider's services have included gathering facts and offering opinions on the customer's efforts to become employed as well as defining the questions, issues and barriers which need to be addressed. The provision of provider-centered advice and information has been an area of concern voiced by many persons with disabilities. It is becoming clear that we must find unique ways to offer advice that shift the focus away from provider ownership of advice and information to a broader, more natural and customer-centered basis. This can be accomplished only through the acceptance of outside sources of advice.

It is important to distinguish between two aspects of informed choice -- information and opinion. *Information* relates to the body of knowledge or facts associated with an issue or a decision. It would seem that by this definition, information would be free of opinion or personal bias. However, since most providers work for systems with rules and traditional responses to certain situations, it is often difficult to know whether an interaction concerning informed choice is factual or biased in some way.

Opinion refers to the feelings that someone has concerning a subject or problem. Since the opinion aspect of advice is almost inherently biased, good advice should contain alternate avenues for customer consideration, as well as the opinion of those offering the opinion. Indeed, good advice is an individualized blend of **information, opinion** and workable **options** offered to a customer in a manner which can be understood and utilized.

SYSTEM INNOVATIONS IN EMPLOYMENT SERVICES

Innovations in the process of planning and delivering individual employment services and systemic level innovations are now operating that hold bold promise for putting choice and control in the hands of people with disabilities.

At the heart of choice in employment for people with disabilities is change in the individual level planning and processes where personal decisions are made. Only when preferences are developed and choices are made at the personal level will meaningful employment and careers result in long-term control and satisfaction by people with disabilities. Personal employment decisions for people with disabilities must occur, however, in the context of the service system that has the resources for developing and supporting employment for individuals with disabilities. While changes are needed, and are emerging in the individual processes of employment planning and supports, change is also needed in the system that funds and regulates employment services. Systemic change that fosters greater choice is also beginning to emerge in some parts of the country.

STATE DEVELOPMENTAL DISABILITY AGENCY EFFORTS

In a small number of states, people with disabilities are becoming free to choose the provider of their employment services. For example, in some communities in Oregon, persons with developmental disabilities who are new to the service system and in need of supported employment are provided with a list of community providers of supported employment services. With assistance from the case management system, these individuals and their supporters are encouraged to interview a number of these providers of supported employment in order to decide which they choose for assistance to secure and maintain a job in the community. Once the person has chosen the program, then the funding system provides the resources for that person's employment supports directly to the chosen provider of service.

This approach provides a choice in one way -- a choice of which agency provides supported employment services. However, in this circumstance, an individual must choose from a limited set of providers of service that already exists. In communities where there is but one provider of supported employment services, such a choice has no meaning. In addition, merely providing a choice among vendors does not guarantee that employment planning is conducted with an individual that honors the person's preferences and choices.

In other communities in Oregon and in Washington, not only are people new to the system encouraged to choose the provider of their services, but all of those with developmental disabilities in employment services are allowed and encouraged to choose their provider of service and to leave one provider and be served by another if they wish. This means that funding is assigned to individuals and that the money moves from one provider to another based on the individual's decision about which program they prefer. In order for this to work, funds must be assigned to individuals, rather than having monies block-funded to service providers. Only with resources tied to individuals and with flexibility in seeking non-traditional sources of service can there be a choice of providers. This requires more of a free market approach to services. This commitment to choice at the systemic level, however, must be complimented with the individual level choices discussed earlier in this paper.

Pilot projects in Oregon and Washington are experimenting with another design of individual choice in employment services. For example, for the past several years, the Oregon Developmental Disabilities system has funded "Family Management Grants" for a number of youth leaving high school. In this project, individuals and their families are assigned a given amount of funds (e.g., $5,000). These funds must be spent for employment support. However, these funds may be spent freely on any configuration of employment supports. Individuals might select an existing supported employment service provider. However, they are free to purchase job development or employment supports from anyone they choose. They may choose a neighbor, a friend, a temporary employment agency or a generic business. The only constraint is that the funds may not be spent on someone who lives in the same house as the individual. The individual process for decision-making is supported by a well-designed, person-centered planning process which involves the person and the family, as appropriate. This design invests in the individual level (person-centered planning), gives direct control of the resources to the person, and allows and encourages the use of non-traditional providers of service. There is no expectation that a person has to choose an existing provider of supported employment services. This design provides a greater degree of freedom in choosing providers of supports than a design that requires that the choice be made from only among existing providers of service.

THE CHOICE DEMONSTRATION PROJECTS

The examples above represent a small selection of the efforts to increase choice through state developmental disability agency funds. Since 1993, the Rehabilitation Services Administration has funded seven demonstration projects as a test of the feasibility of increasing choice and as a comparison to the current rehabilitation system. At the system level, the state vocational rehabilitation agencies in Vermont, Washington and Arkansas were selected for the demonstration. As a result of the first four years of the pilot effort, the state agencies in both Vermont and Washington have modified many of their policies, procedures and staff training approaches to reflect the acceptance and importance of consumer choice for customers served through local rehabilitation offices.

The demonstration projects in these two states explored a new role for the traditional rehabilitation counselor. Since counselors have moved away from direct job development and employment assistance over the years, the counselor role has evolved to that of a broker and gatekeeper. However, changes in the 1992 re-authorization of the Rehabilitation Act have lessened the gatekeeping powers once held by the counselor. As a result of statutory and regulatory changes regarding presumption feasibility and expedited eligibility, a counselor's role has largely become that of an account manager and broker. The choice demonstration projects in Vermont and Washington have maintained the best of the information and advice components of the counselor relationship, but they shifted the control and choice to the customer. In this way, the rehabilitation counselor is ideally positioned to assist consumers with management of the resources needed for employment, information concerning the possibilities and limitations of the system, referrals to potential service providers, assistance in dealing with conflicts with providers and other innovative supports which are necessary to assure success under the overall value of consumer choice.

The United Cerebral Palsy Associations' (UCPA) Choice Access project differs from the Vermont and Washington vocational rehabilitation agency efforts in that it is managed by a community service organization. The scope of the UCPA project is targeted more at the issues of assuring successful choices by individuals with disabilities than by a system. However, during the second year of the project, Michigan Rehabilitation Services (MRS), the state rehabilitation agency, adopted the procedures used in the UCPA approach for use in a statewide pilot. The UCPA design provides for individualized budgets controlled by the consumer, independent employment advisors who are hired by the customer, flexibility in the choice of providers and an outcome-based payment strategy which offers boilerplate contracts and other financial forms for use by the participants.

ISSUES IN IMPLEMENTING CHOICE AT THE SYSTEM LEVEL:

PROVIDER ISSUES

The Choice Demonstration Authority included in the Rehabilitation Act of 1992 proceeds from an assumption that if persons with disabilities could control the money available for the purchase of services and equipment, that the process of becoming employed would be more efficient, more satisfying and possibly less expensive. At this point, it is probably safe to say that consumers find the control of money more satisfying. It is also possible that such an approach may be less expensive, especially when the high administrative costs of traditional services are considered. However, there are major provider hurdles to be cleared if the approach is to be considered efficient, especially for persons with more significant disabilities.

The problem is provider contracts. Persons with significant disabilities are often not able to achieve employment simply through the purchase of business products, equipment, assistive devices or other similar transactions. They typically need a variety of services to assist them with planning, representation, analysis, job site support and numerous job-related activities such as transportation and personal assistance. The difference between purchasing a product and negotiating for a service is significant. It is somewhat like the difference between buying a vacuum cleaner and paying to have one's house cleaned.

PROVIDER RELUCTANCE

Providers of services for persons with disabilities have traditionally maintained a service relationship with funding sources at the local, state or federal level. Under this approach, providers basically please the funders and provide the service to persons with disabilities. *This disconnected relationship has been the focal point of advocacy by persons with disabilities and their advocates to remove providers from their position in the middle. In this way, the funding relationship would exist between the service recipient and the provider since the funding source would flow funds directly to the person with a disability.*

Given a choice between pleasing a general funding source or a specific person -- typically with significant disabilities and strong preferences -- providers naturally tend to gravitate toward the more traditional and comfortable relationships. This has significant implications in a demonstration which places control of the money in the hands of service recipients. Traditional providers have demonstrated that they are not excited about the prospect of becoming a part of a market economy within the human services field.

The recognition of this issue presents a challenge to state vocational rehabilitation agencies, developmental disabilities agencies or independent entities which may wish to implement a voucher demonstration within their state. It cannot be assumed that if persons with disabilities have money to spend, providers will come.

The following strategies are suggested to increase the willingness of providers to participate in a voucher demonstration:

- Link the receiving of traditional contract dollars to the willingness of providers to accept a reasonable number of persons with vouchers,
- Clarify to providers that personal budgets likely represent the direction of future funding and that the state funding source embraces the concept,
- Provide ample opportunities for providers to receive training on the demonstration's processes and offer them opportunities for input into the design,
- Encourage individuals and smaller providers to step up and fill the service needs of persons with vouchers -- in other words, create competition,
- Make sure the suggested rates are reasonable and that payment processes and reimbursement times are as efficient as possible,
- Provide consumer training to persons with disabilities in the demonstration so that they can become informed customers, and
- Welcome generic providers such as employment agencies, community job resources and others into the local provider pool.

TRAINING NEEDS

In the shift towards a more market-like approach to meeting human service needs, the capacity of providers is a critical concern. In an area where providers have traditionally struggled to provide quality outcomes -- employment for persons with significant disabilities -- shifting the control of money, alone, will not be sufficient for success. It is somewhat like having a mortgage approved for the construction of one's dream home and not being able to find a contractor willing or able to build it. The solution to this issue rests in the availability of training and technical assistance for providers.

A state agency or other entity which wishes to implement a personal budget project for employment must build in the provision of training and ongoing technical assistance to traditional agencies; to new, independent persons who may decide to become providers; and to generic providers who have not had experience offering support to persons with disabilities.

RECRUITMENT AND DEVELOPMENT

Perhaps the best way to insure that persons with disabilities have access to willing providers is to increase the number of providers available for selection. This requires a different approach to recruitment and development of providers than is called for under a traditional funding relationship. Traditionally, funding sources have carefully, even reluctantly, sought out new providers. This occurred due to the expectation on the part of the providers that continued funding would be made available for support of a group of targeted individuals. Under a voucher system, state agencies can encourage provider development without incurring the responsibility for continued funding. Providers will survive or fail based on their ability to attract and please customers who need employment supports.

It is of critical importance that state agencies realize that providers will not embrace a person-controlled budget strategy easily. Traditional providers will likely need strong and regular encouragement to participate and generic and independent providers will need to feel welcome and included in meetings and trainings.

DISTINCTIONS AMONG PROVIDERS

While there are no officially recognized categories of providers, the following headings offer a useful distinction in the types of providers encountered in a voucher project:

1. **Traditional Agency** -- This type of provider is an organization or company which has a current funding relationship with the state vocational rehabilitation agency, developmental disabilities agency, Medicaid agency or other similar funding source for persons with disabilities.
2. **Independent Agency** -- This is an organization or company which has emerged to respond specifically to the market created by the voucher project. Independent agencies often perform similar services such as medical rehabilitation or develop from an individual provider growing into an agency or company.
3. **Individual Provider** -- This is an individual, often a former employee of a traditional agency, who offers employment services directly to individuals with disabilities as a sole proprietor.
4. **Vendor** -- This is a company, agency or individual who sells products or indirect employment-related services to project participants.
5. **Generic Provider** -- This is a company, individual or agency which traditionally provides employment services in the community, but not to persons with disabilities.

An effective demonstration or system on vouchering needs all these types of providers in order to meet the needs of a diverse group of persons with significant disabilities.

Gatekeeper Issues

Public rehabilitation agencies are currently struggling with how to provide vocational rehabilitation services in a manner that promotes and requires participant self-determination and control of both the decision-making process and the use of service dollars. At the root of the struggle are the frequently held assumptions or a facsimile of the following: responsible stewardship of public funds demands that funds are controlled by the public agency. If participants are going to receive quality services, then those services need to be directed and controlled by individual(s) with professional expertise. The recipients of services require scrutiny prior to being trusted by professionals. This is manifested by how few states allow self-reporting to be the sole source required for eligibility determination. These assumptions create a dichotomy for many public rehabilitation agencies. When current policies and procedures reflect the above underlying assumptions, then implementing a service that facilitates participant self-determination and control becomes, at best, difficult and frequently impossible. Choice, self-determination and participant control require a different set of assumptions, policies and procedures.

THE ROLE OF THE STATE AGENCY'S POLICY AND PRACTICES

The challenge facing public rehabilitation is to examine what gatekeeper issues need to be kept, while removing the ones that impede participant choice. Certainly there is a need for polices and procedures that enhance and insure a quality service for participants, that reflect responsible use of public dollars and facilitate participants having self-determination and control in their rehabilitation services. The trick becomes how to establish the correct balance, a balance which clearly defines the parameters that the agency and participants must function within, but allows the participant to direct the process. The common fault is to err on the side of requiring extensive accountability and proof prior to allowing the participant any real control. *A choice policy or self-determination policy cannot just be overlaid or added to the current polices. Agencies need to rigorously examine their policies and change them accordingly.*

ACCOUNTABILITY

A critical component of removing counselor control and replacing it with participant choice and control is believing that the participant will use it effectively. In order for an agency to place control and choice with the participant, it must insure that it has the structure to provide the participant with information, because without providing the participant with solid information choices will not be effective. The questions to consider around information are: what information is given to participants, how is that information conveyed, how large is the circle of people that provide the information, who owns the information, is information written about the participant or for the participant, what role do they have in providing input on the information.

The gatekeeper issue which raises the largest concern centers squarely on who controls the dollars. Public agencies need to examine the assumptions they hold around participants controlling their dollars. If control of vocational dollars is not given to participants then the promises of choice and self-determination are hollow.

RECOMMENDED FEATURES OF SYSTEMS WHICH SUPPORT INCREASED CHOICE

These examples provide insight into important features of a system that encourages support in order to give meaning to the individual level choices for individuals. Funding agencies and states are in a position to re-create structures that support the provision of meaningful choice in employment. Revising the processes for individualized employment planning is necessary but not sufficient. Revising the system that controls regulations and funding must also occur. The following are features of a system that embraces the value of choice in employment.

Assignment Of Funds To People Rather Than Programs

Conventional funding strategies have provided money for programs to operate certain kinds of services. Programs then open their doors to individuals offering either the services they think people with disabilities need or the services the funding source requires. Typically, the funding is controlled by the provider of service by contract with the funding agency. If a person with a disability leaves the program, there are no changes in the program's level of funding because the money is assigned to the program--not to the person.

To assure real choice, this practice must change and money should be assigned to individuals. If money is assigned to people, then the money can follow the person to the service provider of their choice. This also implies a "free market" approach in employment services wherein the customers -- people with disabilities -- are free to select those providers they wish based on their preferences and confidence in whom they choose.

Individualized Funding Rates

The "one rate fits all" approach to employment services may be convenient for funding structures and provide the surface appearance of fairness; however, everyone associated with employment services knows that "being treated equally does not mean treating everyone the same." The cost of employment planning and support varies greatly with the individual and the job match. As such, the rate of funding should be individualized for each person. Naturally, it will be important that some reasonable range be established. Also, funding agencies must be able to anticipate, compute, and afford some average cost of services over time. However, even when long-term funds have been attached to individuals, the tendency is to assign the same rate for each person. The concept of personal choice, as well as supported employment overall, will benefit from individualized rates in a critically important way. When set rates of funding follow individuals -- whether with a personal budget or controlled by the system, the mathematical concept of average disappears. A fixed or set rate for services will almost certainly be based on some existing average costs of traditional block funding. Those rates include the entire range of costs, above and below the average, experienced by service providers in offering employment to persons with disabilities. However, when the average amount becomes the budget amount for a person, the figure becomes a capped amount. The way to avoid this potential for unfairness, as well as to save money from those who will require less funding than the average amount, is for systems to individualize the budgeted amount of funds to be received by each person with a disability.

Flexible Definition Of Service Providers

In addition to promoting selection of service providers, the system can foster choice and creativity by accepting a more flexible definition of service providers. Conventional wisdom, as well as many state and federal regulations, have supported the "qualification" of providers. While this practice ostensibly is designed to assure that quality services are offered to customers, it actually limits the number and variety of sources available for the provision of employment services. Additionally, the practice of qualifying providers is viewed by many advocates and persons with disabilities more as a way to assure the funding needs of a select group of providers rather than a means of assuring quality in employment services. In a free market where individuals choose providers, services can be selected based on individual preferences, satisfaction and outcomes. Credentials and certification of providers can be a quality factor for consideration by customers rather than a pre-condition for inclusion in the array of possible providers. With a looser definition of service provider qualifications, individuals and their supporters can develop or recruit a variety of non-traditional individuals or organizations for employment supports. For example, a person with a disability might choose a neighbor who works in a certain industry to help them get a job because of the contacts that person has within that industry. Another person might select a former staff person from a residential program because of their long-standing relationship. Another person might select a temporary employment agency for assistance because someone they know works there. Others might select from more traditional service providers. With a more flexible definition of provider of service, choice can be much more creative and much more individualized. This is particularly important for persons with disabilities who live in small towns or rural areas which may have only one traditional provider (or none at all) to experience a true choice in providers.

Investment In The Process Of Helping People To Understand Options And To Make Decisions

The social service system also has a responsibility to make an investment in, and commitment to, the individualized processes that are necessary to support people with disabilities, including persons with significant disabilities, to understand options and make decisions. This implies a role in the system for a position which might be referred to as a "choice planner." This person would assist individuals to consider possibilities and to develop or select employment support providers. This role should be independent of existing service providers to avoid conflicts of interest. The social system has a responsibility to recruit, train and support people who will fill this role. Without this kind of role in the system, the free market cannot be totally successful in offering meaningful choice that results in employment that is meaningful and satisfying to the individual with a disability.

Support For Self-Employment And Entrepreneurial Activities

Choice provides the unique opportunity for persons with significant disabilities to join that most essentially American club -- self-employed entrepreneurs. When decisions concerning service dollars are controlled by systems and programs, the chance to start a business of one's own is difficult and unlikely. Agencies funded by state developmental disabilities monies rarely support individuals to become self-employed and state vocational rehabilitation agencies have placed so many controls on this option that entrepreneurship is often the least utilized approach to employment within various states. However, when we consider that between 11% - 13% of all Americans are self-employed, it should not surprise us that many persons with disabilities will opt for this type of employment when they have control of their resources.

To be fair, there have been understandable concerns regarding the promotion of self-employment by systems and agencies. There is a fear, based on the assumption that many small businesses will fail in their initial years of existence, that persons with disabilities who try the entrepreneurial route will be left unemployed and possibly in debt within a short time. Additionally, there have been concerns about the lack of interaction with other, non-disabled persons if home-based businesses are selected. It is feared that people who are already isolated and alone will become even more so as a result of their employment choices. There are further concerns about the ability of traditional human services to effectively support persons who need access to successful business strategies and practices, as business is not an area in which human service agencies have done well. State funding agencies have been concerned that paying for the cost of developing small businesses will be more expensive than payments to providers for employee-based employment. Finally, there is a concern that persons with more significant disabilities, particularly persons with intellectual disabilities, will not have the skills necessary to be successful in business.

When the value of choice and objective reality is considered in relation to these concerns, however, a shift towards an acceptance of self-employment by those responsible for policy and funding is warranted. There are several studies which carefully examined the assertion that a majority percentage of entrepreneurial businesses fail in the first year or two of business activity (Aley, 1993; Duncan, 1994). These studies found that when factors such as voluntary closure, retirement, changes in ownership and sales of businesses were factored out, that entrepreneurial efforts failed at the rate of 18%-20% over a period of eight years (Arnold & Seekins, 1994). This is obviously far better than the retention/failure rates for regular competitive employment.

The issue of isolation is more complex. It is true that some forms of self-employment such as home-based businesses might restrict interactions with persons who do not have disabilities, as required by supported employment. However, this is an issue of competing values. Which is more important--self-determination/choice or integration? While many would assert that both values are critically important, it is clear that some persons with disabilities may choose a more isolated form of self-employment over an integrated job with an employer. In this case, it seems most respectful to support the choice of the person with a disability.

While it is probably true that human service agencies currently have limited expertise to share with persons seeking self-employment, it is not necessary to limit support to these traditional sources. There are varied, generic resources in almost every community which can provide the information and support necessary for persons with disabilities to make informed and effective choices about their business plans. Choice and self-determination allow people to look outside the traditional supports funded by systems and take advantage of naturally existing community resources.

The anticipated high costs for self-employment are a largely unfounded fear. The experience of the five-year, RSA-funded choice project demonstrations is that the costs for self-employment are only about 12% - 20% higher than the costs of regular employment. When the opportunity to build capital and other assets is factored into the equation, entrepreneurial businesses are justified.

Perhaps the thorniest issue of self-employment involves the impact of intellectual disability on decisions, success and cost. There is a possibility that decisions about persons with developmental disabilities owning their own businesses might be influenced more by supporters, family members and providers than by the persons themselves. A commitment to effective person-centered planning techniques can help assure that the preferences of persons with the most significant disabilities direct the pursuit of self-employment. The success of new businesses will probably depend upon supports offered to the individual, just as in regular employment. However, it is possible that an employee, supplier or business customer, rather than a job coach, might be able to offer some of the supports needed. Finally, there is almost no available data on the cost of self-employment for persons with cognitive disabilities. It is likely that the cost for these persons, as in regular employment, will be more than the 10% - 20% increase stated above. The trade-off, however, might be in the ability to more finely target an employment match when all the business opportunities in a community are made available to persons with significant disabilities.

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THOMAS NERNEY

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MR. NERNEY HAS BEEN AN INDEPENDENT CONSULTANT AND LECTURER ON HUMAN SERVICE REFORM. HE HAS CONSULTED WITH A WIDE VARIETY OF PUBLIC AND PRIVATE GROUPS IN THE UNITED STATES, INCLUDING NUMEROUS DISABILITY, PARENT AND ADVOCACY GROUPS. HE IS A FORMER KENNEDY FELLOW IN PUBLIC POLICY AND A MARY SWITZER DISTINGUISHED FELLOW, US DEPARTMENT OF EDUCATION.

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MICHAEL CALLAHAN

DR. CALLAHAN IS THE PROJECT DIRECTOR FOR THE UNITED CEREBRAL PALSY ASSOCIATION'S (UCPA) CHOICE ACCESS PROJECT. THIS IS A FIVE-YEAR PROJECT TO EXAMINE THE FEASIBILITY OF PROVIDING DIRECT VOUCHERS TO PERSONS WITH SEVERE PHYSICAL DISABILITIES AND FOR THEM TO PURCHASE THE EMPLOYMENT SERVICES OF THEIR CHOICE. HE IS THE FORMER PROJECT DIRECTOR OF UCPA'S RESEARCH AND DEMONSTRATION PROJECT ON SUPPORTED EMPLOYMENT AND THE UCPA SELF-DIRECTED STAFF TRAINING PROJECT FOR SUPPORTED EMPLOYMENT, A PILOT PROJECT TO TEST THE FEASIBILITY OF AN INDIVIDUALIZED , COMPETENCY-BASED CURRICULUM FOR STAFF DEVELOPMENT. HE WAS ALSO PROJECT MANAGER FOR UCPA'S NATIONAL DEMONSTRATION PROJECT FOR SUPPORTED EMPLOYMENT IN THE LATE 80'S. THIS THREE-YEAR PROJECT INVOLVED SEVEN SITES IN THE STATES OF NEW JERSEY, ALABAMA AND ILLINOIS. IT EMPLOYED 115 PERSONS WITH SEVERE PHYSICAL DISABILITIES IN JOBS USING SUPPORTED EMPLOYMENT.

DR. CALLAHAN HAS ALSO WORKED WITH MARC GOLD & ASSOCIATES FOR SEVENTEEN YEARS, THE LAST FOURTEEN OF WHICH HE SERVED AS PRESIDENT OF THE ORGANIZATION. MG&A IS A TRAINING COMPANY WHICH PROVIDES TECHNICAL ASSISTANCE TO SYSTEMS, AGENCIES AND FAMILIES INTERESTED IN INSURING THE COMPLETE COMMUNITY PARTICIPATION OF PERSONS WITH SIGNIFICANT DISABILITIES. MIKE ALSO STUDIED VOCATIONAL REHABILITATION WHILE AT SYRACUSE UNIVERSITY IN A DOCTORAL STUDIES PROGRAM. AT SYRACUSE HE WORKED WITH A FEDERALLY-FUNDED PROJECT WHICH PROVIDED SUPPORTED EMPLOYMENT OPPORTUNITIES TO STUDENTS GRADUATING FROM LOCAL SCHOOL DISTRICTS WHO WERE LABELED AS SEVERELY DISABLED.

IN THE 70'S, DR. CALLAHAN WORKED IN A WORK ACTIVITY CENTER AND GROUP HOME FOR ADULTS WITH DEVELOPMENTAL DISABILITIES AND HE WAS A SPECIAL EDUCATION TEACHER FOR FOUR YEARS. HE IS AN EDITOR OF A POPULAR "HOW-TO" BOOK ON EMPLOYMENT FOR PERSONS WITH SIGNIFICANT DISABILITIES, GETTING EMPLOYED, STAYING EMPLOYED AND CO-AUTHOR OF A SOON TO BE PUBLISHED BOOK KEYS TO THE WORK PLACE. HE LIVES IN OCEAN SPRINGS, MISSISSIPPI WITH HIS WIFE AND DAUGHTER.

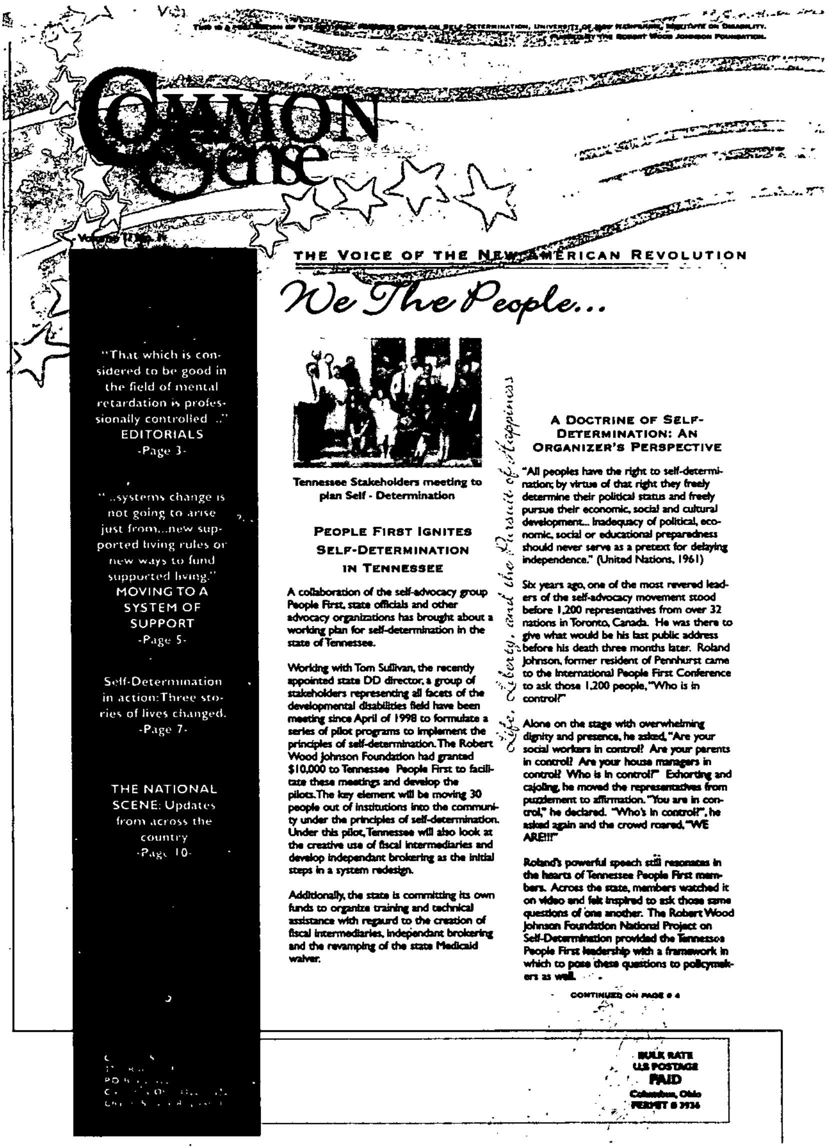
DAVID MANK

DR. MANK IS THE DIRECTOR OF INDIANA UNIVERSITY'S INSTITUTE FOR THE STUDY OF DEVELOPMENTAL DISABILITIES (ISDD), THE UNIVERSITY AFFILIATED PROGRAM(UAP) OF INDIANA. IN ADDITION, HE IS A FULL PROFESSOR IN THE SCHOOL OF EDUCATION'S PROGRAM IN SPECIAL EDUCATION, DEPARTMENT OF CURRICULUM AND INSTRUCTION.

DR. MANK HOLDS A BACHELOR'S DEGREE IN PSYCHOLOGY AND ENGLISH FROM ROCKHURST COLLEGE IN KANSAS CITY (1975), A MASTER'S DEGREE FROM PORTLAND STATE UNIVERSITY IN SPECIAL EDUCATION (1977), AND A DOCTORATE IN SPECIAL EDUCATION AND REHABILITATION FROM THE UNIVERSITY OF OREGON, EUGENE (1985). A PROLIFIC WRITER AND RESEARCHER, DR. MANK HAS AN EXTENSIVE BACKGROUND IN EDUCATION AND EMPLOYMENT FOR PERSONS WITH DISABILITIES. HIS INTEREST ALSO INCLUDES A FOCUS ON THE TRANSITION OF PERSONS WITH DISABILITIES FROM SCHOOL TO WORK. OVER THE PAST FIVE YEARS, DR. MANK'S WORK HAS EXPANDED TO ENCOMPASS NOT ONLY PERSONS WITH DEVELOPMENTAL DISABILITIES, BUT THOSE WITH MENTAL ILLNESS, PHYSICAL DISABILITIES, AND PERSONS WITH TRAUMATIC BRAIN INJURIES.

SINCE 1985, DR. MANK HAS MAINTAINED RESPONSIBILITIES FOR GRANT WRITING AND MANAGEMENT OF 13 FEDERALLY FUNDED PROJECTS IN WHICH HE HAS BEEN THE PRINCIPAL INVESTIGATOR, DIRECTOR OR CO-DIRECTOR. HIS BACKGROUND IN THE CORE FUNCTION DOMAINS OF THE UAP AT THE UNIVERSITY OF OREGON IN THE AREAS OF RESEARCH, TRAINING AND TECHNICAL ASSISTANCE, DEMONSTRATION PROJECTS, AND GRADUATE PERSONNEL PREPARATION PROGRAMS CORRESPOND WITH THE PURPOSE AND SCOPE OF ACTIVITIES AT THE ISDD.

DR. MANK IS A MEMBER OF THE EDITORIAL BOARDS OF THE JOURNAL OF THE ASSOCIATION FOR PEOPLE WITH SEVERE HANDICAPS (JASH), THE JOURNAL OF VOCATIONAL REHABILITATION, THE JOURNAL OF DISABILITY POLICY STUDIES, AND A CONSULTING EDITOR FOR THE JOURNAL ON MENTAL RETARDATION. HIS WORK HAS BEEN RECOGNIZED AT THE NATIONAL LEVEL WITH AN APPOINTMENT TO THE EXECUTIVE BOARD OF THE FOUNDATION OF THE ASSOCIATION FOR PERSONS IN SUPPORTED EMPLOYMENT. HE HAS ALSO BEEN APPOINTED TO THE WORLD ASSOCIATION FOR SUPPORTED EMPLOYMENT WHERE HE IS INVOLVED IN DEVELOPING A SUPPORTED EMPLOYMENT NETWORK IN ITALY, SPAIN, BELGIUM, ENGLAND, AND IRELAND.



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COMMON SENSE

THE VOICE OF THE NEW AMERICAN REVOLUTION

We The People...

Life, Liberty, and the Pursuit of Happiness

"That which is considered to be good in the field of mental retardation is professionally controlled .."
EDITORIALS
-Page 3-

"..systems change is not going to arise just from...new supported living rules or new ways to fund supported living."
MOVING TO A SYSTEM OF SUPPORT
-Page 5-

Self-Determination in action: Three stories of lives changed.
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THE NATIONAL SCENE: Updates from across the country
-Page 10-

Tennessee Stakeholders meeting to plan Self - Determination

PEOPLE FIRST IGNITES SELF-DETERMINATION IN TENNESSEE

A collaboration of the self-advocacy group People First, state officials and other advocacy organizations has brought about a working plan for self-determination in the state of Tennessee.

Working with Tom Sullivan, the recently appointed state DD director, a group of stakeholders representing all facets of the developmental disabilities field have been meeting since April of 1998 to formulate a series of pilot programs to implement the principles of self-determination. The Robert Wood Johnson Foundation had granted $10,000 to Tennessee People First to facilitate these meetings and develop the pilots. The key element will be moving 30 people out of institutions into the community under the principles of self-determination. Under this pilot, Tennessee will also look at the creative use of fiscal intermediaries and develop independant brokering as the initial steps in a system redesign.

Additionally, the state is committing its own funds to organize training and technical assistance with regaurd to the creation of fiscal intermediaries, independant brokering and the revamping of the state Medicaid waiver.

A DOCTRINE OF SELF-DETERMINATION: AN ORGANIZER'S PERSPECTIVE

"All peoples have the right to self-determination; by virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development... Inadequacy of political, economic, social or educational preparedness should never serve as a pretext for delaying independence." (United Nations, 1961)

Six years ago, one of the most revered leaders of the self-advocacy movement stood before 1,200 representatives from over 32 nations in Toronto, Canada. He was there to give what would be his last public address before his death three months later. Roland Johnson, former resident of Pennhurst came to the International People First Conference to ask those 1,200 people, "Who is in control?"

Alone on the stage with overwhelming dignity and presence, he asked, "Are your social workers in control? Are your parents in control? Are your house managers in control? Who is in control?" Exhorting and cajoling, he moved the representatives from puzzlement to affirmation. "You are in control," he declared. "Who's in control?", he asked again and the crowd roared, "WE ARE!!!"

Roland's powerful speech still resonates in the hearts of Tennessee People First members. Across the state, members watched it on video and felt inspired to ask those same questions of one another. The Robert Wood Johnson Foundation National Project on Self-Determination provided the Tennessee People First leadership with a framework in which to pose these questions to policymakers as well.

CONTINUED ON PAGE # 4

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COMMON Sense

Why Common Sense?

By 1775, many Americans were ready to break away from British control. British rule denied Americans the freedom to determine their own futures and set their own course. Some Americans were unconvinced. They feared both the confrontation that would be required to assure freedom for Americans and the changes that would result.

In early 1776, Thomas Paine published a pamphlet called "Common Sense." This small pamphlet changed the course of history. His words fired up Americans and brought them together to fight for what Thomas Jefferson, in drafting the Declaration of Independence, called "Life, Liberty and the Pursuit of Happiness." Many years later, President Eisenhower said that the Declaration of Independence was much more than a historical document that called people to action but "a voice of conscience establishing clear, enduring values applicable to the lives of all people."

Thomas Paine's pamphlet "Common Sense." stands as a charter of human liberty and dignity. Historically, minority groups have been forced to struggle to benefit from the promise of the Constitution and The Bill of Rights. For too long, people with disabilities have been denied their rights to Life, Liberty and the Pursuit of Happiness. It is the goal of the Self-Determination movement to change all that and to continue the mission of Thomas Paine to make the Declaration of Independence apply fully to all Americans. It just makes common sense.

PROFILE

C. EVERETT KOOP, CHAIR OF THE NATIONAL ADVISORY COMMITTEE

"Each issue of Common Sense will profile a member of the Self-Determination National Advisory Committee."

C. Everett Koop

Dr. C. Everett Koop was born in Brooklyn, New York, on October 14, 1916, graduated from Dartmouth College in 1937 and received his M.D. degree from Cornell Medical College in 1941. After serving an internship at the Pennsylvania Hospital, he pursued postgraduate training at the University of Pennsylvania School of Medicine, Boston Children's Hospital and the Graduate School of Medicine, University of Pennsylvania, from which he received the degree of Doctor of Science (Medicine) in 1947. After promotions up the academic ladder, he was named Professor of Pediatric Surgery, School of Medicine, University of Pennsylvania in 1959 and Professor of Pediatrics in 1971. He is presently the Elizabeth DeCamp McInerny Professor of Surgery at Dartmouth Medical School.

A pediatric surgeon with an international reputation, Dr. Koop became Surgeon-in-Chief of Children's Hospital of Philadelphia in 1948 and served in that capacity until he left academia in 1981. He was the Editor-in-Chief of the Journal of Pediatric Surgery.

Dr. Koop was appointed Deputy Assistant Secretary for Health, U.S. Public Health Service (PHS) in March 1981, and sworn in as Surgeon General on November 17, 1981. Additionally, he was appointed Director of the Office of International Health in May 1982. As Surgeon General, Dr. Koop oversaw the activities of the 6,000 member PHS Commissioned Corps and advised the public on health matters such as smoking and health, diet and nutrition, environmental health hazards and the importance of immunization and disease prevention. He also became the government's chief spokesman on AIDS. He resigned on October 1, 1989 and continues to educate the public about health issues through his writings, the electronic media, and as Senior Scholar of the C. Everett Koop Institute at Dartmouth.

The recipient of numerous honors and awards including 37 honorary doctorates, he was awarded the Denis Brown Gold Medal by the British Association of Pediatric Surgeons; the William E. Ladd Gold Medal of the American Academy of Pediatrics in recognition of outstanding contributions to the field of pediatric surgery; and a number of other awards from civic, religious, medical and philanthropic organizations. He was awarded the Medal of the Legion of Honor by France in 1980, inducted into the Royal College of Surgeons of England in 1982, and the Royal College of Physicians and Surgeons of Glasgow. In May 1983, Dr. Koop was awarded the Public Health Service Distinguished Service Medal in recognition of his extraordinary leadership of the U.S. Public Health Service. In September 1995, Dr. Koop was awarded the Presidential Medal of Freedom.

Dr. Koop is a member of the American Surgical Association, the Society of University Surgeons, the American Pediatric Surgical Association, the National Academy of Science, the Institute of Medicine, the American Philosophical Society, and other professional societies in the U.S. and abroad. He is a fellow of the Royal Society of Medicine, the American College of Surgeons, the American Academy of Pediatrics, and the Society of Behavioral Medicine, and a member of the American College of Preventive Medicine. Dr. Koop is Chairman of the Board of Trustees of the National Museum of Health and Medicine Foundation, and Chairman of the National SAFE KIDS Campaign. He serves as an international advisor to AIDS Care Education and Training (in the United Kingdom) and is a member of the National Advisory Boards of the International Health and Medical Film Festival, Inc. and the Texas Heart Institute.

Dr. Koop is the author of more than 230 articles and books on the practice of medicine and surgery, biomedical ethics and health policy. He was awarded an Emmy in 1991 in the News and Documentary category for "C. Everett Koop, M.D.," a five part series on health care reform. He is married to the former Elizabeth Flanagan and has three living children, Allen, Norman and Elizabeth Thompson, and seven grandchildren.

"Pamphlet"

EDITORIALS AND LETTERS TO THE EDITOR

THE LAST BEST HOPE OF EARTH

This is our first edition of Common Sense. It is a tabloid newsletter dedicated to communicating the efforts of thousands of individuals throughout the country who are attempting to implement the principles of self determination: freedom, control of resources, support and responsibility. These are basic American principles deeply rooted in the most fundamental of all documents in our culture, The Declaration of Independence and The Bill of Rights.

Common Sense was Tom Paine's contribution to the development of American democracy. In it, Paine articulated the universal desire of all humans to be free from governmental constraints that limited their individual freedom. Long before his time, Paine preached the equality of all human beings, opposed slavery and advocated the rights of all, including women. At its heart, self determination is nothing more than the natural extension of these basic American rights to those with disabilities who remain the last population in America forced to trade in these inalienable rights simply because they need support in exercising them.

Self-Determination for persons with disabilities is now sowing a foundation in over 100 communities in 29 states. People with disabilities, family members, friends, policy makers, progressive provider agencies, service coordinators and case managers, state and county officials as well as countless others, are struggling with re-designing the current system we euphemistically call "long term care" by replacing it with a system founded on freedom and responsibility. These struggles and successes will be featured in the pages of Common Sense.

Self-Determination is not another attempt to tinker with the present system. Self-Determination is not another expression of choice. In fact, choice has become the present system's shaky response to the very idea of real freedom. Choice only becomes meaningful when it occurs within the framework of freedom.

Self-Determination reveals all of the fault lines in the present system. It uncovers the conflicts of interest that are endemic in most of the current activities ranging from planning with individuals with disabilities to contracting mechanisms which constrict the freedom of individuals with disabilities and families. It forces all of us to confront current expenditures and examine their value in the lives of people with disabilities. It exposes the incredible range of inequities in funding that have no rational relationship to the level of support a person may need. Finally, it forces us to pay attention to the tens of thousands of individuals and families on waiting lists for elementary supports.

Self-Determination is about changing the behavior of those who run the present system, not trying to change people with disabilities. It is about moving from a system of liability assurance to a system of quality assurance based on what individuals with disabilities and families indicate constitutes quality. Self-Determination is not about training someone to get ready for freedom and choice. It is about removing the barriers to freedom and choice that the current system imposes. It assumes that individuals with disabilities will learn within the same context that everyone learns as an adult in this culture. It assumes that only those with a personal commitment to the individual and chosen by the person with a disability will provide assistance in exercising these fundamental rights and responsibilities.

Finally, Self-Determination means that those who accept responsibility for the legal and ethical basis for this or any long term care system, will take seriously the struggle for equality and freedom that must become the hallmark of the new system.

In his 1862 message to Congress, Abraham Lincoln summed up the meaning of freedom in a way that should provide ample reflection for all of us. Lincoln said:

"In giving freedom to the slave, we assure freedom to the free & honorable alike in what we give, and what we preserve. We shall nobly save, or meanly lose, the last, best hope on earth."

-T.N.

BUREAUCRATIZING VALUES

"In the real world, people die for their freedoms. In the field of mental retardation, they hold conventions or invite each other to conferences. In the real world, people learn from each other, and protect each other. In the field of mental retardation, one must be licensed to teach, certified to treat, and commissioned to protect. That which is considered to be good in the field of mental retardation is professionally controlled.

What is least restrictive about the real world derives from thousands of years of human discourse under such diverse leaders as Attila and Lincoln, Pharaoh and Moses, George III and George Washington, Martin Luther and Martin Luther King. What's most restrictive about the world of mental retardation derives from 200 years of professional interest in pathology rather than the universality of people. Professionals have created much of the need to do something about the problem of too restrictive environments forced upon the mentally retarded. We have created or been much of the problem, and now we seem anxious to do something about our unholy work. Indeed, we must do something, but less to rescue the mentally retarded than to redeem ourselves, less to obtain their freedoms than to establish ours, less because they need us than because we need them."

1981, Burton Blatt, Professor, University of Syracuse and Past President of AAMR.

INCLUDE MEDICAID ROLE IN LONG-TERM CARE FOR THE ELDERLY

(The following letter is a reprint from Letters to the Editor, USA TODAY, Feb. 24, 1998)

President Clinton made it clear in his proposed Fiscal Year 1999 federal budget that it is time to shore up our nation's health care system, which is fast becoming overstressed by an aging population. And so, policy makers and a presidential commission are preparing to reconfigure a struggling Medicare system.

But by addressing only Medicare, they will fail to acknowledge the full scope of the problem; they will have missed completely the complex issue of long-term care for the elderly, an issue well beyond the scope of Medicare.

Consider this: The system that provides public funding for long-term care is not Medicare, but Medicaid, a government welfare program. Nearly 70% of the United States' nursing-home population is supported by Medicaid. The majority of this group are middle-class citizens never thought to be destined for the welfare rolls. Medicaid's future grows more tenuous with every passing year as the elderly population grows. In 1994, one in eight Americans were 65 or older; by 2030, the senior population will rise to one in five. The fastest growing segment of the population includes those 85 or older, one fourth of whom reside in nursing homes.

Face it. The longer we live, the more likely we'll need long term care. One recent study estimated that one in five Americans over age 50 is at risk of needing long-term care sometime within the next 12 months. Only one in four can afford to pay for a single year of nursing home care's $41,000 average annual cost.

Medicare typically provides full coverage for the first 20 days of care after a hospi-

COMMON Sense

cal stay; coverage ends after 100 days.

At the least, it is a bad system that requires elderly patients and their families–already struggling to cope with their loss of health and independence–to exhaust their savings and go on the public dole. But beyond that, it is fiscal suicide to ignore the fact this system will not survive the surge of advancing Baby Boomers.

President Clinton is right: it is time to focus on health care for the elderly. The president's Medicare Commission will be doing only half its job if it does not address long-term care at the same time, entertaining a variety of innovative solutions that address the entire continuum of elderly health-care needs.

Dr. Fernando Torres-Gil, Los Angeles, CA (The writer, a UCLA professor and director of the Center for Policy Research on Aging, served as assistant secretary for aging in the Department of Health and Human Services from 1994 to 1997.)

~A DOCTRINE OF SELF-DETERMINATION ...CONTINUED from page #1 ~

In meetings throughout the past year, People First members strategized ways to bring the "stakeholders" to the table with a commitment to initiate self-determination efforts. In doing so, they were successful at having self-determination included as a requirement in the community plans for two class action lawsuits against Tennessee's developmental centers. Planning for the 30 individuals to be included in the first Tennessee self-determination pilot project began last month.

In Tennessee, the path to liberation is just beginning. The experience of other states in planning and implementing self-determination will be invaluable. However, unlike many reforms that people with disabilities have weathered at times with passive or outright resistance, self-determination is one that Tennessee People First members have embraced.

People with disabilities across the country are working toward the promotion and implementation of self-determination. As planning for self-determination proceeds, many questions are emerging within and without the self-advocacy movement regarding the relationship between self-advocacy and self-determination. As such, it is imperative that these questions be addressed within a context that is in keeping with the underlying values and practices of the self-advocacy movement. To do less than this or other than this is to deny the collective voice that has brought us to this day.

A DOCTRINE OF SELF-DETERMINATION

In November of 1997, representatives from fourteen state self-advocacy associations came together to discuss the implications of the Robert Wood Johnson Foundation's Self-Determination Initiative. Four of the associations had received technical assistance funding for self-determination from the RWJ Foundation. The knowledge base of the remaining ten associations regarding the self-determination initiative ranged from nominal to active participation in their respective state's planning process. All of the representatives found common ground, however, in their desire to express their beliefs and opinions about this initiative.

> "WE BELIEVE SELF-ADVOCATES ARE THE PROFESSIONALS, ASK US FIRST AND WE SHOULD BE THE DECISION MAKERS AND PLANNERS IN ALL OUR DAILY LIVING ACTIVITIES, SUCH AS WORKING, VOTING, CONFERENCES, LEADERSHIP DEVELOPMENT, AND TAKING CONTROL OF OUR SERVICES AND PERSONAL DOLLARS."

The position statement that emerged from this meeting reflects the underlying intensity of emotion surrounding the engagement of people with disabilities in self-determination efforts. After decades of being told what the choices will or won't be, leaders within the self-advocacy movement are standing up for those very values espoused by self-determination proponents; freedom, authority, support, and responsibility.

DECLARATION OF SELF-DETERMINATION

We, the people with disabilities of America, met in Nashville on November 1st, 1997 to define Self-Determination as our basic civil rights including all the freedoms guaranteed by our Constitution and our Bill of Rights.

We believe self-advocates are the professionals, ask us first and we should be the decision makers and planners in all our daily living activities, such as working, voting, conferences, leadership development and taking control of our services and personal dollars.

As a disability community we are all one unified voice, we include everyone, we are not "special," we respect and trust each other and are willing to help each other in the fight for rights.

We also stand firm that the enforcement protections of the ADA will assure self-determination for all people with disabilities. We Are Self-Determination!

The authenticity of this position statement calls for it to serve as the centerpiece of a doctrine of self-determination from which other principles may emanate. The following ten principles of this doctrine are intended to address emergent questions regarding the "proper place" of people with disabilities in the formulation of self-determination initiatives as well as provide standards for its emergent practice.

The Ten Principles

Principle 1: The foundation of self-determination, like the self-advocacy movement must be based on unerring belief in oneself and belief in one another.
Principle 2: The goal of self-determination unequivocally must be liberation for all persons with disabilities, both individually and collectively, in all its many forms including mental, physical, economic, and spiritual.
Principle 3: Self-determination in its crafted form of policy and practice must be transformational, in that it results in changed power relations and transformed socio-economic systems.
Principle 4: The core underlying values of self-determination must at a minimum include freedom, authority, support, and responsibility.
Principle 5: Those engaged in the practice of self-determination must regard the restoration of personal control to individuals with disabilities as essential to their true emancipation.
Principle 6: In order for self-determination to attain legitimacy, individuals with disabilities must be part of the planning and implemention process and must be affirmed by and afforded accountability to the larger collective voice of the disability rights movement.
Principle 7: The process of developing and implementing self-determination must be reciprocal in that it pro-

vides for teaching and learning for, by, among, and between all of its proponents.
Principle 8: Those engaged in developing and implementing self-determination must continually promote designs that feature maximal simplicity and thus require minimal interpretation.
Principle 9: Changes in policy and practice that are created to foster self-determination must recognize, accept, and provide for atonement for those harms inflicted upon people with disabilities in the past.
Principle 10: Self-determination must be recognized as only one means to an end that the self-advocacy movement has at hand to further its advance towards liberation.

THE CHALLENGE

"If there is hope in what we have learned in our examination of institutionalization, it is not in any improvement of institutional life—imprisonment and segregation can be made more comfortable, but they can never be made into freedom or participation."

— Burton Blatt, The Family Papers

The call for change in "Who's in Control" is gaining strength and volume. The multitude of demands for reform threatens at times to engulf the highly bureaucratized lives that people with disabilities who receive supports currently navigate. There are also people who remain adrift from services and supports, either by choice or the lack of resources. The goals and desired outcomes of self-determination initiatives must be clearly committed to universal freedom for all.

Ultimately, what this initially means is people will be in charge of their own services. It will be people themselves sitting around with their friends and allies deciding what they want and how having control of the money can make those desires real. It must be clearly understood that there can be no compromise regarding this objective. Those who choose to follow the emergent doctrine of self-determination must also resist customary efforts to sloganize, pervert, or otherwise alter its core principles and beliefs.

The proponents of self-determination are purposely going down an unfamiliar path shrouded in fog. Self-advocates, professionals, family members, policymakers and other stakeholders are sharing the journey. To prevent anyone from becoming lost, the pace must be slow and even with frequent opportunities to stop and get one's bearings. One thing they are certain to discover, however, is despite the fog, the conditions for following one's convictions have never been brighter.

By Ruthie-Marie Beckwith, Ph.D.
Ruthie Beckwith is the advisor to People First of Tennessee.
Reference:
United Nations' Declaration on the Granting of Independence to Colonial Countries and Peoples, G.A. res. 1514 (XV), 15 U.N. GAOR Supp. (No. 16) at 66, U.N. Doc. A/4684 (1961)

MOVING TO A SYSTEM OF SUPPORT: USING SUPPORT BROKERAGE

Michael W. Smull & Gary Smith

A cursory review of current conference themes and agendas gives the impression that achieving a system of support is inevitable and around the corner. Words like choice and inclusion fall glibly from the tongues of managers. However, changes in practice have fallen far behind changes in rhetoric. During recent visits with agencies that say they are providing supported living, I have found managers whose language is impeccable but whose practices are still firmly grounded in program model services. While managers talk support with a convincing fluency and naturalness, when you talk to the people being supported and the staff doing the work you discover a better program, not supported living.

Real supported living requires that we learn how people want to live and then support them in the lives that they want (within the constraints of available resources and any issues of health or safety). It requires efforts that help people to be supported by their communities and have opportunities to contribute to their communities. Real supported living requires that people with disabilities and the people providing the direct supports be empowered. It requires that agencies move from tidy organizational structures where people with disabilities "fit" into program vacancies to a fluid structure that changes with the desires of the individuals supported. It requires that control be shared rather than flowing from the top of a hierarchical arrangement.

The programs being represented as supported living typically fall short in several of these areas. They begin with a superficial understanding of choice. They do not focus on continuously learning how people want to live. They do not challenge themselves to help people get the lives they want. They encourage people to settle for what is readily available. Power is seen as a finite commodity. Sharing power with people with disabilities and the direct support staff is perceived as diminishing the power available to managers and directors.

Why have these clearly intelligent managers engaged in this elaborate self deception? They appear to be quite sincere, they appear to believe that they have made the necessary changes. Why are they "talking the talk without walking the walk?" In the challenge of organizational change, how companies experience it and leaders guide it the authors note that all change involves loss, that "almost any action that disturbs the status quo or represents a threat to an individual's habitual way of doing things is likely to provoke defensive, and often counterproductive, behaviors - behaviors learned early in life." (Kanter, Stein, & Jick)
The loss that managers fear is their perceived power, perceived control, and sense of predictability.

This suggests that systems change is not going to arise just from promulgating new supported living rules or new ways to fund supported living. New "top down" rules results in a few real supported living providers and many agencies that achieve paper compliance but are only providing "sort of supported living" (sometimes known by its oxymoron, the supported living program). Agencies need a more powerful motivation for change and external assessment to insure that each person is supported as they wish to live. Where there are new "top down" rules they tend to focus on new process, not new outcomes, while the new ways to distribute dollars typically fund agencies rather than individuals.

Other "top down" efforts designed to change the system are not likely to be any more successful. Kanter, et al suggest that you need a combination of "bold strokes" and "long marches" to change current practice and the underlying culture of an organization. "Bold stokes are those dramatic changes that can occur in a short period of time while the long march refers to the myriad of small actions necessary to change belief." Because "...behaviors reflect beliefs: If you want to change someone's behavior, you must first change their underlying beliefs." (Kanter, Stein, & Jick)

It is clear that changing beliefs takes extended periods of time and requires that there are incentives for change. Getting real change started and providing real incentives for continuing change is the challenge for system managers. A "bold stroke" that would result in dramatic and immediate change is the creation of local "support brokerage" entities that would:

- empower people with disabilities to have real control over their lives;
- support the best use of limited public funding; and,
- move control (and decision making) as close to the people with disabilities as possible.

These are also characteristics that independent case management was to have. Yet, as several state directors of DD systems have noted, independent case management has not made the difference that they had hoped it would make. The effects that they had looked for were substantial improvements in the lives of individuals and changes in the system of services. They had anticipated that independent case management would move the system from being "provider driven" to "person driven," that the desires and needs of each individual, would determine the nature of the supports provided. Instead they have found that the greatest determinant of quality of life has been the quality of the service provider. The presence of agencies that believe in (and practice) supporting each individual has been more important than the presence of case managers. While a number of systems report that the presence of case managers has positively influenced the system it has not caused the dramatic changes hoped for.

Why did independent case management not live up to expectations? The reasons for independent case management's "underachievement" are complex and vary from location to location. However, anecdotal reports suggest that the following apply in most areas. Independent case management has:

- had responsibility without authority;
- lacked the tools (e.g. person centered planning) needed;
- been independent only in name;
- been co-opted as just another

COMMON Sense

MOVING TO A SYSTEM OF SUPPORT: USING SUPPORT BROKERAGE

-CONTINUED-

compliance check;
- drowned in excessive paper requirements; and,
- had too many people for each case manager to support.

How would support brokerage be different? How could it avoid becoming another change in name without a change in practice? While there is nothing that can be done in design that cannot be undone in implementation, support brokerage can be designed to reflect the lessons that have been learned from case management. The first of these is independence. Support brokerage entities should be independent of any entity that provides services or has multiple responsibilities. Beyond the typical requirement that residential or day providers cannot provide support brokerage, county (or state) based systems, such as services boards should not be the providers of support brokerage either.

In outline, support brokerage entities should be locally based private, not-for-profit corporations which would:

- be responsible for the planning for and the funding of services to all people with developmental disabilities within its catchment area;
- have boards of directors where people with disabilities (who are receiving services or are waiting for services) are a majority, with representation from both groups – parents or other family members of those receiving services and those eligible for services are the second largest group;
- people appointed by state and local authorities are present but represent the smallest group;
- have an active mission statement which requires that people be supported in the lives that they want and that they be assisted in being a part of their communities;
- be required to have "bottoms-up" rules which state that the primary goal is to support people with disabilities (not agencies) and where accountability is defined in terms of meeting the goals of the individual;
- assure that support brokers have competencies in learning how people want to live;
- recruiting community resources supporting people in the lives that they have chosen;
- demonstrate that each support broker knows the significant issues of every person with whom she or he does brokerage;
- support people in their choices (within the limits of available funding and the constraints of assuring reasonable health and safety) including the choice to "fire" their support broker;
- have access to the resources necessary to assist agencies in changing from offering programs to supporting individuals.

strengthen the role of families, friends, and others supported in communities....

Support brokers focus on assisting people with disabilities when they are:
- entering the system for the first time;
- in crisis; just unhappy with the life they are being supported in and;
- renegotiating plan implemetation.

Individual support brokers spend the time necessary to learn how each person wants to live and develop an outline of what will be necessary to support that person. The support broker works with the person to arrange and negotiate the costs of the supports. While the supports are being developed and implemented, the support broker maintains intense involvement. As the individuals and the support brokers are satisfied with the implementation of the supports the degree of involvement decreases. Unless there is an indication of dissatisfaction or inadequate supports the support broker's involvement is reduced to periodic monitoring, at a frequency determined by the desires and needs of the individual. The minimum frequency for contact would be twice a year.

"HELPING PEOPLE ACHIEVE THEIR DESIRED LIVES WILL REQUIRE CHANGES IN AGENCY AND SYSTEM ACTIVITIES, PRACTICES, AND RULES..."

How involved each support broker would be involved with each person would depend on the desires and issues of the person. In some instances people want simple things like an environmental modification or single services like respite. What these people want is only enough assistance to get what they want and not a flood of paper or a parade of officials. Other people need significant assistance in determining how they want to live, how they can get the supports, and on-going efforts to make sure that they are happy and safe. The degree of support that most people need will vary widely over their lives. We need a system that provides people who need assistance in negotiating services with the support they need while it empowers people who know what they want (and where to get it) to do their own negotiating.

Helping people achieve their desired lives will require changes in agency and system activities, practices, and rules. The changes needed can be classified as:
- those that only require local effort - "just do it" changes;
- those that require technical assistance to be successful: and
- those that require permission- a change in the practices or rules of those who fund and regulate.

This article will be continued in the next issue of Common Sense. It appears in full on our website, www.self-determination.org.

Reference: "The challenge of organizational change, how companies experience it and leaders guide it." Kanter, R.M., Stein, B.A., Jick, T.D. Free Press, NY (1992)

Michael W. Smull is with Support Development Associates, Maryland.
Gary Smith is with the National Assoc. of State Directors of Developmental Disabilities Services.

RICHARD'S STORY

Richard Messler was admitted to Southbury Training School in 1965, at the age of 21. He received no educational or vocational rehabilitation and did not have any visitor from the outside between 1968 and 1991. He had no spoken language, and he learned none while he was there. He was considered beyond rehabilitation. Richard seemed destined to spend the rest of his life at the Institution.

Richard (center), companion Janet (r), and friend Alice (l) celebrate his 2nd anniversary of leaving a state institution.

In 1991, Jean N. Bowen, Executive Director of WeCAHR, and Mark Olander, now Arc/Connecticut President met Richard for the first time while visiting a building. Jean, WeCAHR advocates and Tom Nerney, who became his guardian, began an effort to change his life.

That effort came together on December 13, 1995 when Richard moved into a home of his own. Gaining control of the money for Richard was a critical part of the plan because it allowed Richard to move into his own home rather than into another group setting. A fiduciary (or fiscal intermediary) was hired to help Richard pay his bills and receive the money from the DMR. Kirky Barnes, Richard's coordinator assures Richard has all the support he needs, and a young mom and her son live with Richard in the home.

Richard loves to draw and create paper collages. He has been taking private art lessons. Richard has new friends in his community and most importantly, Richard is happy!

PETER'S STORY

-By Alice Shanley

Peter started using Facilitated Communication (FC) in April 1992. After years of guessing and hoping, I was right in my assumptions! He was able to communicate his likes and dislikes, aspirations and so much more. He had been in Datahr Rehabilitation Center workshop since early 1985 and was generally described as a good worker, though autistic behaviors seemed to preclude advancement to less supervised, better paying placement or competitive employment. With FC, he communicated that he hated the workshop and wanted to study computers.

The Bureau of Rehabilitative Services (BRS) sent him for private instruction once a week at a school where he studied Lotus. He made good progress. After several months, he was given private instructions once a week by a remedial teacher. Again he made very good progress, but BRS discontinued that contract as its objective was job training, and BRS felt Peter was adequately trained for filing alphabetically and numerically.

Peter recognized there were terrible gaps in his education and began to express an interest in learning more math and history. He had also rebelled against going to the workshop and would only attend 3 half days per week. In 1994, he started volunteer work one morning per week doing typing at WeCAHR, and took private swim lessons once per week.

His advocate and I began discussions with Datahr about his day program. Datahr agreed to release Peter's day program funds for the development of a new program. We interviewed people for the position of an instructor who would introduce Peter to the Internet, use computer software for instruction in math and history, work on community exposure, and include some physical exercise. We also had to find an off-site location for computer access. This took time and there were several set backs.

In September, 1996, a community computer lab was located. Peter has had some exposure to the Internet, remedial math and language. He has instruction 3 mornings a week and the program also includes some community experiences and physical exercise. It took some searching to find the resources and instructor. Bi-weekly phone conferences keep me informed and help develop new strategies. Peter is very happy to be learning, and hopes future funding will enable him to increase his learning time.

DRUSILLA'S STORY

-By Brendan and Shirley Sniffin

In August of 1996 after becoming frustrated with the lack of job prospects and the performance of the agency that was supplying a job trainer for Dru, we asked our DMR case manager and WeCAHR to help us get control of Dru's funding.

We applied for and received a grant through DMR. With this money, we were able to hire our own job trainer to work directly with us to see that Dru's employment needs are met. It has been a learning experience, some of which is positive, some negative. It does require more work on our part - record keeping, managing resources and time involved. An accountant helps us to figure the payroll and taxes. On the plus side, we get weekly progress reports and Dru gets undivided attention. As an example, we were recently able to head off a situation that was fast getting out of control. Management was not allowing her to progress in her job, resulting in a loss of self-esteem. Through job training monitoring of the work place and support of Dru, we were able to acquire a transfer to a new job with the Company. The manager at the new site is more receptive to Dru and her needs. In the short time Dru has been there, we have noticed she once again feels like a member of the team, and is eager to go to work and meet the new challenges of the job with a smile.

Not only have we realized positive results, we feel this has helped educate employers in dealing with employees who have disabilities. We would recommend to anyone willing to apply themselves to follow this route, for the positives have far outnumbered the negatives!

MINNESOTA BREAKS NEW GROUND WITH MEDICAID WAIVER PLAN

CONSUMER DIRECTED COMMUNITY SUPPORT

Consumer-directed community supports are services which provide support, care and assistance to an individual with a disability, prevent the person's institutionalization and allow the person to live an inclusive community life. Consumer-directed community supports are designed to build, strengthen or maintain informal networks of community support for the person. Consumer directed community supports include the following specific activities at the request and direction of the consumer or his/her legal representative:

1)Provision of services and supports which assist the person, family, or friends to:
-identify and access formal and informal support systems;
-develop a meaningful consumer support plan; or
-increase and /or maintain the capacity to direct formal and informal resources.
2)Completion of activities which assist the person, his/her family, or his/her friends to determine his/her own future.

3)Development of person-centered support plans which provide the direction, assistance and support to allow the person with a disability to live in the community, establish meaningful community associations, and make valued contributions to his/her community.

4)Ongoing- consultation, community support, training, problem-solving, and technical assistance to assure successful implementation of his/her person-centered plan.

5)Development and implementation of community support strategies that aid and strengthen the involvement of community members who assist the person living in the community.

-MINNESOTA CONTINUED FROM PAGE 7-

The consumer, his/her legal guardian, and the county agency will assure that consumer-directed community supports are not duplicative of any other service provided to the person. Components of the consumer-directed community supports will be documented as necessary to prevent the person's institutionalization in the individual service plan/personal support plan. Additionally, the county agency shall document how the community support services enable the person to lead an inclusive community life, build a viable network of support, and result in outcomes specified by the consumer or his/her legal guardian.

Provider Qualifications :
A New Definition

Consumer-directed community services will be provided by entities which meet the unique recipient needs and preferences of the consumer as specified in the person's individual service plan or personal support plan. Local agencies are responsible to work with the consumer and his/her legal guardian to assure that the consumer-directed community supports meets the recipient's health and safety needs, consumer preferences, and are directed at the desired consumer outcomes.

Consumer training and education will be provided by individuals, agencies or educational facilities which have expertise in areas such as consumer empowerment, consumer-directed community supports, self-advocacy, community inclusion, relationship building, problem solving and decision making. ■

SELF-DETERMINATION: SELF-ADVOCATES PLANT THE SEEDS FOR CHANGE IN NEW YORK

By Steve Holmes, The Self-Advocacy Association of New York State, Inc.

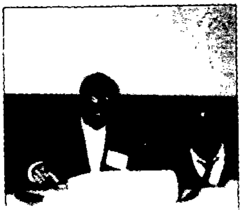
> Our work is a good example of responsibility-we're trying to be role models for others, to give them courage to do the things they might not attempt otherwise.
>
> —Chester Finn

It's March 4th, 1998, lunchtime. We're in the cafeteria of the Empire State Plaza in Albany, underneath the towers of power in New York State. I'm with Clint Perrin, President of the Self-Advocacy-Association of New York State, Inc. (SA), Chester Finn, past President, and Tony Phillips, co-Vice President. We've just finished visiting a number of state legislators in their Albany offices and we're preparing for an important meeting with another key state legislator. We're talking about self-determination and how we can explain what it is in our brief opportunities with these important decision-makers. We're doing what self-advocates in NY state have been doing for a long time: planting the seeds for change.

Now we're talking about the principles of self-determination and how we need to get them across in our conversations. Chester says, "It's important that legislators and providers know that there are some keys points about self-determination, it's not just a new word we're using but a new way of thinking."

"Freedom is being able to do anything anyone else can, having the same choices," says Tony. "It's being free of guidelines and organizational controls," notes Chester. "It's being able to actively plan your own life", adds Clint. "And we should have the authority to control our own supports."

The supports we talk to legislators about aren't the typical ones they're hearing from some of their other constituents, such as money to support "more beds and residences for people on the waiting lists." Self-advocates are talking about new funds to support people's dreams for where they want to live and what kind of work they want to do. Tony uses his own dream as an example. He talks of his interest in becoming a promoter of gospel music, one of his passions. "The government spends a lot of money to keep me in a day hab situation. Why not give me the money and I can find someone to teach me about how to promote a concert?" And we talk about responsibility. Clint adds, "Self-advocacy is about responsibility. Speaking up for yourself, and speaking up for others. That's what our board does."



Chester Finn and Tony Phillips Present about Self-Determination at the NYSACRA Conferences

SA is an organization controlled by people with developmental and other disabilities with a mission to help people speak up for themselves individually and collectively. As a grassroots organization, SA works on a number of levels. Locally and regionally, the organization helps develop and support self-advocacy groups throughout New York State. There are currently over 150 groups and thousands of self-advocate members who support each other on individual and local issues and goals. On a state-wide basis, an eighteen person board of directors, made up of self-advocates from six regions in New York, set the goals and priorities for SA and work on state and national self-advocacy issues like self-determination. Over the years, the SA board has cultivated relationships with state agency leaders, politicians and members of statewide provider agencies, parent groups and other disability organizations. Board members develop budget platforms and make presentations throughout the state on issues that affect the lives of all self-advocates.

When the Self-Determination Project announced the opportunity for "Learning Community" grants, the SA board jumped on the chance and collaborated with the Office of Mental Retardation and Developmental Disabilities (OMRDD) on a project to teach people around the state about self-determination. During this period, board members met frequently with Tom Maul, Commissioner of OMRDD and encouraged him to make opportunities for self-determination available in New York. In December, the executive committee of SA, including Clint, Chester and Tony, presented the Commissioner a proposal for a pilot project for self-determination. He agreed and at this time twenty-four people in New York State are in the process of creating their own life through individual budgets and a process based on the key principles of self-determination: Freedom, Authority, Support, and Responsibility.

"One way we were able to do what we did, was to stay consistent with our message. We kept talking about freedom and giving people a chance to do what they want to do," states Clint. "We didn't want to settle just for creating a learning community, we wanted to see it happen in all parts of New York State," adds Chester.

Members of the Self-Advocacy Association are playing a key role in all aspects of the pilot process, serving on organizing, selection, training, and evaluation committees. SA also received funding from the New York State Developmental Disabilities Planning Council to continue the process of developing a "learning community" by creating a statewide and regional task force to study and promote the concept of self-determination. "We're going to make it happen in New York", affirms Clint. "We got caught up in the steamroller of self-determination." And it's a steamroller fueled by the energy and enthusiasm of the self-advocates in New York State, bolstered by the Commissioner of OMRDD and others' willingness to listen to self-advocates and respond.

"If you have a dream, you can do it," is a favorite quote of Tony Phillips. Self-advocates in New York State have a dream: To help all people with disabilities take control over their own lives; to let their dreams be the focus of change.

We're finishing up lunch in the Liberty Cafe at the Empire Plaza. Time for another chance to teach about self-determination. Chester sums up our discussion and what is basically self-advocate's vision for self-determination. "Now that we've planted the seeds, we're going to see some things grow: A house, an apartment, car, money, work, improvement in people's life, control." As we're gathering up our materials and clearing the table, Clint reflects, "You know, I've been thinking. First we start with a dream which is our self-determination. Our action to make that dream come true is self-advocacy."

(Steve works for the SA Board as the Administrative Coordinator)

NY PROVIDERS SUPPORT SELF-DETERMINATION

(The following is from Newsbreak, a publication of the New York State Association of Community and Residential Agencies (NYSACRA)

Freedom, authority, support, responsibility: Together these four words define the principles of self-determination for the people we strive to support.

In the not too distant future, consumers will embrace the ideas and principles of self-determination New York State. OMRDD, in conjunction with the Self-Advocacy Association of New York State, has begun a Self-Determination Pilot Project. The project has identified 24 consumers in five DDSO areas, Finger Lakes, Central, Western, Letchworth, and New York City. Current State resources will be used, and funding will be tracked in an individual account and controlled by the consumer. Agencies and DDSO funding will remain whole throughout this project.

For providers, self-determination is a means by which individuals (eligible for state DD services) are empowered to gain control over the selection of services or supports that meet their own needs. The principles and values are implemented through new configurations of services and supports in combination with existing services

NYSACRA is involved in various work groups to assist in the evolution of self-determination in New York State. We will keep you posted as the pilot unfolds.

HAWAII'S PROPOSED LEGISLATION EMBRACES SELF-DETERMINATION, INDIVIDUAL CONTROL

Legislation presently submitted to lawmakers in Hawaii will change the way individual plans are developed and administered. Key components of this legislation are:

- "Individualized service plan" means the written plan that is developed by the individual, with the input of family, friends, and other persons identified by the individual as being important to the planning process. The plan shall be a written description of what is important to the person, how any issue of health or safety shall be addressed, and what needs to happen to support the person in the person's desired life. The department shall administer or may provide available supports and services based on a client-centered plan, which resulted from client choices and decision-making that allowed and respected client self-determination.

The Department shall:

1. Assist the individual to develop, with the help of family and friends if necessary, an individualized service plan;
2. Identify the amount of dollars available to the individual to effectuate the individualized service plan; and
3. Allow consumers to direct the expenditure of the "identified funds."

Persons with developmental disabilities or mental retardation shall have the following rights:

- Develop a plan with the input of family and friends that identifies the supports needed to accomplish the plan rather than purchase a program
- Direct the provision of resources, both paid and unpaid, that will assist an individual with a disability to live a rich life in the community rich in community association and contribution
- A valued role in the community through employment, participation in community activities, volunteering, including being accountable for spending public dollars in ways that are life enhancing!"

For more information, contact Bill Chrstoffel, Deputy Director, Hawaii Department of Health, 1250 Punchbowl Street, Honolulu, HI 96801. Phone: (808) 586-4433; e-mail: bchris@lava.net

COMMON Sense

UPDATES... SELF-DETERMINATION ACROSS THE COUNTRY

••••••••••••••••FLORIDA

1997 Project Activities (partial list):
- Request to HCFA for $100,000 in matching funds to better accomplish activities. In January of 1998, Florida was granted $88,000.
- The Developmental Services Multi-year Plan 1998-2000 was drafted by a collaboration of self-advocates, parents, legislators, and others. This plan was published in February of 1998.

A report for using vouchers for services was presented to the House Legislative Committee. A statewide symposium for developing a vouchering/choice system for Florida was recommended and supported.
Some recommended strategies from Florida's Developmental Services Program Multi-Year Plan, 1998-2000:
- Develop a Uniform Wait List Procedure.
- Increase opportunities for self-advocacy.
- Implement vouchers and individual budgeting.

A report for using vouchers for services was presented to the House Legislative Committee. A statewide symposium for developing a vouchering/choice system for Florida was recommended and supported.

•••••••••••••VERMONT

Entitled the "Just Do It Self-Determination Project," Vermont had several project objectives. Among them:
- Establish the Self-Determination Network of stakeholders to share information and develop local resources. Over 170 individuals from across Vermont have participated in training on issues identified by Network representatives.
- Identify and resolve technical issues that have prevented self-directed services. A consultant was hired to explore alternative models for intermediary service organizations to assist people in achieving more control of their service delivery. A group of families, providers and service providers are seeking to choose and implement the most effective model in Vermont.

•••••NEW HAMPSHIRE

There are four goals for the state project:
1. Increase consumer choice and control in supports and services.
2. Increase community capacity to provide services and supports in non-traditional manners.
3. Facilitate organizational change at all levels, and
4. Reduce costs.

To assess progress in each of these goals, New Hampshire has developed evaluation data including:
- The "Who Decides" survey, a measurement tool designed and implemented by People First of New Hampshire that measures the extent to which an individual makes choices in different areas of his/her life. This information has also proven useful for a person's circle of support to focus discussion on the areas for which a person feels they have no control.
- The satisfaction survey;
- Documentation of organizational change; and
- Case studies of participants.

MASSACHUSETTS•••••••••

This state is conducting three pilots to explore three separate approaches to self-determination:
1. The Service Coordinator Group. Twelve DMR service coordinators from eight area offices have targeted 77 individuals to assist in developing custom-designed supports.
2. The Family Governing Board. Half of Boston's neighborhoods represent cultural minority groups and also the highest number of people living in poverty. Aggressive outreach efforts over the past four to five years have resulted in a number of minority groups coming together to express an interest in the RWJ project. Six family governing groups anticipate engaging 250 families to exercise control of their supports and resources through a representative family board that shares their culture and community. RWJF funds a community organizer to work with these boards and build a coalition among the different groups. The emphasis is on family empowerment as a majority of the individuals with disabilities are children.
3. The Provider Group is represented by two provider organizations that have targeted 37 individuals currently served that are interested in customized supports.

TEXAS•••••••••••••••••••

Texas has partnered with the Texas Health and Human Services Commission, the Department of MH and MR, the Department of Human Services and the UAP. Each agency is represented on the Self-Determination Advisory Committee as well as advocates and self-advocates. Three pilot sites are involved and 20 participants at each site have been identified.
Texas has a separate system of services and supports for individuals with mental retardation and those with other developmental disabilities resulting in separate service provider agencies. They are finding fiscal flexibility to be a problem and have been slow to develop state of the art individual budgets for the first 20 participants. Texas hopes to learn from other states about the flexibility offered through HCFA's Home and Community Based Services waiver to reach a solution.

•••••••••••••••••••IOWA

Iowa created a Management Team comprised of consumers, parents, staff members, UAP representatives and others to identify problems in the implementation of the project as well as implementing self-determination statewide.

Iowa reports a few struggles during the first year of the grant. The Management Team continues to work to assure meaningful involvement of the project. Stipends for consumers and family members have been provided.
Communication problems encountered when a few of the pilot sites

were "quick started" and others felt out of the loop. An agreement was signed by three state departments (Human Services, Voc Rehab, and Inspections and Appeals) to oversee and cooperate in the implementation of the outcome based standards in the pilot areas.

WASHINGTON

Washington's self-determination project is titled "Composing a Life." Two project sites were identified and ten individuals or families in each county were the focus of the project. In each location, a staff member was designated as the Community Developer with the task of learning about the families' and individuals' needs in conjunction with the case manager.

The Community Developers were able to facilitate some support connections within the communities where project participants reside. At one project site, people from the neighborhood, both with and without disabilities formed a Community Connector group. The purpose of the group was to offer the opportunity to come together to learn about each other, neighborhood resources and opportunities to become involved in issues to better the neighborhood and support each other. The Community Connector group allows people to connect without the use of service dollars, and holds great promise for people with disabilities to become part of their neighborhood.

CONNECTICUT

During the first year, 27 individuals have been served in local demonstration projects. Prior to the beginning of the grant, the Department of Mental Retardation had begun self-determination efforts and person centered supports for 58 individuals. The department continues to track these individuals as well.

Each person has a support broker and supports individually tailored to the person's situation. Consultants were engaged to assist in defining roles and functions of brokers, identify community-building approaches and build the organizational competency to offer these supports. The department has clarified contract language regarding portability of funds for individuals presently served in supported living and employment and day services.

The department also explored system changes needed to be eligible for Medicaid reimbursement for self-determination expenditures. A consultant was engaged to investigate alternative funding mechanisms such as fiscal agents or intermediaries.

MINNESOTA

Medicaid waiver amendments that promote self-determination were approved by HCFA in December of 1997 leaving local entities the responsibility of ensuring that those using them direct the supports. The waiver amendments promote the development of non-traditional service providers and build on consumer directed services. Minnesota also sees redesigning the traditional role of governmental administrative employees as essential to achieve project goals. Project sites are providing training, mentoring and support for changing the role of case management.

Support to families and individuals controlling their own resources is offered in various ways, such as the use of self advocacy agencies to promote consumer education, as well as individual support offered to each participant. A consumer labor law handbook that will provide a "consumer friendly" approach to issues relating to employer/employee relationships will be finished this year.

KANSAS

Regional Coordinators were placed at each of the two project sites and these individuals have begun to seek out participants for the project. Regional Coordinators also work with the state project coordinator to compile resources and develop training materials. Each site also hired a project Mentor.

Kansas also submitted an amendment to their current HCBS waiver for increased flexibility. Individual budgets will be developed based on tiered rates presently assigned to each individual based on their level of disability. Project staff at each site are responsible for monitoring each budget, and fiscal intermediaries and payment methods are routinely reviewed.

> **" THE $118 MILLION OF NEW MONEY WILL GO TO SERVE INDIVIDUALS ON THE WAITING LIST. THIS INITIATIVE IS AN INDICATION OF THE GOVERNOR'S SUPPORT..."**
>
> **-MARYLAND**

COMMON Sense

WISCONSIN

Three counties (Dane, Winnebago, and LaCrosse) are involved in Wisconsin's grant, and each county takes a different approach based on local history, conditions and needs. Dane County will run all funds through "brokerage houses," which are fiscal management agencies that will handle funds, pay providers through a voucher system, alert brokers and consumers of budget issues, and track spending for reporting purposes.

Winnebago County has achieved major changes in the way services are budgeted and contracted out. They have individualized person-by-person line item costs for each participant with each provider thereby showing consumers what they are spending for services so they can calculate a total budget and demonstrating it is possible to shifts funds between providers or from a provider to an informal or alternative support method.

La Crosse County has entered into partnership for implementation of its project with a major provider of residential and vocational services. They have developed an evaluation tool called "Choice and Control in My Life" to provide outcome based performance measures.

PENNSYLVANIA

Three counties were selected to participate as first year pilots. Each county devised their own goals and objectives. For Allegheny County, a feasibility study was undertaken by a consultant to adopt guiding principles, define the scope of consumer driven supports, and assess management and organizational readiness of the county to implement a revised system, among other tasks.
In Blair County, they have offered training and communication to support system change, and developed a consumer driven system.
Lehigh County reports they have hired HSRI to conduct a feasibility study to assess the capacity and readiness of the present system to manage a consumer driven system.

UTAH

A few of Utah's nine major objectives to carryout self-determination:

- Implement person-centered planning and budgeting. Five provider sites to initiate self-determination were selected, site coordinators and implementations teams were set up. Twenty people were identified by each site to participate in the project.
- Develop a Technical Assistance and Payment Information System.
- The present Medicaid waiver needs to be rewritten to help support and carry out self-determination. A workgroup has been assembled to write the new waiver.

ARIZONA

Entitled "This is My Life," Arizona's self-determination initiative is about putting people in the driver's seat to control their own lives.

Some objectives:

- Change the focus to abilities rather than disabilities within the Division and among providers, consumers and their families. The Peer mentor component of the project plays a large part in this objective. Mentors are matched with participants as a resource to help individuals reach their goals. Mentors have been trained by ABIL (Arizona Bridge to Independent Living) and are part of the planning process and goal making activities. ABIL has also helped establish the People First chapter in Arizona.
- Reduce the average cost-per-consumer so more individuals can be served thereby reducing the waiting list. The debit card approach is one mechanism that is being studied.

MICHIGAN

Michigan has been conducting start-up work with its four local project sites since early Fall, 1996. Michigan made a commitment to conduct an independent evaluation of the initiative, and to that end has developed and implemented a comprehensive data collection process. Data on over 800 individuals has been collected. Michigan's managed care plan for services/supports for persons with developmental disabilities incorporates essential elements of self-determination into its overall framework.

In their annual report, Michigan states, "Much of the local thinking about what managed care is, and how local systems should be re-aligned is built on managed care models which deal with persons who are in acute medical or mental illness episodes, and for whom early intervention is key to stabilization and a restoration of functioning, but where triaging and service substitution hold great promise for cost-control within acceptable outcome parameters. However, some are trying to apply the tenets of 'traditional' managed care to planning and decision-making for persons with developmental disabilities who require long-term support, and where quality-of-life is a primary outcome within the context of long-term supports. The irony is that self-determination is more directly related to managed long-term care than are the tools of the model applied to persons in acute stages of a medical or mental illness."

MARYLAND

With the advent of the Governor's new funding initiative, Maryland feels it is well positioned to implement systems reform. The $118 million of new money will go to serve individuals on the waiting list. This initiative is an indication of the Governor's support of self-determination and the efforts of administration, local news media and advocacy groups in the state.

This will accomplish one of Maryland's main objectives: to balance the needs of those people currently funded with those on the waiting list.

Other Objectives: give people control over the services they receive; create partnerships among people with disabilities and their families, service providers, advocates and Maryland's communities; and reduce the average cost of current services and pass the savings on to people waiting for services.

OHIO

Four counties are participating as pilots in Ohio's self-determination efforts. They report 59 individuals (39 adults, 12 youth and 8 children) are presently participating and expect to add 50 adults and 30 children during the second year. Ohio reports a concern in achieving a more active presence of self-advocates and family members at both the county and state levels of the project direction. Lack of transportation for self-advocates and family members is cited as a barrier to project involvement as well as costs associated with personal assistance during travel time for meetings, etc. Everyone seems to agree that the work involved in each step of the self-determination process is much harder than anticipated, but those involved at the local level report an increased use of creative approaches in solving problems rather than relying or reverting to traditional programs or systems.

HAWAII

Hawaii's project is administered by the Department of Health and has specific objectives to develop new and/or restructure existing programs and policies to support individuals to gain greater control over their lives.

Some objectives:

- Establish a Managed Support Organization (MSO) that will educate individuals with disabilities and family members; establish capitation rates, and administrative and financial systems; develop long-term support systems, monitoring, quality assurance and data collection procedures; and identify legislative and administrative barriers.
- Make system changes at the administrative and legislative levels. Several changes have been proposed and are being considered by the State Legislature (see accompanying information on Hawaii's self-determination legislation). Six HCBS waiver amendments have been submitted.

NORTH CAROLINA

Funding was used to build a base for grass roots consensus and support for self-determination to make it the driving force to reform North Carolina's system of long-term care. A consumer directed Steering Committee was established to work with state agencies in providing the overall direction and implementation of the project. Regional forums are being scheduled with legislators and state officials to discuss the implications of self-determination in system change in the context of the state DD plan.

NEW MEXICO

The Arc of New Mexico met with People First of Tennessee to formulate a plan for a statewide self-determination movement. Leadership training for self-advocates and advisors was held earlier this year with goals of providing the opportunity to discuss a position statement, develop marketing strategies for people to take to local communities, and to develop a strategic plan. The Arc will be sending several people to the annual meeting in Minneapolis to report on the New Mexico project and network with others.

LOUISIANA

The Louisiana Office for Citizens with Developmental Disabilities (OCDD) selected two geographic regions, one rural and one urban, to lead the self-determination project. Thirty individuals who had been waiting for services such as personal care, respite, and medical supplies traditionally available through the Family Support program were offered the opportunity to participate in person centered planning and the implementation process of their services. Efforts were apparently quite successful as families and individuals learned to visualize and vocalize desires and needs, circles of community and family support were created and a state purchasing system more tailored to specific needs were among a few of the outcomes.

ALABAMA

People First of Alabama used funds to develop a strategic plan for self-determination and lay the groundwork for the self-determination movement in Alabama. A multistate planning session brought together self-advocacy leaders from Georgia, Tennessee and Alabama, and Alabama sent five self-advocates to that meeting. Awareness materials and planning results taken from that meeting were brought to the meeting in Tempe in September of 1997 to share with others. A self-determination council comprised of self-advocates, parents and professionals was formed to develop the state strategic plan.

NEW JERSEY

The UAP used funds to assist in the ongoing development of self-determination known in New Jersey as the Governor's Inclusion Initiative. A representative was sent to the meeting in Tempe and four statewide trainings and consultations were held for the 100 individuals and families participating in the project. Funds were also used to send individuals to conferences on purchasing homes and supported living, circles of support, as well as to contract for some technical assistance.

COMMON Sense

-State updates continued from page 13-

COLORADO

In November of 1996, the Developmental Disabilities Services (DDS) submitted a report to the state legislature recommending changes to the service system for persons with developmental disabilities that would promote choice in the face of ever decreasing funds. After the plan was approved, DDS formed a Self-Determination Committee to obtain input from a variety of stakeholders. As a result, a collaborative, statewide multi-phased training project was developed and implemented to reshape current policies and programs.

NEW YORK

The Self-Advocacy Association of New York State (SA) and the NY State Office of MRDD worked collaboratively to create a learning community in the state centered on self-determination and the four principles of freedom, support, authority and responsibility. SA visited projects in New Hampshire and Connecticut and attended the meeting in Tempe, and conducted day long training sessions and workshops that presented the concepts of self-determination to over 1200 people.

HCFA AND NATIONAL PROGRAM OFFICE SPONSOR DAY LONG MEETING ON SELF-DETERMINATION

Michigan, Ohio, Wisconsin, Kansas, Minnesota, and Iowa

The National Program Pffice on Self-Determination together with the Chicago and Kansas City Regional Offices of the Health Care Financing Administration invited the six Mid-Western states with Robert Wood Johnson Foundation Self-Determination grants to spend a day in conversation over issues related to self-determination and Medicaid. Joining the discussion held in St. Louis on May 13 were three of the four remaining states who do not have self-determination projects (Indiana, Illinois, and Nebraska).

Participants at the conference agreed that the meeting was a sucess and only began to touch on important policy issues. Consequently, an agreement was forged to convene the participants once again in the Fall and include additional officials from the Medicaid Branches of HCFA along with other officials.

These regional meetings are part of the National Program Office strategy to increase communication among self-determination states and Medicaid officials.

Roy Froemming, Wisconsin's Self-Determination Project Coordinator (standing), and Don Shumway (seated), Co-Director, National Program on Self- Determination. (Photo by Myron Reinke)

Bob Gettings (l), Exec.Director, NASDDDS and Greg Bublitz(r), HCFA Chicago Regional Office and Chair of the Conference. (Photo by Myron Reinke)

ALL OF MY ASSUMPTIONS ARE NOW QUESTIONABLE

By Ellen Cummings

A few months ago in a northeastern state, a training called "Self-Determination 101" was offered. There was a wonderful mix of people in attendance: people with disabilities, family members, case managers, finance staff, provider staff, and administrators. All came together to get clarification on the basics of implementing self-determination. A handsome young man walked into the meeting room with an attractive young woman. They sat in the first row. During the day, there were small group exercises and discussions about the principles of self-determination and their meaning in peoples' lives. There was particular emphasis placed on dreaming, for it our dreams which sustain us and our dreams which give texture to our lives. The young man was an active participant in every group discussion.

Ellen Cummings

When it came time to reconvene the small groups and report on the activities, he was the one to read what his group had developed. He also told those participating that his dreams were with him always and that his main dream would be to have a family that would love him. The day was full of sharing and learning, but the young man was the one whose input throughout the day was the most profound. These types of training days are grueling. There is a great deal of work and detail with few breaks, and uncomfortable chairs. Despite these discomforts, everyone stayed for the entire day.

After the training, an administrator in the human service system drove me to my hotel. We talked about self-determination and discused some points of implementation; points such as individual budgeting and use of Medicaid waiver dollars. As we pulled into the hotel driveway, the administrator remarked, "I learned a lot today" He stopped the van, turned to me and continued, "I really saw something today that I would never have thought I'd see. The young man in the front row is served in my region. He has a very short attention span. On top of that, he is very aggressive. We have two-to-one staff to manage him." After thinking for a bit, he said, "He stayed the whole day and he participated in everything. He was excited and positive all day. Something is going on here. We hear about self-determination and we immediately think of people who could benefit. But, to be honest, there are also people who come to mind that we don't believe will ever be able to control their lives. I need to think about what I saw today. All of my assumptions are now questionable"

To many of us who work in the system, the self-determination projects and initiatives are viewed as a complex method of system change. Some know intuitively that this change is imperative no matter how difficult; others protest it as being unrealistic or a danger to their livelihood. People who have disabilities and those who love them know that this pursuit of system change is their chance to live the lives they were given, a chance to live a meaningful life rather than a contrived existence

It is the message of freedom and responsibility that captures the attention of folks who have disabilities and those who advocate for them; a simple message of freedom and possibility When Thomas Jefferson was writing the Declaration of Independence, he was asked the purpose of the declaration He replied, "To place before mankind the common sense of the subject in terms so plain and firm as to command their assent" Look at the message of self-determination freedom, authority, responsibility and support It too is plain, firm

All of my assumptions are now questionable If we ever had a thought that self-determination may not be for everyone, our challenge is to open our eyes and our minds to the possibilities bow to the common sense and justice of the matter, and roll up our sleeves to make it work.

(Note. A woman in the training that day was very moved by the young man's dream She and her family have begun visits with him to pursue whether his dream and her families dreams can mesh He may get his family after all!)

-Ellen Cummings offers Self-Determination Training and Technical Assistance-

THE FOUR PRINCIPLES OF SELF-DETERMINATION:

Freedom

TO PLAN A REAL LIFE

Authority

TO CONTROL A TARGETED AMOUNT OF RESOURCES

Support

FOR BUILDING A LIFE IN ONE'S COMMUNITY

Responsibility

TO GIVE BACK TO ONE'S COMMUNITY

IN THE NEXT ISSUE OF COMMON SENSE...

- * Oregon's independent brokerage house
- * Waiting list initiatives
- * Annual Conference recap
- * Part 2 of Moving to a System of Support: Using Support Brokerage

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Ms. GOLDEN. Thank you, Tom.

Now, it is my pleasure to introduce Commissioner Swenson.

STATEMENT OF SUE SWENSON, COMMISSIONER, ADMINISTRATION ON DEVELOPMENTAL DISABILITIES, ADMINISTRATION FOR CHILDREN AND FAMILIES, UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES

Ms. SWENSON. First, let me say I am very happy to see so many people from the choir who could probably tell the same story in the room today. In fact, raise your hand if you know this story by heart.

Thank you. That is a good thing for all of us to recognize. Our knowledge has advanced so far.

I do want to say, also, as the parent of a 16-year-old son who has very involved developmental disabilities and who lives with us at home, that I am very grateful that we are struggling with these problems. I think, as a nation, it does us some good to recognize that we are struggling here with better problems than we used to work with. We are struggling here with problems of how to support American citizens in their citizenship when, in fact, as Dr. Braddock pointed out, maybe 20 years ago, they would not be with us much past the age of majority.

The Administration on Developmental Disabilities programs are located in States. It is the closest thing to a block grant, I think, that we have in the field of studying and understanding developmental disability. In every State, there is a Developmental Disabilities Council that provides grants for demonstration programs and does planning activities. More than half of the membership of the council are people with disabilities and their families.

We also have in each State a protection and advocacy system that protects people's rights and helps prevent abuse and neglect of people with developmental disabilities who are in vulnerable positions. We have in each State now a university-affiliated program to study and research new models, that train professionals in new models and new ideas, and that disseminate new knowledge across the United States. I am very proud of these programs, although I have been associated with them as Commissioner now for a total of 4 months, so I realize I can take no credit.

The Developmental Disability Councils and the University Affiliated Programs and the protection and advocation agencies have participated since 1975 in expanding our expectations of what is possible for people with developmental disabilities in this country, and I want to point out to the Committee something that is extraordinarily important as we deal with this particular issue. That is, the expectations for people with developmental disabilities have completely changed in the last 25 years.

When President Kennedy said he was going to land somebody on the moon, people thought he was nuts, and he did it. When Eunice Kennedy Shriver started the Special Olympics, they had swimming pools that were three feet deep and one lane wide for the swimmers with mental retardation. They had people walk along next to people so that they would not drown as they were competing in their swimming competitions. Now, folks swim in Olympic-sized pools. They do the same exact things that people without disabilities do.

If you could just take that athletic example as a metaphor for what we now expect from persons with developmental disabilities in this country, the same thing applies. We expect more, I expect my son to grow up with his two brothers and have the same independence and have the same citizenship and have the same right to participate in society that his brothers have. That is equivalent to landing on the moon.

The DD programs have helped expand this notion, but we have only reached some families, because when many people who now are aging with developmental disabilities were born, disability was thought to be a private problem. Many people were told, take your child home and love him, and that is exactly what they did. It is very difficult to reach or to help someone understand what is possible if they have no exposure to the new ideas as they are going along.

What I want to point out to the committee is this: I worked for Senator Frist for a year and I answered the phone and I heard the people around me saying, whenever somebody with a disability would contact the office, nothing is good enough for these people. They keep wanting more. Everything we do, next time around, they want more. Well, if I can say one thing to the committee, this is a moon shot. What we have here is an attempt to bring the American democracy home to every citizen in the United States, and our expectations are changing. We do want more.

Hopefully, what the committee will realize today, listening to these numbers, is that expectations are going to be changing for a very large number of people with developmental disabilities across this country. We now know how to support a person with profound mental retardation so they may live in their community. Now, the challenge is, how do we reach all of those persons who do not yet know what is possible, who do not yet have an idea of what is possible? Because once they find out, boom, the decision is easy.

As Jackie Golden pointed out, people are not on waiting lists for institutional placements anymore. They will take it if that is their only option, but it is not what they want once they find out what is possible.

Before I was Commissioner at ADD, I did this volunteer activity for the previous Commissioner. I went around the country to three States: Tennessee, Florida, and Washington State, and chaired a series of family forums. I was a co-chair. My side of the table were families of people who were committed to community supports. The other side of the table, which was co-chaired by Polly Spare of the Voice of the Retarded, were families of people who were committed to having institutional placements available for their sons and daughters. The task was to find common ground.

I would like to share with the Committee what we came up with as common ground. There were 20 people in the room in each of these meetings. The meetings lasted for 2 days. By the way, the way that our systems have been set up over the years, it has been very difficult to get these two groups of people to the table and it has been impossible to find common ground, because, as Dr. Braddock has pointed out, the money tends to be all in one place and the have nots tend to be the people who live in the community.

Here is what we agreed on, and this was unanimous in each forum: the love for our child drove us to the decisions that we made.

Now, John Dewey said, whatever the best parent wants for his child, so every parent should want. What he did not tell us was: How do we tell who the best parent is? I think what I found out in these forums was that what the best parent wants is safety, and security, and belonging, and a sense of self-esteem and love for their child. We all had different notions of how to get this, depending on what we had been exposed to about what was possible. But we were driven there by the love for our child.

We all had a fear of the future, because we could see that models were changing, and systems were changing, and delivery systems were changing, and we did not know what was going to happen to us. People who have disabilities in this country are sometimes called "consumers" of public policy, but often we think of ourselves as "victims" of public policy, more than people who do not have disabilities. We realize that how the system is put together really does affect how we practice our citizenship, how much we are able to be connected to our communities and, indeed, to our families. Very few other citizens are as subject to public policy as people with developmental disabilities.

At the family forums we also agreed, that there was a tremendous need for equity, and those of us who had the most services felt most strongly that we did not want to think that there were other people out there who had nothing.

In fact, Charlie, my son, has had a waiver for several years in Minnesota. We just recently moved to Maryland and left the waiver in Minnesota in order to move out here and take this job. My case manager said, what are you, nuts? In some ways, I guess I am nuts. In other ways, I wanted to know that I was living without a safety net, just like the large majority of families of people who have developmental disabilities are living. It is scary. It is really scary.

But, at one of the forums one of the parents said, I do not want to live in a country, the wealthiest country that has ever existed on the face of the planet, the most complete democracy, where some people get everything and other people get nothing. That is what we are up against with trying to figure out how to bring support to people, and it is often so minimal and so inexpensive. Family support, on an average, costs $2,000 per year per family in this country. That is what we are up against, is trying to find a way for American families to get what they need.

I want to also point out that some of the people around the table at the family forums said that what they felt they needed was less than what the system told them they needed. These are not greedy people. These are not people out to try to make a buck or get more than they deserve. These are people who are really up against the wall, and who need some help. But they don't want to take any more than they have to.

The title of this forum is, "May We Rest in Peace." I sat in a room of 20 parents in three States and asked the question, whether, in their hearts, they wanted to die before their children or outlive their children. You can imagine how difficult a question this is to ask of a parent. I assume if there are parents in the room, none of you would wish that your child would precede you in death. Everyone in all three of these States, parent in the room said they hoped their child would precede them in death because they did not trust what was out there to provide even a modicum of a reasonable life for their child if they were gone, if their advocacy was no longer present.

That is the challenge. That is the challenge we have in front of us, is to make sure that if one has the accident, or in my case, the opportunity of having a child born to you who has needs, that we do not automatically put you into that psychological category where you have to live your life hoping that you will outlive your children. It is not good enough for this country. It is not good enough for what we know how to do.

I am very honored to be included in a panel today with the people who can tell you what has happened over so many years, with people who have numbers that can describe what is happening in the entire country, and with people who are truly making the new models happen, but I hope that I can, if I can do nothing else, focus us on the notion that this really should not be a private problem for families to take home a child and love him and live with that all by themselves.

One more thing. I know my time is up. I did these forums in three States and I do have programs in 50 States and three territories, and I have recently moved from Minnesota to Maryland. The Federalist Papers make it very clear that our Constitution is neither wholly Federal nor wholly national. It is Federal insofar as it governs commerce between the States. It is national insofar as it governs the citizens' rights.

I would like to submit to you today and to the committee for its consideration that the civil rights of a person with developmental disabilities are vastly different across the United States depending on how forward-looking the human services department is from State to State, and I do believe that that is a problem that we have to address. Thank you very much.

Ms. GOLDEN. Thank you, Commissioner Swenson. That is a very powerful statement.

Next, I would like to introduce Diane Coughlin, who is the director of Developmental Disabilities Administration in Maryland. Maryland has tackled this issue and some of the things that they have done are very innovative and they also participate in the Robert Wood Johnson program, as well. Diane.

STATEMENT OF DIANE COUGHLIN, DIRECTOR, DEVELOPMENTAL DISABILITIES ADMINISTRATION, MARYLAND

Ms. COUGHLIN. Thank you. It is a privilege to be here and it is very difficult to follow so many esteemed speakers. What I will have to offer is somewhat redundant, and hopefully a little bit uplifting. While we have not fully addressed all of the problems that we have in Maryland, I think we are well on the way to tackling some of the biggest issues, and in particular, addressing the plight of elderly caregivers.

A snapshot of Maryland. As Dr. Braddock mentioned, we have a population of about five million people. My administration, the Developmental Disabilities Administration, serves about 16,000 people and we have an annual budget of $340 million. Most of the services rendered are done so through private agencies, which we regulate and fund. Services in our State, like in most others, if not all, are not an entitlement. People need to meet eligibility requirements, and then we provide services up to the level of appropriation that we have received. That creates for us, as it does for many States, a waiting list for services. The demands for years have exceeded the amount of money and our ability to render services to people with developmental disabilities.

Dr. Braddock mentioned that our waiting list, as cited in the Sun paper about a year ago, was about 4,700 people. It grew a little bit to 5,400 or so as of January 1 of this year when we began a waiting list initiative, and I will come to that in a moment. Maryland, like other States, is facing the situation of having many, many people on our waiting list with elderly caregivers.

We have had increases in our budget over the last several years, over the last decade or so, and those increases have done very little to address our waiting list. It has remained relatively static over the last decade, and because we have only been able to provide additional services to people in the most dire circumstances, as Lorraine put it, the dead or dying.

Unfortunately, that has created, a system in our State which is inequitable. People who receive services, folks who are, if you will, fortunate enough to get into the service delivery system—if you can call having your caregiver die or be extremely infirmed lucky—if you are lucky enough to get in, you can get pretty much whatever you want. You can get a full residential program. You may receive day services, support services, behavioral interventions, and so forth. In fact, even if you do not want all of that, that is pretty much what you get. You get the whole menu.

We are trying to change that, and with the help of the Robert Wood Johnson Foundation, who graciously provided us with a grant to change our system, we are going to be able to offer folks a little bit more of an "a la carte menu," if you will. We want to give people control over the supports and services they receive. We believe it is imperative to lower the average cost of services by creating more flexibility in our system, and we want to use those savings to serve people on our waiting list.

We began that initiative in 1997, and at that time, we never contemplated that we would receive a large appropriation to address our waiting list. I have to tell you that, in part, the waiting list initiative that followed a year later was because we were determined to reform our service delivery system to give people only what they need, to provide flexible services, and to achieve some cost savings in our present service delivery system.

In 1998, because of a grassroots effort and many other factors in our State, Governor Glendening launched a 5-year waiting list initiative. This is a $118 million initiative based on four premises: To provide day services for everyone, meaningful day services, work or other meaningful activities; to provide family supports to keep families together and keep children at home; to provide community-supported living under the premises that Tom so eloquently outlined of self-determination, not fitting people into slots, as we have typically done in our system, but providing the living supports necessary so that people with disabilities have homes; and finally, to add additional money to our service delivery system so that people who provide direct support in a paid capacity are given an adequate wage.

We began this initiative on July 1, and during fiscal year 1999, we anticipate serving 2,000 people from our waiting list, 300 individuals receiving day services, some 1,400 people receiving family and/or individual supports, and 250 individuals receiving residential supports. That bears a particular mention to this audience. Recognizing the needs of elderly caregivers, we have prioritized people with the oldest caregivers for residential services, so that in this first year of our waiting list initiative, people whose caregivers are age 70 or older will receive the opportunity to have residential supports.

We were able to get this waiting list initiative because we have been engaged in changing our system and because we have embraced the concepts of self-determination. We are absolutely committed to the fact that the new money that we are receiving to serve people on our waiting list will be spent in accordance with the principles of self-determination. Those two initiatives are linked inextricably, philosophically and practically, throughout our system. It is very, very important.

Let me also tell you about something that happened a few years ago and was, in fact, a little bit of a forerunner, perhaps, to our massive waiting list initiative, and it is something that may be unique to Maryland. In 1994, members of our advocacy community, largely through The Arc of Maryland, asked one of our legislators to sponsor a bill to establish something called the Waiting List Equity Fund. This was a very innovative piece of legislation that requires my administration to take savings that accrue when people are moved from institutions into the community and use those savings to serve people on our waiting list.

Over the last, I guess we have begun to implement this particular initiative for the past 2 years, we had a very interesting experience. When we promulgated the regulations to implement the fund, we again said most elderly caregivers should receive services first and we began going down the list, starting with the very oldest person in Maryland. We did not have anyone 101, but we did have someone in the upper 90's. We began with a group of 25 people, the most elderly caregivers, all of them, I believe, in their 90's, and many of them told us, no, that they did not want what we were offering.

What we did when we approached these families was say, OK, your name has come up. You can have services from the Developmental Disabilities Administration and we will give you a residential program and your son or daughter can move out and we are going to put them in this place over there and they are going to get this day program. How do you like it? And most families did not like it at all. They were threatened by it. It took away their sense of community and family with the person with the developmental disability and they said, no, thank you, in a number of instances.

We were all stunned by this, and after thinking about it and talking with families, we realized that our approach was entirely wrong, and I guess it was about that time that we began to embrace the concepts of self-determination. We went back to those families and we said, let us think about this. What do you need? What does your family need? And what do you want for your son or daughter after you are no longer able to care for him or her? We developed very, very innovative supports for these families. Most people then said, oh, yes, we would appreciate that, and we saved an awful lot of money in the process.

That particular piece of legislation has also been paired with another bill in our State called the Community Services Trust Fund, which requires us to deposit into a trust fund the proceeds of any lease or sale of property that had previously been under the auspices of my administration, so that as we free ourselves of the bricks and mortar of institutions and use that property to make some money. It is then deposited in a trust fund, the interest from which is deposited annually into the Waiting List Equity Fund. It is a wonderful way to create an ongoing revenue stream to serve people with developmental disabilities.

Despite the sobering testimony of the people that preceded me and the very serious situation that we all face in this field, I think that in Maryland we have a sense of hope. We believe that we are beginning to grapple with this challenge. We certainly do not have all of the answers, but we think we are well on the way to really making a difference in the lives of people with developmental disabilities, particularly those with elderly caregivers.

What the Federal Government could do to help me as a State Director, and I do not have much new to offer—I think my colleagues have said most of these things—but I would again reiterate, efforts to embrace and strengthen laws and regulations which protect the rights of people with disabilities and mandate their full participation in society are essential. Affording States greater flexibility in how we achieve that goal is very, very useful to us. Encouragement to States and incentives to prevent crises and invest in families early is very helpful to us.

I think anything that the Federal Government could do to assist States or require States to keep savings within our own systems, to protect the money that has been earmarked for people with developmental disabilities, would certainly be appreciated by myself and my colleagues. Thank you.

[The prepared statement of Ms. Coughlin follows:]

Senate Special Committee on Aging Forum
Can We Rest in Peace?
The Anxiety of Elderly Parents Caring for a baby Bloomers with Disabilities
September 18, 1998

In Maryland, the Developmental Disabilities Administration (DDA) regulates and funds the service delivery system for people with mental retardation and other developmental disabilities.

Community services funded by the Developmental Disabilities Administration (DDA)are not entitlement and the demand for such services has exceeded the available funding. As a result, a waiting list for all categories of DDA. funded community service exists. With the lifelong need for service among people with developmental disabilities, attrition in the system has not been sufficient to address the needs of those who are waiting. Crises or emergencies occur when aging caregivers can no longer provide for the needs of their family member, become disabled themselves, or die. Actual emergency needs have exceeded the requested and appropriated budget for emergencies, placing hardships on families as well as a strain on the service delivery system attempting to provide services.

In Maryland, the waiting list for services is approximately 5,400 people. This number has remained relatively stable over the past several years despite increases in funding for DDA. Most of the individuals on the waiting list are receiving no services of any kind from the DDA at present and many of those people and their families are considered to be "in crisis". Of particular 61. An additional 38% of the people on the waiting list have caregivers in the age range of 41-60 years. Historically, it has only been those in the most dire circumstances who have benefitted from increases in the DDA budget. By necessity, the entirety of DDA's base budget has been devoted to the provision of ongoing services for those already in the system.

In 1997, Maryland received a grant from the Robert Wood Johnson Foundation to begin systems change through a Self-Determination Initiative. This effort will:

- Make it possible for people to have more control over the services they receive and how the services are provided;
- Build upon existing partnership between people and their families, service providers, advocates, state and local governments, and Maryland's communities;
- Lower the average cost of current services; and
- Assist people and their families who are waiting for services.

In 1998, recognizing that savings from the aforementioned systems change effort along would be insufficient to address the waiting list, Maryland launched a five year, $118 million Waiting List Initiative. In FY 99, $34.2 has been appropriated for this purpose. The Waiting List Initiative is based upon the following principles:

- Every individual must be provided with a **day program** that meets his or her needs for personal growth and habilitation. These programs must be structured to support the needs of the family/caregiver by providing respite and the opportunity to maintain employment.
- **Family support services** must be made to available to enable families to provide for the needs of their developmentally disabled children in their own homes. This includes services such as service coordination; in-home assistance (respite care, home health services, nursing care); home and vehicle modifications and adaptive equipment; parent-to-parent support; and specialized services like clothing, supplies, equipment, transportation, or other unique supports needed to help families raise children at home.
- **Community supported living** for adults is predicated on the principle of self-determination. This is the guiding principle of the Robert Wood Johnson project, which seeks to develop new and creative solution and alternatives to support individuals and their families in the community.
- **Adequate funding of direct care staff** must be provided in order to ensure safe and quality programs.

In FY 99 it is projected that approximately 2000 people from the waiting list will receive services. In this first year of the Initiative we expect to provide 300 people with day services, 625 people with individual support services, 800 people with family support services, and 250 people with residential services. Individuals with elderly caregivers have been prioritized for residential services. Individuals with elderly caregivers have been prioritized for residential services and everyone on the waiting list (as of 1-1-98) whose primary caregivers is age 70 or older will be offered services this year.

The waiting List initiative and the Self-Determination Initiative we are complementary to one another, and they are linked together philosophically and practically. Utilization of the principles of self-determination will create efficiencies and savings to serve those on the waiting list. In turn, each new dollar spent on the Waiting List Initiative will be done in accordance with self-determination thus furthering the reform of the service delivery system.

In Maryland we are:

Moving From a system that:	Moving Toward a Person: Directed System that:
plans and coordinates supports only within existing service models	Plans and coordinates supports and services that helps people live their dreams
determines quality through process and professional standards	Determines quality by asking people if they are satisfied with the supports and services they receive and if they have outcomes they want.
has professionals who know and work the system	Has people and their families making informed choices with the help of people knowledgeable about options
pays for a package	Pays for supports and services a person wants, needs, and receives

Also tied to the Waiting List Initiative is Maryland's Waiting List Equity Fund. In 1994, the legislation enacted a bill to create a "Waiting List Equity Fund," This is a nonlapsing special fund established to serve those on the waiting list. The legislation was developed on the premise that institutional care for someone with a developmental disability is more expensive than community based care. So when someone moves from an institution in Maryland into the community, the savings are deposited in the Waiting List Equity Fund. Monies in the fund are then used to serve individuals who are on the waiting list, those with the most elderly caregivers receiving services first. Maryland also established a Community Services Trust Fund to receive the proceeds of the sale or long term lease of state property under the auspices of DDA Interest from the trust fund is then deposited into the Waiting List Equity Fund on an annual basis.

In Maryland we believe that we have made great strides in addressing the waiting list for services for people with developmental disabilities. We are particulary pleased that we have prioritized for services those individuals who have elderly caregivers. We recognize the extraordinary contribution that they have made in caring for their sons and daughters and it is our goal to give them "peace of mind" about the future.

Diane L. Coughlin
Director
Maryland Developmental Disabilities Administration

Ms. GOLDEN. Thank you, Diane.

Actually, since it is a small group, I would like to open this forum to questions from the audience, and since it is small, I think we can keep it sort of informal and your questions and our answers will be part of our record and there will be a committee print from this forum, so I would welcome questions from the audience.

I would like to start, if I could, because I have some questions of my own. The first one that I would like to ask is for Dr. Braddock. HCFA has written the State Medicaid directors to advise them of the relevance of the Americans with Disability Act in their work. Have you seen any movement toward non-institutionalization as a consequence of the Americans with Disabilities Act?

Mr. BRADDOCK. I have not seen any direct non-institutionalization policies implemented as a result of the ADA yet. The ADA is one of the two or three most important pieces of legislation in the history of disability enacted by this Congress. It is a piece of legislation that has global and societal implications and I think we will see the impact of the ADA over the course of the generation that follows. But there may be individual instances in the States where there have been—people have been influenced by its thinking, but I am not aware of any concrete examples. Perhaps other members of the panel are.

Mr. NERNEY. I would like to add, by way of recommendation, that the U.S. Justice Department, the Civil Rights Division, the Special Litigation Section, be encouraged to use the ADA in its institutional cases. They have been reluctant to use it. I think it has only come up a few times in some of their cases, and yet the case law is becoming clearer and clearer that the ADA does apply, and if the Justice Department were to do that instead of just relying solely on the Civil Rights of Institutionalized People's Act, I think we could advance that issue quite a bit.

Ms. GOLDEN. Thank you. Mr. Nerney, I have another question for you. Can you tell me how the relationship between the Robert Wood Johnson Foundation monies for specific projects are used in conjunction with the Federal and State monies for programs like Medicaid?

Mr. NERNEY. The Foundation has an absolute prohibition on its money being used for services. All of the money that we have invested—it is about $7 million so far in small and larger grants around the country—offer systems change and the cost associated with that, frequently personnel, you know, the extra kinds of things you need to bring into place when you are going to really attempt something so fundamentally difficult, I think is what all of our projects would tell you.

Ms. GOLDEN. Are there any audience questions? I would invite you to come up to the microphone.

Mr. MICHAUD. I am Norbert Michaud from The Arc of Northern Virginia and one of the volunteer parents. I work on the Housing Committee. I would like to direct this question to Diane Coughlin. At the bottom of the first page, you refer to building on existing partnerships between people and their families, service providers, advocates, State and local governments, and Maryland communities. Has that evolved to the point where families can contribute to the process financially, where family trust funds can be used? Can you elaborate on what you have done so far on that?

Ms. COUGHLIN. Yes, I believe we have been able to do that in Maryland. Families can own homes and give their homes to their children, who will, hopefully, outlive them. We have been able to do a number of creative things along those lines. Occasionally, we get hung up in some of our own regulations, and I would not tell you that everything has been perfect, but certainly, our thinking is to try to force our system to allow people to contribute as much as they want or can to the care of their family members with a developmental disability.

We have also been able to pass some legislation to allow the establishment of discretionary trusts in Maryland, and while one of our lawyers would have to explain the finer points of that to you, from what I understand, that has been done in such a way that people's earned income will not be affected, their benefits from SSI and SSDI would not be diminished by virtue of having a discretionary trust, and I believe the tax implications of it are beneficial to families, as well.

Ms. GOLDEN. I would like to add to that, because I am a recipient, or my son is a recipient, and we have used the self-determination model to deliver services to him. Initially we were given a very expensive institution for my son to live in a pediatric hospital. We went from there to a group home—again, this is not what we wanted. Now we are using the principles of self-determination and we have given our home to our son and I am his case manager and I coordinate his care and it is an outstanding program and he is soaring in the community and he is a child with significant disabilities.

He is included in his home school, he receives the support from our neighbors and our community. It is just a pleasure—I just cannot tell you, as a parent, what a relief it is to know that he has his own home that will be his home for the rest of his life and I do not have to worry about where he is going to be, from what agency to agency. I have set up a trust fund for him, and worked out those details, as well, and the State of Maryland is very committed to the self-determination principles and it is just a wonderful program for my son that was designed by me and my husband. We designed the supports and identified what he truly needs and it was much cheaper. We saved 15 percent of his previous cost in a group home, which is a considerable sum.

Ms. SMITH. Hi. I am Patty Smith, a parent from Virginia of a daughter and one in that aging group of their children living at home with them. I am also the executive director of the National Parent Network on Disability.

My first comment, I want to address to David Braddock. I am assuming that the zero under Virginia means that you just did not get data? That does not mean that we do not have any—

Mr. BRADDOCK. No, it does not mean that. It actually means that the State said that there was no waiting list, that there were zero people on the waiting list, and—

Ms. SMITH. I was afraid of that. I was afraid of that. I want you to put down one. [Laughter.]

Because I know of one. I am here. That really upsets me, because I am impressed with the data and the information that has been shared here from the State of Maryland, but I noticed that there was not much of any data shared from the State of Virginia.

When I moved here from Nebraska some years back, I thought I was moving to a progressive part of the country and what I was doing was moving to a very regressive part of the country because Nebraska was about 20 light years ahead at that point in time of—even in the thinking. A lot of the programs in that part of the country have kind of leveled off a little bit and maybe have not been quite as progressive, but they have been around so long, everybody just takes it for granted, and this, I think, is disgraceful.

I do not know where we rank, David. Where do we rank now on institutionalization, do you know?

Mr. BRADDOCK. In terms of fiscal effort, you are in the 40's.

Ms. SMITH. Forty-one? Forty-four? Oh, we are only 44th in the country for people in institutions? Then how is it—because we are not putting people into institutions. When you go around that State, you see people 60, 70, 80 years old taking care of their kids. Now, they have started some in-home supports, because my daughter gets in-home supports, but I guess I would like—Jackie, you asked, like, what are some of the next steps? Well, some of the next steps are that we need to get some of these States to at least acknowledge.

Mr. BRADDOCK. If I could respond, one of the recommendations that I have outlined in my testimony is that we do desperately need to conduct independent, objective studies of waiting lists and aging caregiver issues in the American States now. I am not sure we can count on the States themselves to want to fund such studies. We perhaps should get some Federal assistance through the DD councils and the UAPs and so forth, as well as perhaps from HCFA to try to collect such information.

Ms. SMITH. But the Aging Committee could ask for that.

Mr. BRADDOCK. Well, yes, but I am not sure what you would get unless you asked for it in the right way. The Arc for example, has collected waiting list data, as has the University of Minnesota. If it is supplied inappropriately or incorrectly or if it is just stonewalled, as it has been in a number of States, then where are you? There need to be some incentives created so that if a State supplies correct information, there is a likelihood that additional services will be provided to needy families.

DD councils are required under Federal legislation to do State plans and revise those plans annually and, I think, to produce a comprehensive new plan every 3 years. One of the things that perhaps the Commissioner could do under her leadership would be to encourage or require the councils to have sections of those plans that address waiting list issues in terms of quantifying the dimensions of the problem and identifying just precisely what steps each State is taking to address it.

But very often, States are reluctant to supply statistics that suggest there are things that they ought to be doing that they are not doing, and Virginia is one of these States. The State of Iowa did not furnish data on the waiting list, as well, although they did not tell the collectors of the survey at the University of Minnesota that they did not have any data. They said that, "We just do not collect it," whereas Virginia said zero.

Ms. Smith. It reminds me, I was in Russia in the early part of the 1990's and I kept trying to find out how many people they had there with disabilities and they did not have any numbers. They did not know. They had the number of people that had been in gulags, they had the number of people who were like veterans, that had been hurt in wars, and stuff like that, but they had no numbers for people with disabilities, and it really occurred to me after that visit that if you do not acknowledge the people you have got, then you are less likely to do something about it. So I guess I, as one citizen from Virginia, would like to suggest that maybe somebody can get that information.

My second thing I wanted to address to Tom Nerney and the whole business of self-determination and the ADA. I have been asking that question around Washington ever since the ADA passed, and my premise on it was that how can it be that there is such an inequity in the State that I live in when you check the cost of institutionalization, and at that time, I could not get one cent of help for Jane, and now she does get some in-home support services, which have been extremely helpful. I will not say they have not been.

But I still think that the ADA should—we should be able to do something about this absolute inequity of the spending of the money and the way people are treated. They are not being treated properly. And I know there have been Justice Department investigations into the institutions in Virginia and they found some really difficult, bad things there, which would be a bit inequitable if you are treated terribly.

So, I do not know, Tom. You surely must have figured this out by now.

Mr. NERNEY. It is clear to me. I do not know why it is not clear to the Justice Department.

Ms. SMITH. Maybe you should—

Mr. NERNEY. Of course, the ADA applies. Yes, the ADA does. It is interesting. You look at some of the class action lawsuits around the country, the advocacy groups are now filing separately from the Justice Department, totally different grounds, because the advocacy groups are using the ADA in Federal court, but the Justice Department, with some exceptions, is basically not. I think they have an obligation to. I do not think it is a question of discretion on their part.

Ms. SMITH. Well, it is a law, is it not?

Mr. NERNEY. Well, one would think.

Ms. SMITH. Thank you.

Ms. GOLDEN. Thank you.

Ms. CROSER. My name is Doreen Croser. Jackie, I would like to thank you and the members of the committee for bringing this critically important issue to the attention of the public at large. I have just lived this personal nightmare myself. I have just fairly recently lost my mother, who her whole life had taken care of my brother, John, who is now in his mid–40's. This is a critical issue and truly a crisis in the national scene.

I also do a fair amount of speaking on this topic, because I also serve as the executive director of the American Association on Mental Retardation, and there is just one thing that I would like to be sure we mention as we go around and talking and raising consciousness about this issue and that is drawing to the public's attention what a major contribution families who have kept their son and daughter at home for decades make to our society. If you want to think about it in economic terms, what is the average cost of a residential service, David?

Mr. BRADDOCK. In State institutions now, it is $258 a day.

Ms. CROSER. Community, how much a year?

Mr. BRADDOCK. Probably 70 percent of that sum, 60 percent, for out of home residential placement.

Ms. CROSER. Let us say $50,000 a year, and a person who is kept home for a decade, that is a half million dollars in contribution, economic contribution. Spread this over a lifetime. My brother lived with my family for 4½ decades. That is a major economic contribution to our society, and when people get to the end of their lives, that should be drawn to our policymakers' attention so that at least they can get a little service for their son or daughter.

Ms. GOLDEN. True. Thank you very much.

Mr. EGNOR. Hi. I am David Egnor with the Kennedy Foundation and my question is directed to Jackie Golden, to Commissioner Swenson, other members of the panel. Jackie, I was intrigued by the plan that has been developed for your son and I wondered if you would be comfortable telling us what that plan looks like, what services your son is receiving, to Commissioner Swenson, as well, if you are comfortable, with the services your son has received. That would give us a sense of what kinds of services that your children need and how effective they are. Thank you.

Ms. GOLDEN. Sure. It is my pleasure. My son is 17 and he has 24-hour supervision, he is a complex little guy and the happiest little guy I know and he is just a wonderful individual. He deserves the best. One of the things we looked at, what is the best resource that my son has in his community? Well, the answer is really obvious to me. It is his parents, his community, his home that he grew up in up until he was eight, when he was forced to leave because of lack of supports in the community. So it made sense for him to come back home to a community that welcomed him. The same reasons we purchased our home for our family is why we wanted him there, because it was close to doctors, it was close to schools, there are four grocery stores in the neighborhood, it was a wonderful environment for him.

So we gave our home to Joshua and he requires two staff that come in during the week. The two staff are paid staff. We do not live there with him anymore. We have designed his program for someone to live there around the clock and we looked to our own backyard for that person. It is his one-on-one person that was in the school system. He is a young man who is 28. We have asked him to move in with our son, Joshua. For this, he receives free room and board. He is compensated a small stipend because Joshua has a sleep disturbance, so he gets up in the middle of the night and he spends his 2 to 4 o'clock in the morning hours being busy.

So this young man will get up with him, and for that, he does receive a stipend for his efforts there.

The live-in caregiver person's job is to basically oversee the property, so he is free to go and have a job, which is his one-on-one position at school, as well as he works for a hotel in the area.

The other component we need is weekend staff. There are two individuals that work every other weekend. The hours are nine to nine. Activities are flexible, and that is one of the things we pride ourselves on in this program. It is also very much a family oriented program. So if one of my caregivers want to bring their children over to my home, or Joshua's home, they are free to do so, the same way as Joshua can go over to their home. For instance, last week, they all went out bowling together, the families, so it is very much a community-oriented program.

Basically, the support we pay for is his staffing. I bring the case management to the program. I make sure the school happens, the staff is there. I check in on a regular basis. I provide respite to my staff. When they want time off, I am there, or I am here at the committee. But, actually, I provide the respite, and when my weekend staff need time off, I do that. If my live-in caregiver needs a night off, I spend the night with my son. This was our home at one time, so I am very comfortable doing this and providing supports in the home environment.

So that is pretty much the program. Not only is it cost effective, but it makes more sense. It would have been even better, when we first stepped up to ask for services—originally, had we asked for just minimal services, which would have been help with respite, help with our medications that were not covered by insurance at the time, and also help with the costs of diapers alone. Had the State said to us back then, we are here, we are going to give you these flexible services it would have been much better. Instead, we got a very large institution that cost Medicaid $120,000 per year. Joshua was there for 5 years. I could have bought a lot of diapers for that.

Mr. SCHNEIDER. Good morning. My name is Dick Schneider. I live in Fairfax County, VA, that other State that is not represented here for quite obvious reasons.

Dr. Braddock, I would like to submit as testimony to the committee a market research study that we have conducted for Fairfax County, working with the Community Services Board and The Arc of Northern Virginia. The independent housing committee of families representing The Arc has conducted a study of our waiting list in Fairfax County, and I can tell you, there are 350 names on the waiting list. I can tell you we had a response of 185 of those people to a survey. There are some 98 caregivers over the age of 60, 41 over the age of 70, that are in need of residential support services for their family members, and we also understand the level of care that is required, the type of housing preference that is desired, and things of that nature, so I would be very happy to share this information with you, if you would like it.

We commend the State of Maryland for what you are doing, and you are an excellent benchmark for those of us that are trying to push some things in Virginia without a lot of success so far. Thank you.

Ms. GOLDEN. Thank you.

Ms. SWENSON. Jackie, is it okay if I back up for one second and answer David's question?

Ms. GOLDEN. Sure.

Ms. SWENSON. I just want to make one comment. I have recently moved here from Minnesota, and as of today, I am now actually glad that I just moved to Maryland. [Laughter.]

Because in Minnesota, my son, Charlie, who is 16, had a waiver and access to a program called TEFRA, which gave him Medicaid based on his income, not my income. Charlie has a very rare kind of muscular dystrophy. I do not usually talk about him in public, but I suppose that is the whole point today.

He is not medically fragile, but he does have particular medical needs, including having dentistry under general anesthesia, wearing contact lenses because he is legally blind. He wears diapers. He is a big, jolly person and a lovely influence in our home, but he does require 24-hour supervision. He does not feed himself. He does not speak. He does not walk. He weighs right now about 185 pounds at age 16. I was still carrying him up the steps when he weighed 75 and 80 pounds to his second-floor bedroom because the wavier and TEFRA gave us a whole bunch of services that we did not want, which are very expensive, and would not give us access to the things that we actually needed to be able to take care of our son at home, other than the diapers, the contact lenses, and the dentistry, because those were medical.

TEFRA and the waiver have purchased, I think, one out of the four wheelchairs that Charlie has had in his life. The others were purchased using the ordinary insurance that my family carried.

My biggest problem with this program always was it was too much money. I am an American citizen, like all other American citizens. I like being able to take care of my family by myself. I do not like using public money for stuff that I think I should be doing myself. I also have two other sons, though, and I want to send both of them to college, and what I wanted was just what I needed to be able to take care of Charlie at home along with my other kids and not bankrupt the family in the process.

I testified in the Senate in 1993 that I had to lie in order to get the services that I wanted for my son. They were very interested in this fact and asked me whether I really wanted to tell them what the lie was, and I said, well, the lie is that to get a waiver, I have to say that if Charlie did not have these services, I would institutionalize him. I will not because, as I just found out moving to Maryland, we either sink or we swim, but we sink or swim together. He is not going someplace else to live. He is staying with us because we love him and because he is part of us.

I have a hard time when I am with parent advocates and people with disabilities telling them that I have too much money attached to Charlie. Typically, there is a lot of anger in the room, and typically, I take a big hit for that, because people who have nothing do not need to sit there and have some woman like me tell them, well, I figure about $40,000 a year is wasted on my son, allocated to his case and unused or poorly used because these are services that we do not want.

But I think, David, I am glad you asked that question. Nineteen-ninety-three is the first time I testified about this in the Senate in a hearing on the DD Act and I do agree with the gentleman from Fairfax County that it is market studies that we need. We need to understand: What is it people need and want and how much would that cost? That is what self-determination is about, as you heard today. We go to people and say, what do you need, what do you want, how can we get that to you, and what we know and what we find over and over and over again with American citizens is they want to use the least public dollar that they possibly can.

Ms. GOLDEN. That is true.

Mr. BRADDOCK. May I say to Mr. Schneider, we would be really pleased to see the study that you have completed in Virginia and I would really encourage you to also share that with the State leadership in Charlottesville.

The most significant data in my testimony today is that there are estimates 10,584 families in Virginia who are caregivers over 60 years of age; This conflicts with the zero figure that the State furnished the University of Minnesota that conducted the aforementioned waiting list survey. You might describe this as a cover-up, of sorts, of the dimensions of the problem of support for families in Virginia.

Ms. GOLDEN. I have a question for Diane Coughlin. Do you think the Older Americans Act can play a larger role between the area agencies on aging and disability organizations?

Ms. COUGHLIN. Yes, I do, Jackie. I think that both at the local levels, with area offices on aging, and at higher levels through State government, and, of course, here in Washington and with the Federal Government, that greater linkages between developmental disabilities administrations and area offices on aging and their higher-up bureaucracies is absolutely essential and we could do an awful lot.

I was talking earlier today with a colleague about that very matter and we were talking about how some of the age requirements do not make as much sense for people with developmental disabilities, that sometimes people with Down's Syndrome are beginning to experience some of the same difficulties that people that do not have disabilities reach at a later age, that people with disabilities may experience this, you know, as early as middle age, and that the requirements that the aging system places on people for services could be prohibitive. We are very much in favor of people with disabilities having the same access to generic services and services offered through other government entities, like area offices on aging, as everybody else.

In Maryland, we have done some things with that. I know that in some instances where elderly caregivers have wanted to move into assisted living programs, and sometimes there are requirements where you cannot have young people. But we have been able to get some of those rules bent so that an elderly caregiver could move into an assisted living program with their adult child with a developmental disability. Those kinds of efforts and mandates to build those bridges would be extremely useful.

Ms. GOLDEN. Thank you. One of the things I have heard when I was polling different States, from older parents, is that, as they apply to the aging agencies, they are bumped over to developmental disability agencies and basically get lost in the system because there is no coordination between the agencies, so I think that is an issue.

Ms. COUGHLIN. That, indeed, happens, and in Maryland now, we are little worried that because people will view us as flush with money because of the waiting list initiative, that other government entities that have a responsibility to provide services to people with disabilities will not do it, because we have money to address our waiting list.

If I could also make one other comment about the waiting list, there was some discussion about Virginia and about the waiting list. We think that the number of 5,400 that we have used might be an underestimate of the actual waiting list in Maryland. Because for years it was so hard for people to get any services, a lot of folks were not going to sign up. They did not want to bother with our reams of paperwork and go through the rigamarol of having someone come into their home, intrude on them, only to be told that we had nothing to offer them, probably would have nothing to offer for years and years and years. So we believe that there are numbers of people, and I could not tell you how many, but I think that there are substantial numbers of individuals who are eligible for services but are not even counted on our waiting list.

Ms. GOLDEN. The other question I have is how are the funds or the grant that is granted to Maryland from Robert Wood Johnson, how is that money used in Maryland?

Ms. COUGHLIN. It is being used—and we received a grant of about $400,000, spread over a 3-year period which is being used to fund the position of a project director, who is a full-time employee who will be working on our systems change effort. It is also being used to provide training throughout our State. Some of us at various levels have greater understanding of the concepts of self-determination than others and we have found that we needed to do tremendous training throughout our service delivery system of people who provide service coordination and case management, of providers of service, of us bureaucrats, of family members, and of people with disabilities, and so a great deal of the money is being used for that effort, as well. It is not, as Tom mentioned, used for direct service in any way.

Ms. GOLDEN. This is for Tom. Often, public officials worry about accountability, ensuring that taxpayers' money is spent reasonably, responsible economically, and in ways of keeping for the authorized purposes. What ensures accountability in self-determination?

Mr. NERNEY. Let me give it a shot. A couple of things. For the first time, you know where every penny is being spent. You look at the present human service system and it is probably much closer to the field of astronomy. It is a black hole. We spend between $23 and $25 billion every year across the country in the field of developmental disability, and I think the important question is how many of those dollars actually reach the individual.

For the first time, when you construct individual budgets, people—why should we be surprised at this—people are only asking for what they really need and they are only budgeting for those things. We have families who are even—with the individual budgets in some places, point to another family with something and say, give them some of my money. That never happens in the present system.

We are talking about much more accountability from a financial point of view. We are talking about being cost effective, which I think we have an obligation to be, but with incredible flexibility and freedom. Without the flexibility and freedom, I do not think we are going to be cost effective.

The other areas of accountability go to what I would call issues of quality, and I think our entire traditional system of quality assurance is—it is just false. Folks with disabilities and families should be determining what constitutes quality, and I maintain—I say this over and over again—how could you possibly have quality in American culture if you do not have freedom? How could we possibly pretend, with all these fancy quality assurance systems in all 50 States, that there is quality or some semblance of quality where you do not have the basic American freedoms?

Ms. GOLDEN. That is so true, and I agree. I am very accountable for my son and what he is receiving. I said to another parent that I would gladly accept fewer services so she would have something.

Because she was receiving nothing at the time, so those are true words that you spoke.

The other question I would like to ask each panelist very quickly, if we could, before we conclude, is if you could change or we could identify some Federal changes that we can make, what is on your wish list, and I would like to start with Lorraine.

Ms. SHEEHAN. I have many things on my wish list, but the number one would be the bias toward institutions. We simply have to get away from that. We can serve almost everyone on a waiting list if we spend our money more wisely and redirect the money that we have, so that would be my number one wish.

Ms. GOLDEN. Dr. Braddock.

Mr. BRADDOCK. Well, that has been a refrain of mine for about 30 years now, so I think I will support Lorraine. We are doing better in this regard, but we are doing better at the expense of the American taxpayers. Thirteen years ago, there were hearings sponsored here in the Senate on the Community and Family Living Amendments of 1985. How many of you remember those hearings? The purpose of those hearings that were sponsored by the Senator from Rhode Island, Senator Chafee, were to look into the issue of addressing this institutional bias. The Arc was the major mover behind this piece of legislation and it took a lot of criticism because people thought it was such a radical idea and it was too far ahead of its time and so forth.

In effect, what it did was that that leadership established the idea that we can live in an institution-free society as a proposition that we needed to start to debate formally in the halls of Congress. This is, in my view, no longer truly a debate. The agreement has essentially been reached in our society that we will move toward an institution-free society. But during the period of this transition, we are still left with a number of artifacts of legislation and fiscal policies that support caring for people in large congregate care settings, public and private institutions, nursing homes, and the like.

The Senate Special Committee on Aging can do a great deal in terms of providing additional leadership in regard to facilitating the transition in the most reasonable and responsible way so as to be sensitive and fair to families who still value institutions and large settings, but at the same time recognizing that all over the world, the march is toward freedom. The evidence is fully before us in the Soviet Union, with the fall of the Berlin Wall, and in the rights of minorities that have been championed since the 1960's in our society so ably. We are moving inextricably toward freedom and self determination for people with intellectual disabilities specifically and for people with disabilities generally, as well.

Ms. GOLDEN. Tom.

Mr. NERNEY. I agree with both. What you are really talking about is reinvesting existing dollars, sharing them, getting to the question of equity, and I think it may very well be that there are some States where you have to be a little more forceful, where good information is not going to make the difference, and that goes back to the earlier discussion we had about what is the role of the Health Care Financing Administration and what is the role of the Justice Department here? They both have a very important role to play.

It seems to me the committee could do some work just by bringing those groups together with some folks who understand these issues and make sure that as a matter of policy, the ADA is being addressed by both groups. That would be a help.

I still think it would be revolutionary to get into statute the principles. Freedom is not a word that is used in the field of developmental disability, and that will tell you a lot about the present system. I think we need to rethink not only how folks obtain supports in this country, but we have to rethink what we are doing, and that means we have to be very analytical. We have to describe the present situation honestly. We do not do that. And we have to raise all the conflicts of interest, because they are not bad people, but if they have conflicts of interest or the system is based on conflict of interest, then let us at least surface that.

I think we can start with just a few things, HCFA, Justice Department, and getting into statute basic American rights that everybody else takes for granted and saying, look, that is what the system is going to have to support, and it may take us 10 or 20 years to get there, because I think, realistically, it will, but that is where we are going.

Ms. GOLDEN. Thank you. Commissioner Swenson.

Ms. SWENSON. I have been telling the people in my network that I have a dream that my network will not operate as a demonstration project-driven network anymore but that we will take up, now that we are a complete network, take up the responsibility for systems change that I think was built into the DD Act and begin to understand that until all American citizens with developmental disabilities have access to the supports that they need to be free and responsible citizens, we have not done our work. If we continue to think that if we demonstrate that we can do it for a few, we are failing. So that is the basis of my very personal wish.

Ms. GOLDEN. Diane.

Ms. COUGHLIN. I guess I would echo the request to remove the bias toward institutions and further that by saying we ought to have a bias toward communities and families and might underscore that a little bit within the realm of work. I think there are a number of disincentives for people with disabilities. They lose benefits. They lose their insurance and so forth when they work for very, very modest amounts of money, and I think that we have got to take away the bias toward unemployment, as well. If people with disabilities are ever going to be respected in our society, they have got to have money, so that would be my two cents, if you will.

Ms. GOLDEN. I want to conclude our forum today and I want to thank everyone for coming and thank our presenters. They were just wonderful and I am hoping this is just the beginning. Thank you.

[Whereupon, at 12:20 p.m., the forum was adjourned.]

APPENDIX

"Unlock The Waiting List"

A Report on the March 1998
Survey of Caregivers
For Family Members With Mental Retardation
On the Waiting List
For Residential Services

A Project Co-Sponsored by:

The Arc of Northern Virginia
And
The Fairfax / Falls Church Community Services Board

Prepared by:
Richard E. Schneider
Norbert Michaud
April 1998

About This Report

During the past year, a Task Force Committee of The Arc of Northern Virginia was formed to study currently available residential housing options for adults with mental retardation in the Fairfax / Falls Church area of northern Virginia.

The objectives of the Task Force were: 1. To gain understanding of the different residential models currently serving adults with mental retardation, including home types, costs, and county, state, federal policies and practices affecting funding and availability; and 2. To clarify residential needs and preferences of adults with mental retardation, and to seek more cost-effective housing options to accommodate a larger number of people who need to be served.

As the Task Force investigation has progressed, it has become clear that past and current strategies and priorities of Virginia state government have resulted in a serious underfunding of residential support needs, creating a large and growing Waiting List for residential placements (identified by the Community Services Board as 350 individuals with mental retardation in the Fairfax / Falls Church area).

The Task Force, in collaboration with the F/FC CSB, determined that a survey of Waiting List families would provide useful current information regarding residential preferences and the urgency of residential supports for individuals with mental retardation on the waiting list.

It is expected the information and data from Survey responses will be extremely helpful in advocacy efforts and in guiding future strategies, priorities, and funding toward the goal of improving the availability of residential housing for adults with mental retardation when they need it, and in the form they need it.

Acknowledgements

The Task Force would like to thank all families who participated in the Survey. Their time and thoughtful responses to the questions are greatly appreciated.

We are especially grateful for the volunteer efforts of individuals on the Arc Housing Committee who spearheaded development of the Survey and the preparation of this report: Norbert Michaud, Karen Roberson, and Dick Schneider.

Special thanks to Joan Pine, Director of the Community Services Board for her support of the Survey project and her active involvement in survey development and results analysis. Thanks to James Thur, Executive Director of the CSB and to the members of the Mental Retardation Committee (Sarah Escowitz, Chairperson, Ben Pepper, Emile Miller, and Jessica Burmester) for their review and endorsement of the Survey. Thanks to Dennis Brown and Janice Schiff of the CSB for consulting with Task Force members on financial and funding issues.

We also thank The Arc of Northern Virginia (Ray Roberson, President, and Elaine Joyce, Executive Director) for their encouragement, guidance, and input to the Survey initiative.

Finally special thanks to CSB technical, analytical, and administrative staff members: Anita Baker for her invaluable efforts on Survey formatting, data collection, and report preparation; and to Melinda Balser for preparation of mailing labels and completion of the folding, inserting, and mailing of all surveys.

ABOUT THE WAITING LIST FOR RESIDENTIAL SERVICES

As of March 1998, there are 350 individuals with mental retardation who are on the residential services waiting list in the area served by the Fairfax / Falls Church Community Services Board. In order to be placed on the waiting list, a person must be determined to be eligible for mental retardation services, must have a need for residential supports as soon as possible, and must have requested the CSB to place them on the Waiting List.

Waiting list eligibility requires that a person must have had a recent intelligence test by a qualified examiner that finds that the person's intelligence quotient (IQ) or cognitive ability is within the mental retardation range (ie. 70 or below). In addition the person must have significant limitations in two or more areas of life functioning, such as limitations in being able to work, traveling independently, communicating effectively, and engaging in self-care activities.

SURVEY MAILING AND RESPONSE

Surveys were mailed on February 25, 1998 to 350 families of the individuals on the waiting list. Responses were requested to be returned by March 15, 1998 in a pre-addressed, stamped envelope provided with the survey questionnaire. A follow-up "reminder" postcard was mailed to the 350 families approximately one week after the Survey mailing, to encourage survey response.

185 families (53% of the waiting list) responded to the survey.

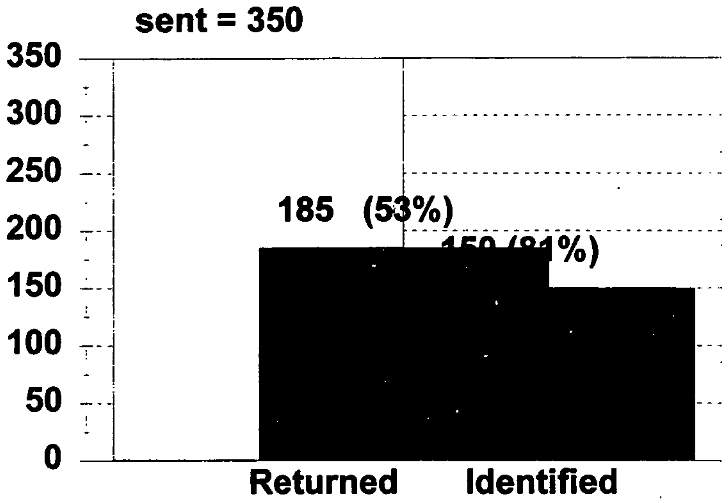
150 families (81% of respondents) identified themselves to The Arc, as part of the response process.

We were gratified by the large number and high percentage of families responding to the survey. The large response is indicative of the high level of interest and involvement families have in the well-being of their family members with mental retardation, and their desire to make known their needs and preferences for residential services. We now know a lot more about the needs of the 185 responding families.

It is important to note that no effort has been made in this report to project these results to the 165 families who did not respond to the survey, nor to assess the needs of the broader universe of families whose children are either still in the public education system, or whose adult children do not quite meet the IQ criteria for mental retardation.

To this extent we strongly believe the results of this survey considerably understate the current and future need for residential support services in the Fairfax / Falls Church area of Virginia.

SURVEYS SENT & RECEIVED
& Those Identifying Themselves



What is the age of the primary caregiver?

The age of the primary caregiver(s) is one of the most important determinants in the need for residential services. One thing is clear - as caregivers age, there ultimately will come a point in time (no matter how dedicated or determined they may be) when they can no longer provide the residential support for their family member with mental retardation.

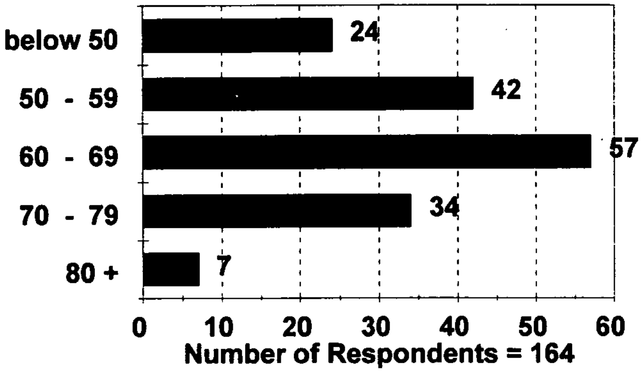
The Survey responses to this question dramatically highlight the rapidly approaching residential crisis based on the ages of the caregivers.

- Respondents are, on average, 61 years old. They range in age from 25 to 89.
- **7 caregivers are over the age of 80**
- **34 additional caregivers are between the ages of 70 and 79**
- **57 additional caregivers are between the ages of 60 and 69**
- **98 total caregivers (60% of all survey respondents) are of an age where a residential solution for their family members must become a critical priority.**

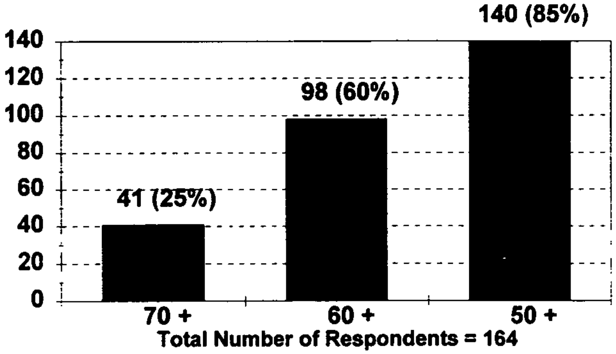
These are facts that must assume greater importance to elected and appointed officials at both State and County levels. The consequences of failing to prioritize policy and adequate funding for residential support services for citizens with mental retardation will become increasingly visible and potentially explosive in a few short years in Fairfax County without a significant alteration of current policy and financial support.

Prioritizing the Waiting List by the age of the primary caregiver offers an opportunity to begin to meet the needs of families in a planned manner, rather than waiting for the coming crisis to become an unacceptable outcome.

NUMBER OF CAREGIVERS
By Age



NUMBER OF CAREGIVERS
Above Certain Ages



What is the current housing situation of your family member ?

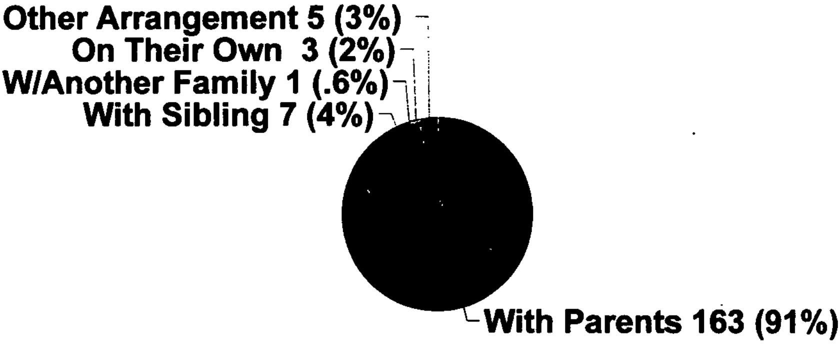
With few exceptions, family members with mental retardation are currently living at home with their parents, or with a brother, sister, or other relative in their home.

The small number of exceptions include living in an institutional setting or in out-of-state group home or assisted living environments.

The nearly unanimous reliance on the parents for residential support, when coupled with the number of parents above the age of 60, underscores the urgency and seriousness of the residential crisis for adults with mental retardation in Fairfax County, Virginia.

PRESENT LIVING ARRANGEMENTS

Number of Respondents = 179



The level of support and supervision required by an individual with mental retardation is an important factor in selecting an appropriate residential environment. What level of support is needed by your family member?

Survey recipients were provided descriptions of three different levels of support and supervision corresponding to criteria used by the State and County in determining support services requirements for individuals with mental retardation.

Recipients were then asked to indicate the level of support required by their family member with mental retardation.

The three categories were:

- Level 1 - Intermittent / Infrequent
- Level 2 - Limited / Moderate
- Level 3 - Extensive / Pervasive

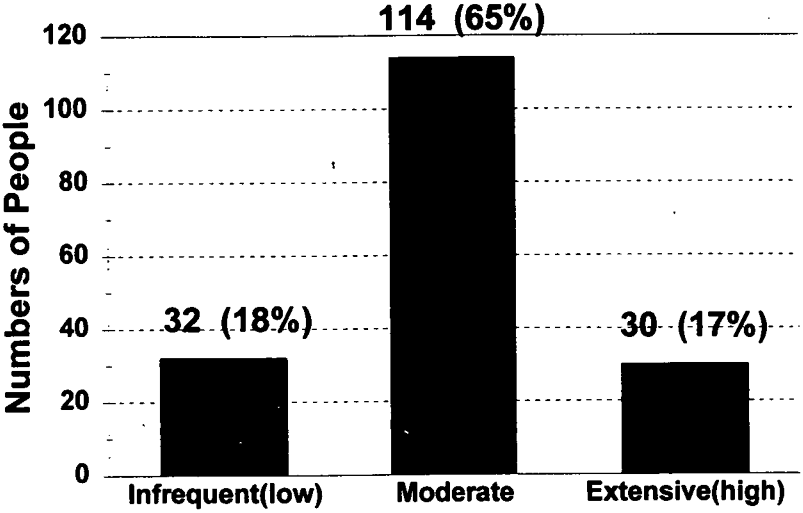
Two-thirds (65%) of the respondents assessed their family member's need as being in the Limited / Moderate category.

Limited / Moderate support was defined as follows:

"Individuals require limited but consistent 24-hour support and supervision. May be somewhat independent in personal care skills and activities of daily living, but may require reminders and hands-on help and support with some activities of daily living and structure / direct supervision in residential environment, at work, and in community settings. Some may require presence / support of an adult within hearing distance for assistance with adaptive skills and / or management of occasional problem behavior."

LEVEL OF CARE REQUIRED

In Residential Environment



ALTERNATIVE RESIDENTIAL MODELS

Survey recipients were provided descriptions of seven (7) different residential types. Descriptions included the size of the residence (in terms of number of residents), and the primary advantages and potential limitations of each environment. After each residential description, survey recipients were asked to rate the level of interest they have in that residential type for their family member with mental retardation. A 5-point rating scale was used where:

0 = no interest
5 = high interest

The seven residential types were as follows:

- Natural Family / Relative's Home
- Supportive Independent / Semi-Independent Living
- Group Home
- Assisted Living Residence
- Foster Care / Supervised Family Living
- Intensive Medical Care Residence
- Sheltered Village

Since survey recipients were free to evaluate each of the residential choices independently, we have focused on the residential models that had the highest level of interest (ie. based on ratings of 4 or 5, or ratings of 3 or 4 or 5).

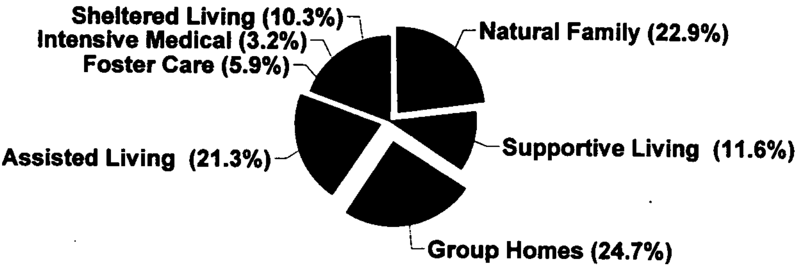
The three most preferred residential types were:

- Group Home
- Natural Family / Relative's Home
- Assisted Living

There was statistically little difference in the preference for residential types based on ratings of 4 and 5, vs. 3,4, and 5.

HOUSING PREFERENCES

% of Respondents Voting 3,4,5



If an out-of-home residential placement is not immediately available, what kind of services would be most helpful? Circle the one most important.

Six (6) choices were offered, primarily focused on respite care and in-home supports, recreation and social activities, and cash payment.

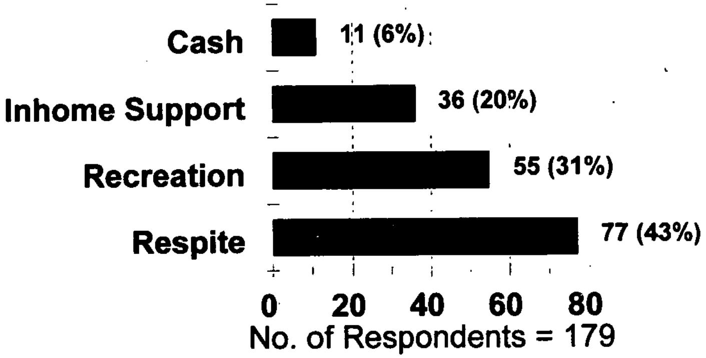
Not surprisingly, caregivers feel a strong need for respite assistance (43%) and in-home support (20%) which can also provide a respite opportunity. The high level of interest in respite support validates understandings by the Community Services Board that **there is strong desire for improved respite service.**

More opportunity for recreation and social activities was highlighted by 31% of respondents.

Cash assistance was viewed as important by a relatively small number and percentage of respondents.

SUPPORT ALTERNATIVES

In Lieu of Housing



How great is the need for residential services for your family member?

Survey recipients were asked to select one of 3 timeframes in terms of the urgency of need for residential support for their family member with mental retardation:

- Critical - need services within 1 year
- Moderate - need services within one to three years
- Low - need services in 3 or more years

The responses reinforce and reconfirm the critical need for residential service for family members with mental retardation. Highlights are as follows:

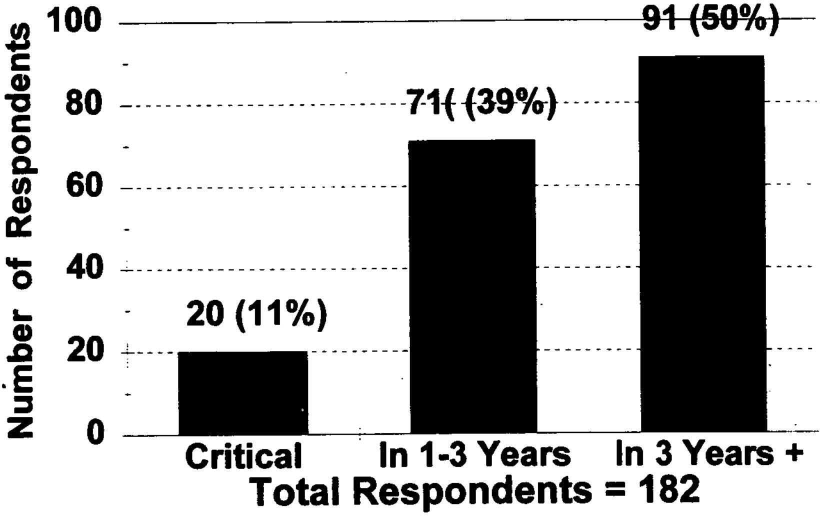
- **20 families (11%) need residential placement within 1 year**
- **71 additional families (39%) need residential placement in 1-3 years**

These are STAGGERING NUMBERS that dramatically forecast an increasingly likely crisis and a potentially explosive issue, if current policies and inadequate funding for residential services are not urgently addressed.

It is worth noting here that no effort was made to project this immediacy of need to the additional 165 families on the waiting list who did not respond to the survey. However, we believe there is strong likelihood the immediacy of their needs may be similar to those of the survey respondents presented here. To that extent, the need for residential solutions on a very near-term basis is most likely considerably larger than reported above.

URGENCY OF NEED

As Indicated by Respondents



What are the 3 primary factors influencing a residential placement decision?

Survey recipients were given a list of 8 possible factors that might influence a residential placement decision. They were asked to select the 3 most important factors affecting a residential decision on behalf of their family member with mental retardation.

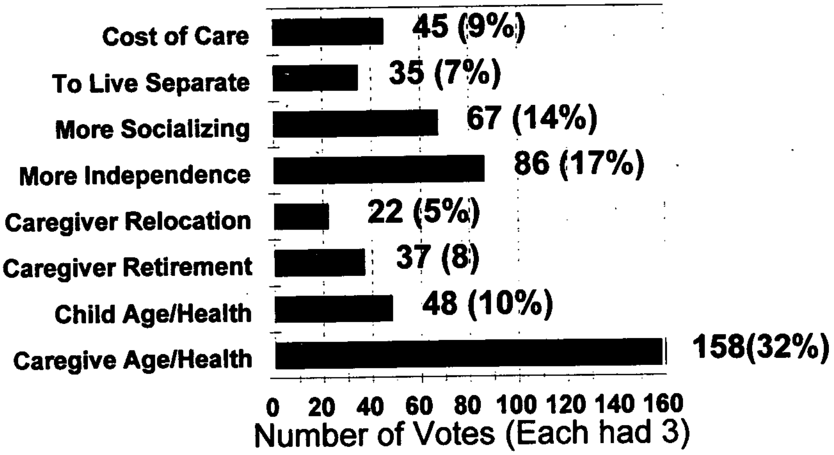
While 8 separate factors were listed, they tended to cluster around 4 primary reasons:

- Age / health of the caregiver or person with mental retardation
- Desire for more independence and socializing opportunity for the person with mental retardation
- Cost of care
- Caregiver retirement / relocation

The most significant factor, representing 41% of the total of all responses, was the age / health of the caregiver or person with mental retardation.

The desire for greater independence and socializing opportunity for the person with mental retardation was also a strong factor, representing 38% of the total of all responses.

[redacted]


Cost of Care
45 (9%)
To Live Separate
35 (7%)
More Socializing
67 (14%)
More Independence
86 (17%)
Caregiver Relocation
22 (5%)
Caregiver Retirement
37 (8)
Child Age/Health
48 (10%)
Caregive Age/Health
158(32%)
0
20
40
60
80
100
120
140
160
Number of Votes (Each had 3)

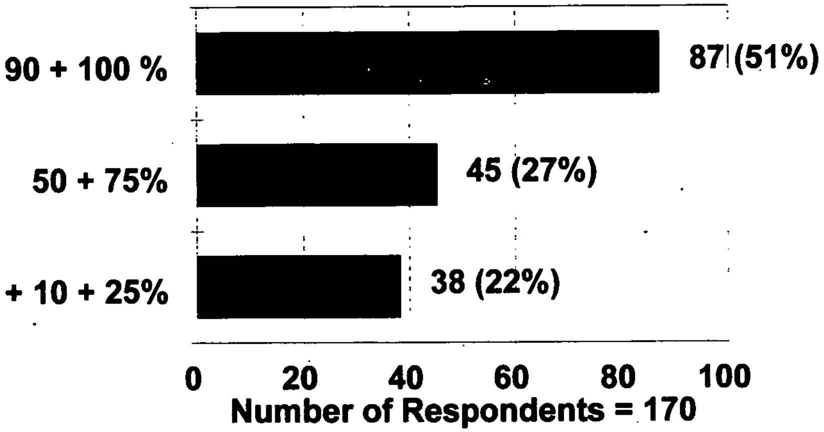
If your preferred residential choice becomes available to you in Fairfax County, how likely would you be to initiate the process to place your family member in that residential option?

Interestingly, when caregivers were asked if they would be likely to take a residential placement if the model of their choice were offered today, **51% expressed a strong likelihood (90-100% likely) that they would. Another 27% of respondents were 50-75% likely to accept a residential placement if their choice were offered today.**

The high interest (90-100% likely to act on a placement preference) expressed by 87 caregivers (51% of the respondents) has a strong correlation with the number of respondents (91 or 50%) claiming an urgency of need for services within 3 years.

TO INITIATE PROCESS GIVEN PREFERENCE

Likelihood by Low/Medium/High Category



What are your <u>three</u> major concerns about your family member living in another residential setting?

The survey listed 8 "concerns" caregivers might have about placing their family member in another residential setting. Caregivers were asked to identify their 3 primary concerns.

The foremost concern expressed was for the "Quality of care" their family member would receive in a residential setting other than the parental home. Quality of care was identified 118 times out of a total of 399 selections – 30%. Additionally, "Being taken advantage of", which can be considered a "quality of care" concern, was identified 39 times representing an additional 10% of the total responses. Added together, "Quality of Care" represented 40% of the responses. This response is understandable in that few parents believe anyone can or would care for their family member as well as they can.

The second greatest concern was "Difficulty of Adjusting and Relating" to a new residential environment and new caregivers. 30% of the responses identified these difficulties as concerns.

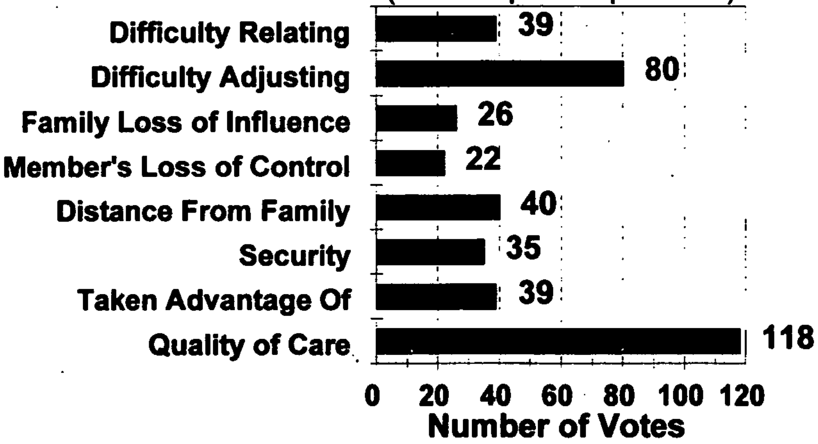
Other concerns were noted as follows:

Distance from family	40	10%
Security	35	9%
Loss of influence by family	26	7%

CONCERNS WITH TRANSITION

Into New Situations

(3 votes per respondent)



Would you be interested in participating in a cost-share residential program where the individual, the CSB, and public contributions pay the cost of services?

Caregivers were almost equally divided on this question.

46% said they would be willing to participate in a cost-sharing residential service.

6% said "maybe" they would be willing.

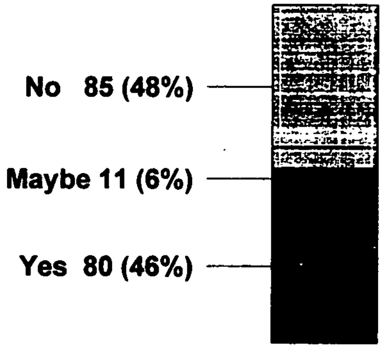
48% said they would not want to participate in a cost-share residential service.

Respondents who did not want to participate were asked to select the 3 most important reasons for not participating from a list of 6 reasons that were described. Respondents were fairly evenly divided in their reasons for not wanting to take part in a cost-shared residential service.

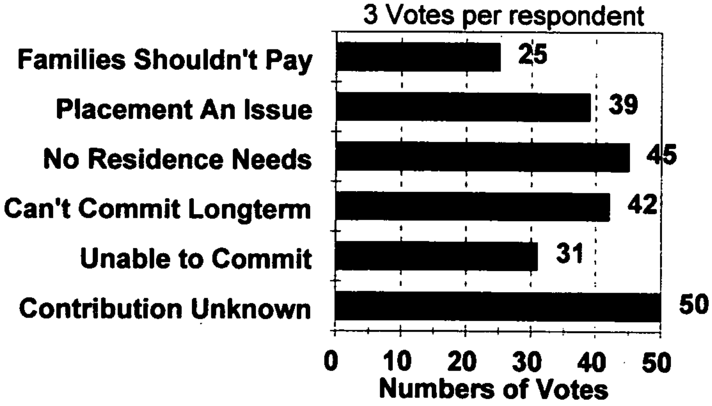
• Amount of contribution is unknown	22%
• Unable to make a long-term financial commitment	18%
• Unable to commit funds at this time	13%
• Not ready for residential services at this time	19%
• Don't know if the residential placement will meet needs	17%
• Don't feel family should have to pay	11%

It is important to note that the number of families willing to participate in a cost-sharing program (46% or more, depending on conditions) suggests that private contributions to funding of residences may present an important residential services cost-reduction opportunity for the State and County, especially if costs to families are within the range of expectation in terms of affordability.

FAMILY WILLING TO SHARE COST
OF Residential Program



REASONS FOR NOT PARTICIPATING
In Residential Cost Sharing



Would you consider being a "foster family"? That is, would you provide an opportunity for another person with mental retardation (with about the same level of ability as your family member), if a subsidy were provided to you for both people with mental retardation?

Overwhelmingly, caregivers expressed a lack of interest or willingness to take on the responsibilities of providing foster care for another individual with mental retardation, even if a subsidy were provided to the foster family for both individuals with mental retardation.

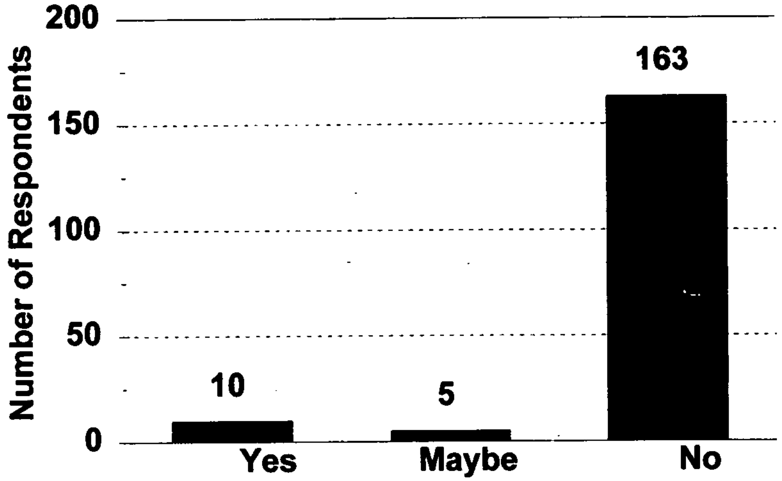
Providing foster care for another individual, and integrating that individual into the family life of the foster family, requires a unique combination of organizational skills, temperament, commitment, love and compassion.

It is significant that 10 caregivers expressed an interest in providing foster care services in their home, and another 5 said "maybe" they would be interested in providing foster care.

At this time the Community Services Board does not have funds to support additional foster care services. It may be important, therefore, for The Arc to try to identify and contact those caregivers who expressed interest in providing foster care, to assess their capabilities and interests, and serve as a referral for individual families interested in private-pay arrangements.

INTEREST IN FOSTERING ANOTHER

If Compensated For Both



FINDINGS

Caregivers: *AGE / Health* **Underlie Growing Need for Residences**

98 of the 185 Respondents are *Over the Age Of 60*

Level of Need: **Low 18%** | **Moderate: 65%** | **High: 17%**

Urgency of Need: *AT LEAST 20 PEOPLE* **Need Housing Today !**

At Least 91 Individuals **Need Residential Services Within 3 Years**

At Least 7 People **with MR/DD are Now Living with Siblings**

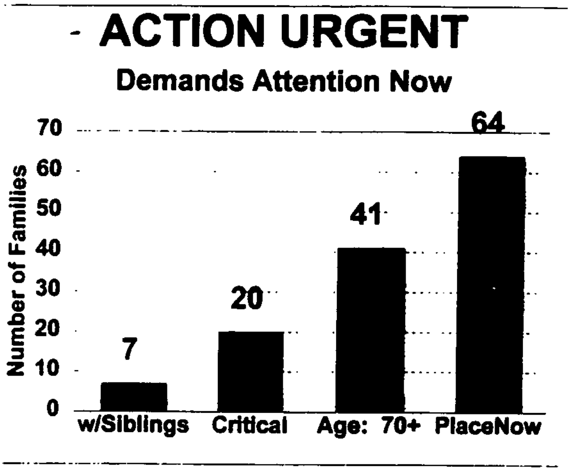
63 Of Respondents Need Respite and In Home Support

Preferences: **Group Homes, Natural Homes** *(With Supports)* **& Assisted Living Models**

Concern: **Quality of Care and Adjustment Difficulties**

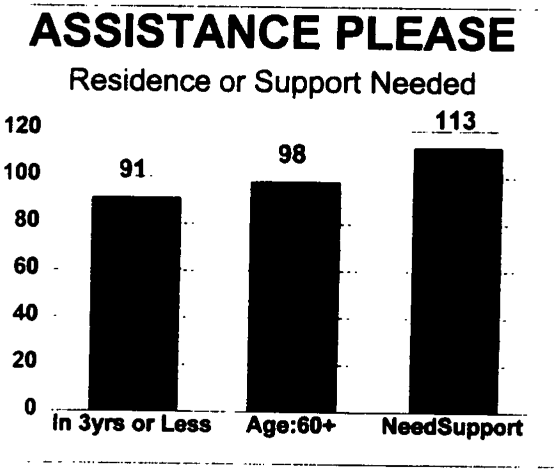
Cost Sharing: **More Cost Sharing Housing Options Could be Developed**

Fostering: **Program Could Be Expanded**



- ACTION URGENT

Demands Attention Now



ASSISTANCE PLEASE

Residence or Support Needed

CONCLUSION

The 185 caregivers who responded to this survey are, on average, in their 60s. For many years they have been providing high levels of care for their adult children with mental retardation. Their family members with mental retardation have been determined eligible by the Community Services Board for residential housing services, and their names have been on the Waiting List – some for many years - because the parent caregivers want residential services for their family members before a crisis occurs, and they want assurance services will be available when they need them.

The fact that such a high percentage of caregivers responded to the survey is a strong indication of the high level of interest and involvement families have in the well-being of their family members with mental retardation, and their desire to make known their needs and preferences for residential services.

The advancing ages of these caregivers gives cause for concern. Seven (7) caregivers are over the age of 80; 34 additional caregivers are between the ages of 70-79; an additional 57 caregivers are in their 60s. A total of 98 caregivers (60% of the survey respondents) are of an age where an appropriate residential solution must be identified, with assurance it will be available within 1-3 years when it is needed. If these results from survey respondents were projected to the 165 Waiting List non-respondents, the critical need for residential services would be even greater.

In the face of virtually no State funding for residential services to reduce the waiting list, Fairfax County is facing a very imminent crisis in its residential support services for its adult citizens with mental retardation.

Caregivers have a good understanding of the support and supervision required by their family members with mental retardation. A majority assess their family members as needing a moderate level of support and supervision in their residential environment and in their activities of daily living.

Caregivers have preferences for the type of residential setting that will be most appropriate for their family members with mental retardation. While continuing to live in the natural family home with in-home supports is the most preferred option, group homes and assisted living residences rank high in preference. If the preferred residential choice were to become available, 51% of caregivers expressed a strong likelihood they would initiate the process to place their family member there.

Caregivers express expected concerns about placing their family member in another residential setting. Principal among the concerns are the quality of care their family member will receive, and the difficulty the family member will have adjusting and relating to the new environment.

Nearly half the caregivers would be willing to participate in a cost-share residential Program.

While waiting anxiously for residential services, and with great concern because of the perceived indifference and lack of priority attention on this issue on the part of Virginia's state legislature, caregivers would like to have greater availability of respite services and more recreational and social opportunities for their family members with mental retardation.

Regardless of whether caregivers are able to wait a few more years before they are forced to relinquish their caregiving roles, or whether they urgently need residential services for their family members immediately, all caregivers need peace of mind that comes with the assurance that an appropriate residential placement will be available when it is needed.

It appears that the process in Virginia for funding and providing residential housing services for the mentally retarded is flawed, and the current crisis-driven system will not begin to meet the needs identified in this survey.

The Waiting List can be a useful tool in planning only if it is applied beyond the sheer numbers it represents. Toward this end, The Arc of Northern Virginia will intensify its efforts to work with the CSB, the Fairfax County Board of Supervisors, and the Virginia state legislature to "unlock the waiting list."

NAMI
The Nation's Voice on Mental Illness

STATEMENT OF MARGARET STOUT OF JOHNSTON, IOWA

ON BEHALF OF THE

NATIONAL ALLIANCE FOR THE MENTALLY ILL

"CAN WE REST IN PEACE? THE ANXIETY OF ELDERLY PARENTS CARING FOR BABY BOOMERS WITH DISABILITIES"

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

SEPTEMBER 18, 1998

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Chairman Grassley and members of the Committee, I am Margaret Stout, executive director NAMI Iowa. I am also a member of the Board of Directors of NAMI and the National Alliance for the Mentally Ill (NAMI). With more than 185,000 members, NAMI is the nation's leading grassroots organization solely dedicated to improving the lives of persons with severe mental illnesses including schizophrenia, bipolar disorder (manic-depressive illness), major depression, obsessive-compulsive disorder, and anxiety disorders. NAMI's efforts focus on support to persons with serious brain disorders and to their families; advocacy for nondiscriminatory and equitable federal, state, and private-sector policies; research into the causes, symptoms and treatment for brain disorders; and education to eliminate the pervasive stigma surrounding severe mental illness. NAMI has more than 1,200 state and local affiliates in all 50 states.

I would like to thank the Committee for holding this important forum on a topic that is of grave concern to our members. The majority of NAMI's family and consumer membership is directly involved in the care of a relative with a severe mental illness. Many of these members are aging parents caring for their adult children at home. They worry every day about the well-being and disposition of their children who are living with disabling forms of severe mental illness. The most profound of these concerns is what will happen to their disabled children in the event that they become unable to adequately care for them if they become sick or disabled themselves. They know that the process of aging will inevitably mean that caring for their adult child in the home becomes an impossibility.

A recent national study by NAMI of its membership found that 42 percent of people with severe mental illnesses were living with their families, and 11.2 percent with other relatives. Only 14 percent of consumers were living in various supervised community housing. The study found that 63 percent of the consumers were male, with an average age of 37, and female consumers had a higher age average. These numbers strongly reflect an aging caregiver population of significant size, caring for adult children at home, that will soon depend on public supports to care for these consumers. These results represent a large-scale crisis that has already begun in this country for consumers, family members, and the public mental health system.

A 1995 study conducted by the New York State Office of Mental Health found that in New York State between 13,400 and 49,600 adults with severe and persistent mental illness, seen on a regular basis in the public mental health system, currently live with their parents. This study concluded that the rate of orphaned adult children disabled by severe mental illnesses is increasing faster than the growth of the general adult population. The study estimated that during the period from 1990 to 1994, between 300 and 1,200 housing disruptions occurred for adults with severe mental illness due to the death of a parent. This study also found that the age of adult children with serious brain disorders living with their parents reveals an alarming trend: 84 percent were 25 years or older, 65 percent were over 30; and 12 percent were over 50. In other words, large numbers of adults well past their 20s with severe mental illnesses live with their parents.

In the 1960s and 1970s, our country entered into a social experiment known as "deinstitutionalization" in which public psychiatric hospitals saw a massive decline in the number of publicly supported inpatient beds. This policy was supposed to result in resources being shifted to treatment and support programs in the community. Unfortunately, in too many states the necessary resources were never invested in service and support programs at the community level. One major consequence of this failure is that families are forced to take on the responsibility for the care of adult children who are severely mentally ill by providing housing and related supports. It is little wonder that surveys show consistently that families are very concerned about what will happen to their loved ones living with serious brain disorders once the family members become too aged or infirm to properly care for their child or eventually die. Parents fear the prospect that their loved ones will become homeless, forced into poor housing arrangements, or left without any community supports.

Aging caregivers of the adult children with serious brain disorders face enormous anxiety and stress over the eventual reality that they will no longer be able to care for their disabled loved ones, and they express increased concern about the life their disabled children will face after they are gone. A survey of NAMI families in 1993 found that the greatest source of psychological pain for 74 percent of respondents was the uncertainty of "what will happen to my relative when I am gone." Parents suffer concerns that their loved ones will be alone and neglected and left in misery when caregivers are no longer around and available to provide emotional and functional support. In addition to facing one's own mortality, parents have additional anxiety about abandoning an established dependency relationship with a disabled adult child.

Mr. Chairman, it is very clear that the evidence from these studies and surveys demonstrates an impending national crisis for people with serious brain disorders and their families. The public system intended to meet the housing and community support needs of people with severe mental illnesses is simply not equipped to handle existing demands for services, much less the estimated infusion of seriously disabled adults when their parents die. These numbers are expected to swell as parents of the baby-boom generation caring for their severely disabled loved ones become unable to provide care and eventually die.

The resources and community supports needed to care for this impending influx of baby boomers with disabilities simply are not there. Adult children with severe mental illnesses will be abruptly removed from their homes with nowhere to go, and they will continually cycle through hospitals, jails, other families and the street. The most critical need is housing. In a recent report prepared by HUD for Congress, "Rental Housing Assistance - The Crisis Continues," it is estimated that the number of people with disabilities with worst-case housing needs may have grown to 1.1 million to 1.4 million people. Worst-case needs are defined as unassisted renters with incomes below 50 percent of the local median who pay more than one half of their income for rent or live in substandard housing.

This affordability crisis is compounded by recent changes in federal housing policy that are placing ever larger portions of the inventory of affordable public and privately-owned assisted housing off limits to non-elderly people with disabilities. A 1996 study by the Consortium for Citizens With Disabilities (CCD) Housing Task Force found that this federal policy of "elderly only" designation of public and assisted housing will result in the loss of 273,000 units for non-elderly adults with disabilities by the year 2003.

A recent survey by NAMI of New York State reported that there are 277,000 people with a severe mental illness in New York State. The majority of these disabled individuals are living with their families. This survey also reported that 59 percent of respondents said that their loved ones had already been waiting a year or more for housing. These families expressed overwhelming concern about what will happen to their children when they are no longer there to care for them.

Before the previously mentioned study took place, the New York Office of Mental Health concluded that 20,000 new beds would be needed to meet the needs of adults with severe and persistent mental illness. This estimate was based on inpatient numbers, adults with severe mental illness and the homeless, and individuals living in the community. It is important to note that this figure did not include the estimated number of adults with mental illness who would face a crisis due to parental death each year. As of the date of the study, April 1995, increased funding from state and federal agencies supported only 1,000 to 1,500 new beds each year, instead of the stated need for 20,000 new beds.

What Must Be Done

No single federal policy enactment could possibly address the complex nature of the issue of aging parents caring for adult children with disabilities at home. Rather, a multifaceted approach is needed to ensure that those adults with severe mental illnesses still living at home are able to access the housing and supports they will need after their parents are unable to care for them. NAMI would like to offer the following suggestions:

1) Promote PLAN programs to allow families to ensure that assets are available for their children

Planned Lifetime Assistance Network (PLAN) programs are independent, non-profit programs designed to help families develop future-care plans for their children with severe mental illnesses. Most PLAN programs provide direct services to families to help them put in place a plan that relieves them of the daily burden of care and ensures access to care that is needed long after a parent(s) die. PLAN programs provide families with expertise on issues such as establishing supplemental and third-party needs trusts. This allows families to secure access to housing, treatment, and long-term community supports far into the future.

As private, non-profit organizations, PLAN programs are not looking to become part of a federal program. Nevertheless, key federal agencies whose mission is to serve people with severe mental illnesses and other disabilities (the Health Care Financing

Administration, the Social Security Administration, the Center for Mental Health Services, the Administration on Developmental Disabilities, the Department of Housing and Urban Development, among others) can do more to develop public-private partnerships that will help make PLAN programs more accessible to families that need assistance in planning for the future.

2) Allocate sufficient federal housing resources to make up for the loss of housing that continues to occur through "elderly only" designation

In recent years, Congress has begun to make important progress in addressing the tremendous gap in resources needed to alleviate the emerging housing crisis for all people with disabilities, including adults with severe mental illnesses. Under the leadership of your colleagues Senator Kit Bond of Missouri and Representatives Jerry Lewis of California and Rodney Frelinghuysen of New Jersey, Congress has allocated nearly $150 million for Section 8 vouchers and certificates for non-elderly adults with disabilities. These resources are intended to make up for both public and assisted housing that has been lost through "elderly only" designation.

Despite this progress, HUD has yet to demonstrate an understanding of this problem and has thus far failed to articulate a federal policy with respect to housing for persons with disabilities. Efforts by NAMI and many of our allies in the disability community to get HUD to focus on the impact of "elderly only" designation or the implications for aging parents caring for adult children with disabilities at home have been largely ignored. We encourage you and your colleagues to continue your efforts to allocate resources within the HUD budget for people with disabilities. We at NAMI support such direction from Congress, given the absence of a commitment to this issue within HUD.

3) Invest in successful programs such as PACT, which offer the best hope for community-based treatment and supports

While focusing on access to affordable housing is important, NAMI also believes that supports are needed to help the most severely disabled adults – those most likely to be living with aging parents well into adulthood – live in the community. One of the most promising models for providing community supports and services to persons with severe mental illnesses is the Program for Assertive Community Treatment (PACT).

PACT is a service-delivery model that provides comprehensive, locally-based treatment to people with serious and chronic mental illnesses. Unlike other community-based programs, PACT is not a linkage or brokerage case-management program that connects individuals to mental health, housing, or rehabilitation agencies or services. Rather, it provides highly individualized services directly to consumers. PACT program recipients receive the multidisciplinary, round-the-clock staffing of a psychiatric unit, but within the comfort of their own homes and community. To have the competencies and skills to meet a client's multiple treatment, rehabilitation, and support needs, PACT team members are trained in the areas of psychiatry, social work, nursing, and vocational rehabilitation. The PACT team provides these necessary services 24 hours a day, seven days a week, 365 days a year.

Now in its 24th year, the PACT model has been replicated in communities throughout the country and continues to demonstrate an unprecedented degree of success with the populations it serves. In particular, PACT has proven (1) to decrease the time persons with severe and persistent mental illnesses spend in hospitals and (2) to facilitate the community living and psychosocial rehabilitation of these individuals.

Currently, there are only six states that offer PACT statewide. Twenty-four states and the District of Columbia have begun model demonstrations. NAMI believes strongly that increased adoption of this program will further the goals of widening services for adult children with serious brain disorders who depend on services from our nation's public mental health system. This is especially the case for adults who are currently being cared for by aging parents at home.

What role can the federal government play in promoting PACT? NAMI recognizes that publicly funded mental health services are still largely a function of state and local government. Nevertheless, two important federal programs – Medicaid and the Mental Health Services Block Grant – offer tremendous opportunity for investment in PACT programs at the state and local level. In the case of Medicaid, NAMI believes that both Congress and HCFA (the federal agency that administers Medicaid) can do more to encourage states to integrate PACT into Medicaid as a distinct service. In the case of the Mental Health Block Grant (a program that is substantially smaller than Medicaid), NAMI supports efforts to fund a new supplement to the program to be used exclusively for PACT. Such an approach would help ensure that a defined allocation of federal dollars would go to the intensive community supports and services needed by the most severely disabled adults with mental illnesses.

4) Address the current work disincentives in the SSI and SSDI programs

As has been documented by countless studies, – and as many NAMI members know first-hand – current policies in Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs discourage people with disabilities from working and living independently. NAMI believes that they are in need of substantial reform. People with disabilities (including adults with severe mental illness who have found effective treatment), want to work, but less than half of 1 percent of the beneficiaries leave the Social Security rolls and become self-sufficient. Their attempts to work are undermined by the inability to obtain affordable health care and the loss of cash assistance. Such assistance is critical to living independently and an inability to obtain it makes them highly unlikely to become or remain self-sufficient.

Today, 7.5 million Americans with disabilities depend on assistance from SSI and SSDI. The cost to the taxpayer is $73 billion annually and will continue to increase at 6 percent a year. Social Security disability payments are the fourth largest entitlement expenditure by the federal government. If 75,000 of the 7.5 million Americans with disabilities, just one percent, become successfully employed, savings in cash assistance would total $3.5 billion over the work life of the individuals.

Your colleagues, Seantors Jim Jeffords of Vermont and Edward M. Kennedy of Massachusetts, have developed a solution to this problem, the Work Incentives Improvement Act of 1998 (S 1858). This important legislation:

a) provides increased choice for individuals with disabilities who seek vocational rehabilitation services and supports so that they can become employed;
b) strengthens public-private partnerships to support people with disabilities to become employed;
c) continues access to Medicare when an individual with a disability goes to work,
d) awards grants to states to enable them to create and operate infrastructures so that workers with disabilities can buy-in to Medicaid for health services that are necessary to become or remain employed;
e) allows states to include a category of "working Individuals With Disabilities" who, without health care services (including prescription drug coverage not currently available through Medicare), would drop back onto the Social Security rolls, and
f) provides grants for Work Incentive Planning so persons with disabilities can navigate the complex world of disability work incentive programs and federal and state health care options, so that such programs work for them in their effort to work; and
g) directs Social Security to conduct demonstration projects which will gradually phase out the loss of cash benefits in the SSDI program as a worker's income rises, instead of the current cash cut-off that so many disabled persons who return to work face today.

Passing S 1858 this year would be a major step forward toward helping adults with severe mental illnesses move toward greater independence. Reforming the existing policy will make work pay and help many families that have been forced to keep their loved ones with severe mental illnesses trapped in poverty in order maintain eligibility for federal entitlements. NAMI urges Congress to pass S 1858.

Conclusion

Mr. Chairman, NAMI would like to thank you for your leadership in holding this important forum. The emerging crisis resulting from aging parents serving as the main source of housing and supports for persons with severe mental illnesses has been ignored for far too long. Policymakers at the federal, state, and local levels tend to focus too heavily on the short-term pressures of current programs. It is always easier to ignore a challenge that appears to be years away. This challenge, however, is fast approaching. The rapid process of aging in our society has placed us on a direct collision course as hundreds of thousands of adults with severe disabilities—who have for years been cared for by parents in their own homes—begin seeking housing and community supports from already overburdened public programs. On behalf of NAMI's consumer and family membership, I thank you for efforts to focus the attention of Congress and the nation on this critical issue.

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