Help for Caring

for older people caring for an adult
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A Manual for Area Agencies on Aging Aiding Households with Persons with a Developmental Disability

1996
(Adapted Version 2003)

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Caregiver Assistance Project in Aging and Developmental Disabilities

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Contents

About the Manual

The population demographics of the United States are changing. There are now more older Americans that ever before in our nation's history. More attention is paid to how older Americans live and age. This is also the case with adults who have lifelong disabilities - including developmental disabilities - for they too are part of the "greying" of our nation. Although there are adults with developmental disabilities enjoying life on their own, many older Americans with developmental disabilities still live at home with parents or other relatives, a spouse, or friends.

The aging of people who live at home and the needs of people who care for them is drawing more attention. Many states and localities are recognizing that the initiatives they have developed to aid carers - people who look after older relatives, spouses, or friends - also need to encompass older carers who still look after an adult with a developmental disability. Thus, the need for this manual. We have designed this manual to provide information on adults with a developmental disability and their carers, and introduce models that can be employed to aid "two-generation" elderly families. We also explore approaches to aiding families from a variety of cultural backgrounds, a growing aspect of our nation's population.

In this manual we look at the differences between the developmental disabilities system and the aging network, provide useful tips on implementing a program on aiding older carers, and explore some of the situations you may encounter when finding such carers. While we are not setting a standard for such initiatives, it is our intention to add to the means that agencies use to help households of older persons. We trust the this manual will be read and used in the spirit in which it was developed.

Who is this manual for? The manual was developed from a demonstration project of national significance funded by the U.S. Administration on Aging. Thus, the major focus is on how agencies in the aging network that already help older persons can also implement an initiative to help carers of adults with a develop-mental disability. The manual can also be used by other agencies or persons who want to do the same. Additionally, while we speak of developmental disabilities in the manual, what we suggest can equally apply to any situation involving people with a range of lifelong or latelife disabilities.

"You don't think about that so much when you're 40, 50, or 60 - but when you get to be 70, you start thinking..."

"I pray to God everyday that he dies the day after I do."

"I wish Armageddon would come so I wouldn't have to worry any more."

From the article, "Matter of Life and Death - For Aging Parents, Fears for Their Disabled Charges," written by Laura Muha and published in *Long Island Newsday* (May 2, 1994).

"I know she is going to be lonesome, and I know nobody will take my place. Not everybody has the patience. You have to have a lot of patience with Karen."

"It's good to know if you are dying and have children that the children should be able to take care of themselves. That way you can die peacefully."

From the article, "Who Will Provide for Her Daughter?" written by Robert Whitaker, and published in the *Albany Times Union* (April 28, 1991).

"Sometimes when I'm bathing Johnny and he gets ornery I think, 'God, give me the strength,' because it's hard now that I'm older, and my patience sometimes runs out. I worry about getting Johnny settled somewhere before something happens to me."

"I feel like I have 10 good years left, but I guess she'll probably live longer. I don't know what she'd do if anything happened to me."

"It's been understood for 15 years that I would be the one to take on my sister when my parents can't, but I'm hoping it will be a couple years off, since I have two teen-age children, and they're very embarrassed about their aunt."

From the article, "As the Retarded Live Longer, Anxiety Grips Aging Parents," written by Tamar Lewin and published in the *New York Times* (October 28, 1990).

Chapter 1

Why Should Older Carers Be Targeted for Assistance?

Terms such as "carers," "caregivers," "care-takers" all mean the same thing -- they refer to anyone who has assumed the responsibility for looking after someone else. In this manual, we have chosen to use the term "carers" to refer to such persons.

The federal Administration on Aging has long recognized that older families and others who care for a relative with a developmental disability are in need of special supports. These families may need special attention because, unlike other carers who have recently begun looking after an older relative, they have been providing lifelong care and because of their own aging may be increasingly in need of special supports.

Who provides such care isn't limited to what we traditionally consider a family. Such persons may also include non-traditional carers, such as other relatives, grandparents, friends, neighbors, and anyone else who may need support so that he or she may continue to provide primary care.

The number of such carers is growing. Why? There are a number of reasons, most of which center around the increases in the number of older adults in general and the number of adults with a develop-mental disability living at home.

We are seeing major changes in the age composition of our nation's population because of increased longevity and improved health status. This same phenomenon is evident among adults with developmental disabilities, many of whom continue to live with their families.

Current beliefs are that most people with a developmental disability will have a life expectancy typical of other people. With younger generations of older people remaining healthier and less impaired longer than older generations, this trend should continue. We also know that like most of the Western world, we are experiencing an unique phenomenon as the large post-war age group become older. This "baby boom" generation is contributing 50-year-olds to our population at the rate of one person every eight seconds and is thus dramatically changing the age composition of our nation's population. This demographic "greying" of America's population is also affecting people with developmental disabilities.

Researchers tell us that many more adults with a lifelong disability are continuing to remain at home. This generation lives with parents in their 70s and older. There is also the generation that lives with parents who are younger. These older parents represent the *lost generation* (referred to in the essay by Nancy Breitenbach found in the Appendix) and make up most of the families who are generally not known to service agencies. As both these groups of parents become known to local agencies, they add to the numbers of such families of all ages who may need help.

Thus, both the growth of the numbers of older adults with a developmental disability and the numbers of carers who themselves are aging are contributing to an increasing concern over this particular population.

In this chapter we offer some information on this population and its needs and begin to explore why developing a special initiative in your community for this group is necessary. In the following pages, we address the following

- ❖ what do studies tell us about older carers?
- ❖ why is it beneficial to help these carers?
- ❖ what supports do federal and state governments offer this population?
- ❖ how can you make a convincing case for aiding this population?
- ❖ what are some situations that may

call for special intervention?

What Is a Developmental Disability?

The term *developmental disability* characterizes a group of conditions or disabilities that occur prior to, at birth, or during childhood, and interfere with normal growth and development. People with such disabilities may have difficulty being fully independent in work, housing and social settings and this difficulty may continue through old age.

Generally, to be classified as a *developmental disability*, a condition must interfere with functioning in several life activity areas - such as caring for oneself, making life decisions, and earning an income. In most states, "categorical" conditions such as intellectual disability [*mental retardation*], autism, cerebral palsy, epilepsy, and sensory or neurological impairments qualify as a developmental disability. However, to be a developmental disability, the impairment must have first occurred prior to the twenty-second birthday.

A federal "functional" definition can be found in the Developmental Disabilities Bill of Rights Act. The federal definition, used by the state developmental disabilities planning councils and protection and advocacy agencies, may vary from the state definition used by state agencies. Some states use the federal functional definition; others use a categorical approach.

However, it is the state definition that determines who is eligible for state supported services. Since each state's definition may vary, please check with your state's developmental disabilities authority or agency for the definition in use in your state that is used to determine eligibility for services.

What Supports Do Federal and State Governments Offer this Population?

Over the past several years, the federal government has targeted aid to older carers under provisions of the federal Older Americans Act. Under the Act, the responsibility for a wide range of planning, coordinating and funding activities is vested in both the state aging agency (known as the state unit on aging or SUA) and the area agencies on aging (AAAs).

The area agencies on aging are the local entities responsible for planning, coordinating, advocating and developing a comprehensive service delivery system at the local level to meet the long and short term needs of older persons in their designated service area. Older carers of adults with a developmental disability are part of the natural constituency of such agencies.

In 1987 and 1992, Congress amended the Older Americans Act to encourage the state units on aging, the area agencies on aging and state and local disabilities agencies to cooperatively plan and develop services for older persons with a disability. The Act encouraged localities to provide special assistance (such as permanency planning, respite, in-home assistance, and other activities) to older carers who provide "uncompensated care" for adults with a developmental disability. "Uncompensated care" means not getting paid to provide care.

The federal government, through the Administration on Developmental Disabilities, also supports aging and developmental disabilities initiatives at a number of universities. These university based aging and developmental disabilities centers provide training and education, as well as consultation, to local aging and disability agencies and families.

Recent changes to the federal Developmental Disabilities Bill of Rights Act also require a representative of the aging network to be appointed to the state's developmental disabilities planning council. The Administrations on Developmental Disabilities and Aging also engage in many cooperative endeavors which benefit states and localities, and target issues faced by people who are older and who have a disability.

Many states, as part of their general services for people with a developmental disability also provide supports to older carers. Each state's legislative mandates differ with regard to the nature and extent of these services, as do their targeting and policies. What they do is governed by the availability of fiscal resources and administrative practices.

For many years targeted family support services for *older* carers were virtually non-existent. Most, if any, family supports were targeted toward younger age parents. Recently, many states have expanded their support services to include aid for older families.

To find out what programs or initiatives are available in your state, contact your state developmental disabilities agency or its local office or representative.

Our Challenge

Over the past few years, the media have begun to carry a growing number of stories about the challenges of older persons who are caring for an adult with a developmental disability and this has helped to broaden the types of services and supports made available for older carers.

Many of the stories that have appeared in the media present the perspective that with the increasing age of the carer, new concerns are coming to the forefront about how these "two-generation elderly families" cope, and what the future will have in store for adults with a disability when their carers are no longer around.

Some of these stories focus on the concerns raised by older carers, others illustrate the tragic consequences of what can happen when families that are disengaged from service agencies or other sources of help. To help understand the situations of carers, we have included their stories throughout this manual.

The situations and needs of older carers are also explored in greater depth in an essay by Nancy Breitenbach, titled *The Lost Generation,* which we have included in the Appendix (see page 113). This essay is based upon a presentation given by Ms. Breitenbach at a pre-conference event for the 1995 White House Conference on Aging. Her essay succinctly captures many of the concerns of parents and the dilemmas that they face.

What these concerns are and how agencies can begin to help such families is the subject of this manual. We will explore issues facing older families, describe the types of family situations found in our communities, and provide useful information on how agencies can develop and maintain programs to help such families.

What Do Studies Tell Us about Older Carers?

The need to provide assistance to older carers with family members with a developmental disability has been well identified in recent studies.

For example, researchers at the University at Albany's Center for Excellence in Aging, found that almost 40% of elderly parents, with day-to-day care and oversight responsibilities for adult offspring with a developmental disability, generally were not using day services available from local intellectual or developmental disabilities agencies. Indeed, most of these families were "hidden" from the formal system.

Other studies, like those conducted by Drs. Marsha Seltzer and Marty Krauss at the University of Wisconsin and Brandeis University and Dr. Diane Seneels at the University of Leuven, have found parents con-fronted with many challenges as they continue to provide a home for their son or daughter with a disability.

Such studies of older families have noted that there generally is

- a reluctance on the part of some elderly families to become associated with the formal developmental disabilities system
- a reticence on the part of some families to even begin to anticipate the inevitability that their son or daughter with a developmental disability will outlive them
- a strong interdependency between carers and their son or daughter and an inability of elderly carers to reflect upon their own aging and plan for themselves or for their offspring
- a lack of coordination between services and the immediate and long term needs of such families

Such studies have noted that families with continual carer responsibilities need access to respite and other types of social and community supports. These families, as they grow older, are not only experiencing problems associated with

Parent's Deaths Were Fatal To Helpless Son

RUTHERFORD, N.J., July 27-- For a week before he died, officials say Barry Jacobs, who was mentally and physically handicapped, lay on his living room couch without food or water, unable to help himself as his parents lay dead in the same room.

Mr. Jacobs and his parents were found dead on Tuesday at the Hastings Village condominiums after neighbors complained of a foul odor from their one bedroom apartment.

At a news conference today, an assistant Bergen County prosecutor Sharyn Peiffer, said it appeared that Barry Jacobs, 38, died 24 to 48 hours before the Rutherford police climbed through a window of the locked apartment and discovered the gruesome scene.

Ms. Peiffer said Abraham Jacobs, 70, and his wife, Shirley, thought to be in her 70s, appear to have died of heart attacks 7 to 10 days before their bodies were found.

Mr. Jacobs, who was thought to have had cerebral palsy from birth, had depended on his parents to feed and move him. Prosecutors said their deaths left him stranded on the couch, unable to reach a telephone less than 10 feet away.

“The worst thing is that the man, laying there, was not able to help himself,” said the Acting Bergen County Prosecutor, Charles R. Buckley. Ms. Pfeiffer added, “The preliminary indications are that he probably died as a result of not receiving food or water.”

Police officers who entered the apartment found Abraham Jacobs slumped in a recliner next to the couch where his son lay. Shirley Jacobs was found on the floor nearby.

In layman’s terms, they died of natural causes, Ms. Peiffer said. Heat cannot be ruled out as precipitating the heart attacks that we believe the couple suffered.

Ms. Peiffer said an air-conditioner was on the fan setting. The temperature inside was 96 degrees when the bodies were discovered.

The New York Times, July 28, 1995

the caring that they have provided all their lives, but are now confronted by their own aging and changing life situation.

The studies also noted that there is a need to locate, inform and draw into the aging network older carers, establish mechanisms to link such carers to family support networks often available through aging, social or disability agencies, and provide supports and services that will sustain the carers for as long as possible.

The alternative could be a massive failure of caring capacities on the part of older parents and a precipitous demand on out-of-home services for both the carer and those for whom they provide care.

Why Develop an Initiative That Targets Older Carers?

Many of the studies that have been conducted with older families suggest that there are "two generation older families" who, with age become vulnerable at some point in their lives. While some, as Drs. Seltzer and Krauss have observed, are *anticipators* and are either short or long term *planners*; others are *avoiders*, who have put off planning and may find the end of caring disturbing and threatening. For some, this "empty nest" situation is often seen by the mother, in particular, as the end of her central role in life and as something to be avoided.

Others may experience some unexpected change in their lives, like the loss of a spouse or a change in living conditions, and this may cause them to become overwhelmed and in need. Helping such two generation older families can be highly beneficial to a community. Many older parents or other carers have assumed the responsibility of lifetime care for their son, daughter, or other relative, thus bearing the cost of providing a home in the community for their offspring. They are now growing older together and may be in need of special help.

Older parents worry about what will happen to their family member if they are no longer capable of caring for him or her, and they identify this concern as an ever-present source of stress and anxiety. Some want to have a plan for the future, but often feel too overwhelmed by their day-to-day responsibilities as carers to focus on the problem. They need legal and financial planning assistance to set up viable guardianships and trusts, and they need casework and advocacy to identify, access, and coordinate needed supports and services, now and in the future.

Obviously, these concerns are experienced even more intensely by aging parents and other aging carers.

Paradoxically, elderly parents, who are most vulnerable in terms of physical health and fixed financial resources, are typically the very parents who have *not* benefitted from recent policies promoting main-streaming, equal education, supported employment and independent living options for children and adults with developmental disabilities.

These are mostly parents who have had to cope with their adult child being at home for many years, with few services and supports, and who experienced decades of community isolation and "going it alone."

What are some of the major needs of these families? Our project found that many of these families have the same needs as other families in caring situations. They want

- ❖ services that meet their immediate needs (such as, respite, house-keeping assistance, transportation, and emotional supports)
- ❖ help with getting financial supports or determinations of eligibility
- ❖ help with obtaining financial planning information (such as, information on entitlements, guardianship and trusts)
- ❖ help with negotiating the service system and advocacy for obtaining services for which they are eligible
- ❖ assistance with obtaining Medicaid and working out problems with social services agencies
- ❖ help with making decisions about their lives or the lives of the person for whom they are caring

What they don't want or need is unnecessary intrusions into their lives. They don't want to feel that someone is coming to talk with them who could eventually disrupt their lives, or possibly take their son or daughter away from them. They don't want to feel threatened or "put upon" and they don't want change imposed on them.

What they do want is someone who will listen to them and provide help when it is requested.

Making the Case for a Carer Assistance Initiative

> "*. . . there is a problem . . . something should be done about it . . . it can be dealt with . . .*"

Many older families are quite capable of continuing their family responsibilities without special help. However, there are also families whose situation may be such that some help would make their lives that much better. Also, there may be those families in crisis, like the ones illustrated in this chapter, whose situations are quite dire and because help is not available, eventually face a calamity.

How do we meet the need presented by such older families is the problem. However, even when people agree about doing something to aid such families, getting such an initiative going is not always easy. In making the case for such an initiative, it is useful to understand that such carers are usually the "first line of defense."

Helping "two-generation older families" is analogous to the crew member's instructions given on airliners that tell us that in emergency situations "you should don your oxygen mask first, then your child's." Helping to stabilize the carer is often the first step in helping the older adult with a developmental disability.

Area agency on aging directors we spoke with have suggested some reasons for developing a helping initiative. These include

- such older persons, as members of the aging community, are a natural constituency of the aging network and as such have needs that have to be addressed; further, under the Older American Act aging agencies have an obligation to aid this population
- many of these families or carers have been providing lifelong care for someone with a developmental disability, care that might otherwise have been the responsibility of state or local government agencies; now that they are growing older they need aid with their own lives
- by not helping such parents the problem can eventually become more costly for the community, since emergency or long-term out-of-home care for a person with a developmental disability is expensive, often difficult to find, and requires an investment of considerable staff time for emergency casework

The potential for reducing the need for expensive levels of services is an important argument. One area director noted that ". . . when the family falls apart, there are two people who fail." The costs involved with having to provide emergency supports or having to immediately find alternative housing for either can be high. Providing supports to maintain a situation that otherwise may be in jeopardy will be less costly, both in terms of the cost of care and the emotional toll on carers and adults with a developmental disability. Handling emergencies also drains scarce agency resources.

It is important to be sure of your facts. Another director pointed out that you should be careful not to make the fiscal argument your main one. Take care not to exaggerate the numbers issue -- don't say there are too many such families in your area. Otherwise, it will seem overwhelming from a budgetary point of view and appear too costly an initiative to take on. Make the point that in most instances, the services provided to such carers are like the services you already provide to other seniors or their families.

Also, as one director put it: "It's an ongoing problem among such families -- but it's not an overwhelming one." Keep in mind that often minimal supports are enough to keep the family going by connecting them with other service providers and aiding them with the right referrals.

This director went on to note that "as such families grow older, their needs change and they may need help in areas they hadn't considered . . ." It is important to emphasize that older carers assumed the responsibility for a lifetime of care for someone with a lifelong disability. Perhaps, now as they have grown old, these "perpetual carers" are entitled to some help in recognition of years of personal sacrifice.

Some of the Situations Faced by Families

Families and other carers find themselves in many different situations. Here are some situations we encountered, which may be typical of those encountered anywhere.

Mrs. M. is an example of a carer who only wanted some minor assistance.

> *Mrs. M. is a 72 year-old widow of two years with a 38 year-old son with mild intellectual disability. They live together in their family home in a small town. The son attended special education classes and then worked at a sheltered workshop, but hated it. He has always lived at home and receives Social Security payments.*
>
> *Mrs. M. contacted her local area agency on aging for more information on supple-mental needs trusts, after an article on these had appeared in the agency's Senior Circle newspaper. She had a will which provided some financial planning for her son, but had not revised it in several years. Mrs. M. was given several articles on estate planning, guardianship, and supplemental needs trusts, and counseled about her options.*

Since Mrs. M.'s son asked for another day service and she was encouraging him to be involved in some daytime activities, the worker made a follow- up call to inform her of openings in an adult recreation program. She was having health problems and said that she would think about her son's day services when her health problems were resolved. The area agency on aging also put her on a mailing list for carers of adults with developmental disabilities that it maintained.

Mrs. M. was referred to the local developmental disability agency, which followed up with future planning and encouraged her son to get connected with appropriate community services, such as the recreation program.

Mrs. M. and her son are typical of families that have not used any community support agencies in the past. When Mrs. M. does take action, and develops guardianship and estate plans, her son will more likely be better cared for after her death. If Mrs. M.'s house were to become her son's home upon her death, he could live there for the rest of his life in familiar surroundings and be supported by the provisions of the trust

If she doesn't, her son will probably suddenly enter the developmental disabilities system upon her death and could end up lodged in a residential facility until an appropriate living situation can be found. The resulting placement, even if only temporary, could be very costly. Local residences can cost up to $80,000 annually compared to the $10,000 or so it would cost for recreation, casework, and in-home supports.

Sometime families require more involved assistance as their own health and situation deteriorates. The following situation illustrates a typical family that has been providing prolonged care for an adult offspring with a severe disability.

> *When the project outreach worker first met the K. family, they consisted of a 78 year-old mother, an 84 year-old father, and their 36 year-old daughter. The daughter was severely disabled from an allergic reaction to a DPT shot received when she was an infant. Since that time, she has needed almost 24-hour care. She is unable to feed herself, or walk without assistance, or talk. She awakes five or six times a night and each time one of her elderly parents must get up with her.*
>
> *Twenty years ago Mr. K. took early retirement to help his wife care for their daughter. This worked out well until a few years ago when Mrs. K.'s health began to fail, and she was unexpectedly hospitalized. At that time, the family tried to become connected with the developmental disabilities system, but was unsuccessful. The daughter originally received a wheelchair when she was ten years old. The family had no positioning equipment or bath lift. The mother's back was permanently damaged from lifting her daughter in and out of the bathtub. Except for minimal assistance from an aide, the K. family had until recently received no services.*

Since the K. family became connected with the carer project in their area about a year ago, the daughter received a new wheelchair and their home had a bath lift installed. In addition, other modifications have been installed and the daughter was enrolled in a Medicaid waiver program. Unfortunately, these supports may not be enough since Mr. K. died suddenly a few months ago. Since then, carer project staff have arranged for a home health aide and are working on admission to an assistive living facility for both mother and daughter, since Mrs. K.'s own health problems are progressively preventing her from caring for her daughter in her home.

This family's situation is not uncommon. Many such parents have spent their lives caring for a relative only to find that as they grow old, their own needs overcome their capabilities to continue to provide care.

In many situations there may only be one carer involved. They have been coping for a long time and now they are worried both about their own future and the future of their adult child. The following situation may be typical of such carers.

> *Mrs. L. is 72 years-old and has lived alone with her daughter for the past twenty years since her husband died. They came to the United States from China some 35 years ago. Mrs. L. lived in a mostly Chinese community and had little need to learn English. Several years ago, Mrs. L. was diagnosed as having Parkinson disease and now needs frequent medical care*
>
> *Mrs. L. is the only carer for her 46 year-old daughter with intellectual disability. Since Mrs. L. only speaks Chinese, she is largely dependent upon bilingual services whether they are for herself or her daughter. Her wish is to move and live in a residential setting operated by a local Chinese organization. She hopes to receive care for her health condition. However, she has been turned down many times because she is still caring for a her daughter with intellectual disability.*

The carer aid unit has been providing support services to Ms. L. for several years now. They have tried to focus their services on reducing her worries and concerns regarding the care of her daughter and in finding her another place to live. In the meantime, they have been successful in obtaining financial supports for her day-to-day needs and rent supports from a federal housing aid program. They continue to search for a home care facility and have encouraged her to prepare her daughter for living in an independent setting of her own.

In other situations, the complexity of the family may affect offers of help. The following situation illustrates the dilemmas faced by carers when they are faced with multiple challenges.

> *Mrs. P., a woman in her early sixties, is caring for her husband and her brother-in-law who has a developmental disability, but who is otherwise physically well. Her husband has cancer and is receiving treatment at home. Her brother-in-law had lived in another state with his parents until their death and then went to live with another of his brothers. This other brother could no longer care for him and was going to have him placed in a "home."*
>
> *Mrs. P. and her husband agreed that they would rather her brother-in-law come live with them, and he has been with them for some 14 years. Now with her husband's illness, Mrs. P. is feeling a bit overwhelmed. A public health nurse comes twice a week to care for her husband and do blood work. Mrs. P. had shared with the nurse that she would like some assistance if it were available. At Mrs. P's request, the nurse*

made a referral to the local Arc chapter.

An agency representative from the Arc chapter spoke with Mrs. P. about the various services they provide. However, there was a problem with transportation and the family did not show an interest in the options offered. The family wanted respite, but due to their location the Arc could not arrange for this service. It is very difficult for the family to get out due to the risk of infection. There is a strong sense of family responsibility in terms of caring for the brother-in-law despite these circumstances.

This family exemplifies those situations where some minimal aid could provide welcome relief to the family and potentially open up new opportunities for the adult with a disability.

Lastly, the carer may be someone once removed, but who takes a special interest in an older adult with a lifelong disability. The following illustrates this type of situation.

Mr. G., age 72, has been capable of living on his own. Over the years he never received any services after dropping out of school in fifth grade. He has been coming to a two day a week meal site for about seven years. He is divorced and held a janitorial job at the local school in a rural farm community until he retired eight years ago. He lives in a trailer park in his own trailer and his sister, who has looked after him since he was young, lives in the trailer next door. An extensive network of people provide small amounts of help in the form of rides, help with shopping, and general social support. He participates in activities at his church.

His sister called the Office for Aging home delivered meals program because she was going into the hospital and was concerned he wouldn't get enough food while she was away. She was concerned about people taking advantage of him, which has happened frequently in the past, and about his future if she becomes too ill to support him. She doesn't think any of the people around who help Mr. G. will be willing to provide the extensive support she currently provides him.

What have these situations told us? That these families face many of the same challenges and dilemmas as other families. The situations they face in planning and caring for a son, daughter or other relative with a developmental disability are similar to a wife caring for her husband who has just suffered a stroke or a husband and daughter trying to care for their wife and mother who is in an advanced stage of dementia.

What may be different is that these families have been caring for a long time -- most likely over the lifetime of the adult with a develop-mental disability. For the most part they have been successful at what they have done. Now, because of their own aging, or changing life situation, they need help.

This is why older carers should be targeted for assistance. ▲

Chapter 2

Carers of Adults with Developmental Disabilities - Who are They?

> ***Families don't see themselves as "carers." They see themselves as family members taking care of their own.***

As stated at the beginning of Chapter 1, we have chosen to use the term "carer" for this manual. We feel that "carers" rather than "caregivers" or "caretakers" is more descriptive of the people who provide a wide range of help, without financial reward, for persons with a disability who live in the community.

Many carers provide "hands on care" but others may also help in a less tangible way by providing emotional support or participating in decisions which affect care.

When we use the term "carer" we are referring to the range of family, friends and neighbors. Carers in a household can be parents, siblings, nieces, nephews, grandparents or any relatives. They can also be friends, spouses, neighbors, housemates or anyone else who helps.

Caring can require an intensive effort such as when someone assumes responsibility for the daily safety, welfare and activities of a person with a disability. Or caring can occur on an occasional basis, such as when neighbors or friends look in on a neighbor or friend. In most situations, it may be something in between.

In this manual, we have excluded situations where a person with a disability controls his or her own situation and engages and directs a personal care attendant or helper. However, we recognize that in many situations adults with a disability living in a household may be responsible for their own needs and decisions. Indeed, in our project, several adults were identified who served as the primary carer for an older parent.

Who Are the Primary Carers?

Usually one person is responsible for most of the daily care of the person with a disability and for major decisions about his or her daily life and activities.

In formal caring situations, the responsibility tends to fall primarily on women. Many older carers are widows and mothers of a child with a disability and have provided care throughout the life of their child.

In some households, other family members, such as grandmothers, aunts, wives, sisters and cousins are the primary carers. However, don't be surprised to find fathers, husbands, brothers and nephews as primary carers also. Grandparents are also increasingly providing care for grandchildren.

Many carers also provide care for other family members such as young grandchildren or other adult members with an impairment or disability. Someone who cares for a parent, a spouse or a sibling, as well as a person with a developmental disability often has to balance a number of responsibilities.

> *Mrs. T., age 76, has taken care of her 74 year old sister with intellectual disability since their parents died 35 years ago. When Mrs. T. fell and broke her hip, her sister could only stand out in the street and yell for help. During her mother's hospitalization, Mrs. T.'s daughter took care of her aunt. Because she works outside her home, she hoped to involve her aunt in some outside activities. However, Mrs. T. would not allow her sister to attend any service programs and felt she should stay at home as usual. The aging agency learned of the sisters when Mrs. T.'s daughter called to request home delivered meals when her mother came home from the hospital.*

Primary carers often receive help from a range of family members. Cousins, grandchildren, aunts, brothers, husbands and sisters provide social and emotional support as well as practical

Some Carers . . .

A grandmother in her 70s who is the sole source of support for her 25 year old grandson with severe cerebral palsy.

A 74 year-old mother who is caring for her daughter with intellectual disability who has recently been diagnosed with cancer.

Three neighbors who occasionally look in on a 60ish woman with mild intellectual disabilitytardation who lives by herself in a small village.

A woman in her 60s who looks after an adopted teenage son with intellectual disability.

A grandmother in her 70s who is the sole support for three adult grandsons, all of whom attend a work program sponsored by a intellectual disability agency.

A 92 year-old widow who lives with her 62 year-old son with a disability on a rural homestead.

A 65 year-old recent widower who is the primary source of care and support for his 28 year-old son with Down syndrome.

A recently widowed mother in her 70s who is caring for her adopted 19 year-old daughter with cerebral palsy.

A son in his 30s with mild cerebral palsy who looks after his infirm mother.

A mother in her 80s who cares for her 52 year-old son with severe intellectual disability and cerebral palsy.

A sister in her 70s who lives with her older sister with intellectual disability.

A couple in their 70s who care for their daughter in her 40s with intellectual disability. The father has a war-related disability.

An 82 year-old great-grandmother who cares for a nephew with both intellectual disability and mental illness, two great grandchildren and a brother who is now impaired.

A grandmother in her 70s who cares for a daughter with an intellectual disability and three grandchildren, all of whom have learning difficulties.

The parents, grandparents, three siblings and several cousins with whom a 45 year-old man with a disability lives; they all share the responsibility for looking after him.

A 40ish daughter with a seizure disorder and her elderly father who look after each other.

help with

- transportation
- making care related decisions
- financial management

- short term respite
- recreation

The importance of this type of help is highlighted when family members are no longer able to assist. Death, illness, new disability, relocation or change in life circumstances of family members may leave significant gaps in care. Recently widowed carers are often faced with a more difficult experience and may need help after the death of their spouse.

Siblings of persons with a disability, who often have families and jobs of their own, have unique stresses. During middle age, they must balance their own family and career demands with the care of aging parents and a brother or sister with a disability. They are often expected to assume total responsibility for their sibling after the death of their parents. In some families, this means that a brother or sister will provide care well into their old age and that their children may eventually become involved in caring for them and the person with a disability.

On the previous page, are descriptions that typify the carers we encountered.

Friends and Neighbors Help Too

Non-relatives may also help out. Some examples we found were a landlord, a sibling's former girlfriend and neighbors. These individuals helped by

- running errands
- picking up groceries
- dropping off a meal

However, help from friends and neighbors varies widely by individual family and cultural groups. Some families may actively seek help from churches, social and service organizations. Other families do not seek or accept help from such resources.

Caregiving Styles

Not all carers and their families provide care in the same way. You can expect to see some differences in caring style by gender, cultural group and age. However, you cannot assume that all women or men, all older people or families of a specific cultural heritage, will hold similar attitudes about the caring role, disability, social activities and the use of community services.

Attitudes Toward Caregiving

Carers may view their role as primary carer in different ways. For instance, many women see their role as a natural responsibility and have provided care over the lifetime of a family member with a disability. For them caring may be seen as a vocation.

In contrast, other primary carers, often men, may approach the responsibility of caring more as a job and may break it down into a series of tasks. In some cases, the personal identities of men are less tied to their roles as carers.

These varying perceptions toward the role of caring will affect how people seek out and accept assistance as well as the degree to which their personal identities are intertwined with their caring manner and self-defined responsibilities.

Attitudes Toward Disability

Disability has different meanings for different people. Often how we view disability is affected by our cultural values and experiences. A person with a disability in one society or family may be stigmatized or shunned, whereas in other societies they may be treated more equitably. Because of these differences in perception, some people may view disability or the person with a disability with shame, sadness, indifference, or as a "gift from God."

Families who have recently immigrated to this country may be more likely to retain their traditional view of disability. The view of disability of those families who have assimilated may be based on combination of their family's beliefs and the immediate culture.

Some carers may view disability as a threat to their own self image and may be very uncomfortable around a person with a disability. Seeing someone with a disability may remind them of their own vulnerabilities.

Attitudes Toward Use of Community Services

Just as families differ in the way they perceive disabilities, caregiving and participation in social activities, there are differences in how families feel about using community services. For instance, many younger carers may be more likely to use services in the developmental disabilities system than older carers.

Why? For the most part, many older carers have not had formal services available to them. Years ago, the only service option the families had was to place their child away from the home, often in institutional care. Older carers often express fear that placement

Telling Jack

Mary McHugh

Hands reach out to touch me, pull me, grab me as I walk into the home for retarded adults where my brother has lived for the last 20 years. "What's your name?" they ask. Where's your mother?" Like children. But they are adults. Retarded adults, from their 20's to their 70's. I just want to do what I came to do and get away as fast as I can.

I hate coming here. It reminds me of shopping trips with my mother and brother when I was a little girl. I felt embarrassed by my brother, who walked with short, shuffling steps, clung to Mother's hand, smiled and looked at Mom when someone spoke to him. I felt as if everyone was staring at us. When I was a teenager I didn't want my friends to know that I had a retarded brother. I was ashamed of him and ashamed of myself. I knew I should love him, should help my mother, should be a good girl. I tried, but I never learned to love him.

I reminded myself that my brother had been brain-damaged by a careless doctor. I tortured myself wondering what he could have been if the accident hadn't happened. An engineer like my father, a lawyer like my husband? Just a few minutes more oxygen and the spark of intelligence would be there in his eyes. Instead there's a worried, frightened struggle to understand. He knows enough to realize that he's missing the point; he's embarrassed that he's not as smart as other people.

Now it is my job to tell him that our mother is dead. And somehow I must learn to take her place.

"Jackie's waiting for you," the supervisor says.

My brother comes toward me, then backs away as I try to kiss him. "How's Mother?" he asks.

"Let's go in your room, Jack," I say.

He is taller than I. His face would be handsome if the light of intelligence were reflected there. At 57 his hair, like mine, is still a dark blond with only a few gray strands. I am two years older. He turns toward me, smiling, not wanting to hear what I have to tell him.

"Jack," I say, taking his hand, "Mom died last week of a heart attack."

He brushes his tears away with the back of his hand. Who taught him that it was wrong to cry? I put my arms around him, but he stiffens.

"What will happen to her car?" he asks. He fastens on details when he can't fully grasp the meaning of something.

I'll take care of it for her, Jackie," I say, hugging him. He's like a little boy, I think. My little boy now.

"I'll make sure you're O.K. honey," I say. "I'll come and see you. I'll write to you."

He is quiet for a minute. I can't tell what he is thinking. I don't know him at all. I went to college, married, had children and saw him only occasionally after my parents put him in the home in Florida when he was 37. Busy raising my children, I often forgot to send him birthday cards and Christmas presents. I didn't visit or call him. I would say, "I don't feel anything for my brother." But of course I felt a lot--a lot of resentment and anger.

I take him out to lunch and try to think of things to talk about. He looks down at his ice cream and says softly, "It's a shame about Mother dying."

My God, I think, he's the retarded one, but I'm the one pretending she hasn't died, not talking about her.

"Yes, it is a shame, Jack," I say. But you know, we were lucky to have her for 93 years. She loved us so much."

"I knew she was either 92 or 93, but I couldn't remember which one," Jack says.

Numbers are like a lifeline to Jack. He could often recall birthdays, street addresses and ages when I had forgotten them.

"It was good of you to remember that, Jack," I say.

He smiles. I feel a rush of love for him that overwhelms me, surprises me. I hold his hand as we walk to the car. The embarrassment is gone. I'm my mother now.

Three months later I take a week off from my job as an editor in New York to go to Florida and take Jack to the beach for a week. This time I don't dread the trip as much as I did before. I want to find out how much he understands, how much he feels, if he's happy.

Our motel room has a large picture window facing the ocean. The sight of the white caps, the wide beach, the sea gulls, soothes me. It will be O.K., I tell myself. I can do this.

Jack clicks on a "Golden Girls" rerun on TV. I'm surprised to hear him laugh out loud when Rose says she wants to be frozen when she dies. I didn't expect him to laugh at the same things I did. I don't know why.

He surprises me all the time. He reads the names "New Mexico," "Oklahoma," "Mississippi" on the pieces of a jigsaw puzzle of the United States I bought him and figures out where to place them. I had taught him to read when we were children playing school, but I had no idea he could read that well now.

One night we go for a walk on the beach.

"Do you know what my daughter Kyle gave me after Mother died?" It was a star. There's a company that names stars for people who die, and Mother's is near the Big Dipper. See, it's right up there."

He tries hard not to cry, but I am not as successful. Mother took full responsibility for teaching Jack, encouraging him to take care of himself, worrying about him every day of her life. She was the one who traveled the bad roads from New York to Boston in the 30's to see the doctors at Children's Hospital. She bathed, dressed and later shaved him every morning until he went away. Dad retreated into golf and Scotch and left Jackie to my mother.

I asked her one day if she minded, and she said, "Sometimes I would just like to get up in the morning and not have to take care of Jackie all day. I would like some time off."

But she didn't complain. She just did what she had to do. People used to say to her, "Jack was given to you for a reason." And I, watching her struggle to care for him, to do her best for me, to manage her marriage with a brilliant, difficult man, used to think, Oh, sure. He was given to her to make certain that she suffered enough, to make me feel guilty that I can't love him. I wondered what kind of a God would decide we needed a retarded child to prove a point.

"Does my dad have a star, too?" Jack asks.

Again I am caught off guard. Why, he loves Dad, I think. He loves that angry, cold man who ignored him when he was growing up. He must have wanted to be like him. I know so little about this boy.

We go to Disney World and he clings to my hand, and I realize that he is afraid of losing me. People stare at us as we eat in a western saloon where they play "Home on the Range." But when I look up to confront them I see that their expressions are kind, concerned.

"Remember, Jack," I say. "Dad used to play the piano and sing that song when they had parties."

He laughs and remembers with me.

We go back to the motel tired and hot. I fill the tub with warm water. His room mother told me he needs help with his bath. I'm not sure how to do this without embarrassing him, but he doesn't seem to mind. I scrub his back and arms and hand Jack the washcloth to bathe his genitals.

"Do you mind my helping you with your bath?" I ask.

"No," he says.

If you've lived in a home for retarded people for 20 years, you probably don't have much privacy.

Bathing him, feeding him, looking after him, brings back the years of taking care of my own children. At night I tuck him in and say, "I love you, Jack," and realize that I mean it--at least for this moment.

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is the main intent of the formal service system. Some said to us: *"We thought you might have come to take my child away."*

When older carers do request help, it may be only for assistance with a simple problem, such as transportation to a doctor's appointment or help with solving a billing problem with their local utility. The request may be for services unrelated to the specific needs of the person with a disability.

When they are approached about services related to the caring role or responsibilities, carers often express mixed feelings. Some are adamant about not accepting any help, whereas others may be willing to at least begin talking. Others may be glad to get some help, but on their own terms and in their own time frame.

Participation in Social Activities

Carers are often unable to do the everyday things that others take for granted, such as

- go to church
- go on vacation
- leave their homes
- attend senior centers and nutrition programs

Many carers are socially isolated from friends and neighbors and often do not participate in organized social activities. Also, older carers who are retired from work may not have the freedom of movement or income to do as they please.

> *"Our neighbors retired and went on interesting trips, to places they always wanted to go. We never get to go anywhere - we can't retire from our responsibilities."*

Why Are Some Families Reluctant to Use Services?

The feelings of carers about accepting agency services stem from several sources

- negative experiences with the disabilities service system

- difficulties talking with service providers

- the complex and often impersonal way agencies function

Past Experiences with Service Providers

Some families, especially those whose children were born during the 1930s, 40s or 50s, were turned off from any formal contacts with "agencies" years ago. When a child with a developmental disability was born during this era, many parents received little support in coping with the trauma of having a child with a disability. They often received conflicting or discouraging advice, for example

- doctors, nurses, social workers and other professionals offered a pessimistic view of the child's future; *"He will never live to be ten."*
- professionals often told parents that they were not capable of providing care and encouraged institutionalization; *"He should be sent to Northampton."*
- school systems were totally unresponsive to their needs; *"I was told there was no place in the school for my son."*
- services that professionals thought would help families did not meet the family's needs; *"They offered me counseling but what we wanted is for him to be enrolled in school."*
- families, after multiple applications for services, were often refused; *"It was a closed door everywhere we went."*

Many aging carers have vivid memories of these experiences and still remain angry. They have given up on the services system, and don't seek out information about the services available today.

Difficulties Talking with Providers

Families may not be familiar with the professional jargon which has developed over time and continually changes. A term such as "developmental disability" has little meaning to most families. They may describe adults with disabilities as children or as "retarded" or "slow."

It is important to remember that words such as "retarded" represent the terms that families were presented with when the person with a disability was born. Also it was acceptable then to refer to adults with disabilities as if they were children.

In the 1950's, for example, the only readily available advice to families of persons with disabilities was a book by Pearl Buck serialized in *Readers Digest* under the title, *The Child Who Never Grew.*

Professional terminology often does not translate into other languages. Terms such as *developmental disabilities* have no equivalent in many Chinese dialects. In some cultures "disability" is not a specific concept. The person is just a person!

In addition to the barriers posed by

workers' use of professional jargon and abbreviations, many families have difficulty accessing services because English is not their first language. Many informational materials are in English only, and many workers are English-speaking only. It is often difficult to obtain translations. Although some materials are now available in Spanish, materials in other languages may not be available. This is often a significant impediment for older parents whose primary language is not English.

Agency Rules and Functions

Agencies are usually funded to develop and provide services to address a specific need in the community. As a result, agencies operate within rules and regulations which specify criteria for service eligibility as well as the extent of the services.

Unfortunately, this often has the effect of creating within an agency a singular focus on "the client" instead of the family. An agency cannot offer a service to someone in the family who does not meet the eligibility criteria. The staff of a disability agency may address the needs of the person with a disability but not the aging carer or others in the family.

Similarly, staff of an aging agency may focus on the needs of the aging carer but not the needs of the person with a disability who is under 60 years of age. Yet the need may be a family need. For example, "agency specificity" is a significant barrier when the family needs housing. Many senior housing complexes or nursing homes do not allow a son or daughter with a disability to live with their parents. Conversely, parents are not permitted to move into group homes for people with developmental disabilities.

Available services do not always meet the immediate needs of a carer or person with disability after help is requested. For example, a family may need respite, but the agency can only offer assistance with transportation to medical appointments.

Another problem is that each community has a maze of services with specific functions which can be very difficult for families to negotiate. Families seeking help for multiple problems report that they find themselves telling their story and giving the same information over and over again.

Families Can Be Users and Non-users of Local Services

Not all older families are non-users of services. Some are long term users of services. They may have helped set up local parent organizations and support groups. They may also have

Some Challenges . . .

A mother with a son with Down syndrome had to search for six months for a doctor who would treat her son's heart condition.

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Another mother wanted her son tested when he was 14 to determine how to best help him. After two months of testing, the state school said that he would never function higher than the three month old level and that institutionalization was their only option. The parents took him home and have been caring for him for the past 30 years.

✻✻✻

A father sought medical help for his son with intellectual disability, but was rebuffed by the community's physician who told him his son was retarded and that was why he was having problems.

✻✻✻

A parent advocate complained about some of his peers who were "closeting" their adult children.

✻✻✻

A grandmother, caring for a grandchild with a disability as well as her other grandchildren, asked how agency workers can propose to buy shoes only for the child with the disability when all her grandchildren need shoes.

✻✻✻

An older mother was distraught because the agency's senior housing program would not let her daughter who has intellectual disability move in along with her.

✻✻✻

One mother related having to drive 150 miles each way to take her adult son with cerebral palsy to a dentist willing to take her son as a patient.

✻✻✻

A couple with a son in his thirties, bought a small home. They also found three other couples with an adult son or daughter looking for a place to live, and developed a small "cooperative" home for all four. Now that they have the home, they are looking for a source of support funds for the day-to-day upkeep of the home.

✻✻✻

A mother was unaware that her 40 year-old son was eligible for Medicaid.

carefully organized the lives of their sons or daughters to participate in a range of opportunities in their community.

In our project, we found that there were families who used services when they were offered to them. Many of the families we had contact with were getting some form of aid or supports from the local social services, aging, health or disability agencies and benefitted from home health services. Most were supported by public benefits and retirement income; others were still working. In addition, many of families also benefitted from informal supports. They had access to and accepted help from their churches or other religious organizations.

Our experiences showed that the availability of this type of help from an aging agency as well as active outreach by that agency seemed to help families connect with more services. When families found out that the aging agency had services available, they often initiated the first contact.

The lesson learned was that reaching out to families, being there when help is needed, and providing help when it is requested can be very beneficial.

▲

Chapter 3

Persons with a Developmental Disability - Who Are They?

"I don't have anywhere to go when she dies . . ."

Although the focus of this manual is on persons who are carers, we also recognize that the person with a developmental disability plays a vital role in his or her family.

Each person is a part of his of her family's history and plays a role in both the joys and difficulties that are typical of the lives of any family and in the family's relationships.

Persons with a disability also have an important role in how various family members, especially the primary carers, define themselves. They do indeed contribute to the family in many basic and practical ways, by

- providing companionship
- helping another family member with daily care
- helping with household chores
- providing care to an increasingly frail parent
- supplementing family income
- working in family enterprises

In some families, the adult with a disability may be the carer and helps an elderly or infirm parent or other relative continue to maintain their home and independence. This helps keep the family intact. In these situations, the adult with a disability may be the sole source of support for their relative and may be the only thing that helps sustain the family.

In either situation, the person with a disability has come to play a significant and prolonged role in the family. This fact must be kept in mind in any attempt to intervene in the family situation.

Who Are the People with Disabilities in Caring Situations?

Persons with a disability who are assisted by carers may be young children, teenagers, adults or elderly adults. Most are adults who have always lived with their family.

Some are older adults who live with a sibling or other younger relative, and, increasingly, they are children living with grandparents, great-grandparents or other older persons.

In general, older persons with a developmental disability are not fully independent now nor have they been since childhood. Their disability is lifelong, beginning at an early age and extending into old age.

They may have difficulty in performing personal care activities, earning a living, getting around, making decisions or in exercising judgement. Some individuals may be quite independent, while others may need a lot of help from others.

Because persons with a disability vary considerably in their abilities, it is important to learn as much as you can about each individual's abilities and limitations.

With increasing age or premature aging, adults with a disability may need more assistance than previously needed. Some older persons may easily qualify for aging network services if they are 60 years old or older.

The Care Receivers in Our Project

In our project, the characteristics of persons with a disability varied as you might expect. However, we did identify some general attributes which typify the persons we encountered.

We found that most of the people with a disability we encountered were children, grandchildren, or other relatives of carers. Men and women were found in equal numbers. Most were adults between the ages of 21 and 59, but some were over the age of 60 and some were children.

Most individuals had some

education, primarily at the elementary level. Some had attended high school or vocational school.

Most persons had an intellectual disability as the primary developmental disability. Some had cerebral palsy or a seizure disorder. Although the majority had mild intellectual disability, some had severe and profound mental and physical impairments.

In general, we found that persons with a disability who live with their families or other households represent a broad spectrum of abilities and needs.

The examples cited on page 15 are typical of the situations you may encounter.

How Many Older Persons with a Developmental Disability Are There?

Informed projections are difficult to make since no specific census data exist on counts of older persons with a developmental disability. Various authors have speculated on the possible numbers. One means of estimation was reported by Jacobson, Sutton, and Janicki (1985) in a book on aging and developmental disabilities. They used data from several registries in the United States, the United Kingdom, and Australia and proposed an estimate of about 4/1000 older persons (age 60 plus).

This means that for every one thousand older persons in a geographic area, about four would be older persons with a developmental disability. The 4/1000 estimate offers an outside number for older persons in an area. However, it doesn't take into consideration adults aged less than 60 (which often represent from two to three times more individuals), nor does it provide a way of estimating how many persons may be living on their own, with kin, or in other caring situations.

To arrive at an estimate, we suggest (a) use the 4/1000 method or (b) confer with your state or local developmental disabilities authorities, obtain their census or registry information, and then add a factor of from two to four times to that number. Either of these will provide an outside estimate of the potential number of older persons with a developmental disability in your area that can be used for gross calculations of need.

A more difficult question to answer is how may many adults are there with a developmental disability who may be living with their families? Such estimates are difficult, since much depends on historical family decision-making patterns, the availability of independent housing, and the age distribution of older persons with a disability in your region.

First determine the number of adults living in publically subsidized accommodations in your area (group homes, apartments, other settings), then deduct these from the estimates you made above. The balance should include the unknowns, most likely persons living wtih families or own their own. To adjust for age, the following may be helpful: Among adults living with families, generally the age group 35 to 44 is twice the size as the age group 45 to 64, which is ten times the size of the age group 65 and older.

Some Considerations About People with Disabilities

There are numerous areas that should be considered relative to adults with a developmental disability. Here we will consider only a few key ones, including planning for the future, the problems raised by exploitation and abuse, and help with using community senior services.

Planning for the Future

As noted in the vignette, one of the older men we interviewed said to us, "I don't have anywhere to go when she dies." He was referring to his elderly mother with whom he had lived for 67 years. As he began to confront the reality of life without her, he was frightened.

> *One of our caseworkers ran into a 92 year-old woman who is living with her son of 67. She came to our attention because she needed help with recertification for Medicaid. Her son was in an adult day services program, but was not attending because of vision problems after a recent corneal implant. The caseworker got involved and attempted to provide some supports, particularly around planning for the future. The mother began to think somewhat about what will happen to her son and agreed to some contacts with a local disability agency. The son concerned about his own future, confided that he was worried about what will happen to him when his mother is no longer around.*
>
> A casework supervisor

In our project, the most outstanding characteristic of caring families was their lack of serious thinking about the future living situations of their relative with a disability. Both parents and adults with a disability were fearful of the eventuality of old age. Parents could not imagine their children outliving them. The adult children were uncertain about a future without their parents.

Planning didn't occur for many reasons. Carers may feel they have no viable options or may fear their own mortality. And some carers may be overprotective. You might encounter parents who are not open to considering an alternative living situation for their adult child or who do not want their son or daughter to become involved in programs or go to work.

When working with families who are interested in planning for the future, you may want to broach the subject and involve everyone in planning. The adult with a disability may have some ideas about where he or she may wish to live and about activities in which he or she may want to participate. Often it is the life goals and wishes of the adults themselves that help the parent or other carer to begin to realize that it may be time to consider the future.

An important first step in helping people plan may be to gradually introduce the person with a disability to alternatives. Consider exposing someone gradually to experiences in living apart from the family or having them think about with whom they would prefer to live in absence of their parents or other carers.

Planning can also be stimulated by providing carers with information about financial options and resources and guardianship, and by helping them identify relatives, friends and others who might be available to help.

Because of the seriousness and complexities of future planning we have devoted Chapter 8 to this issue..

Exploitation and abuse

Sometimes workers become concerned that the person with a disability is being exploited by their carers. Persons who are totally dependent on another may be at-risk for abuse and neglect.

This concern is often generated by fears that the financial benefits the person with a disability receives become part of the household income and are controlled by another family member. However, when this happens it may or may not be exploitation.

In some situations, the individual does not receive any benefit from their personal income or is not permitted to participate in any decisions about spending. Here, it is likely that he or she is being exploited.

However, in other situations the carer may believe that he or she is protecting the individual from a burdensome responsibility. This is not wilful exploitation. You can help

"I know of a woman who is 38 and

> *has emphysema, scoliosis and arthritis, in addition to intellectual disability. She lives with her elderly mother. She has never worked or been in any type of program. She has never been to a doctor because the family has no health insurance and is not receiving any government benefits. She and her mother need some help, but the mother is very reluctant to "get services" because she doesn't know what that means and what it will do to her and her daughter."*
>
> A referral

educate carers about the importance of having the individual for whom the funds are meant participate in decisions about their use.

Also, ir the person with a disability is a member of the household, it is appropriate that he or she has the same opportunities to contribute to the upkeep of the household as other family members. Exploitation is likely where their contribution is greater.

Abuse is a greater concern. It may take on various forms. In some cases, a person who is totally dependent upon another may be the victim of advertent or inadvertent neglect. Carers who intentionally mistreat another person, either verbally or physically, are guilty of abuse or advertent neglect

Neglect which is not intentional may occur when a carer is no longer able to meet the demands of providing personal care for a person with a severe disability.

Exploitation and abuse should never be condoned. However, it is important to resist the temptation to rush to judgement about any situation. If you suspect abuse or neglect of a person with a disability by a carer, talk with the family and obtain their perspective. What at first glance appears to be exploitation or abuse may not be so.

Remember also that refusing to accept services or share the worker's values is not abuse. Family members may have been "judged" by agency workers in the past. This may contribute to their unwillingness to easily impart information to strangers or to consider offers of services today.

Using Senior Services

Some adults with a develop-mental disability may wish to use the services available for older adults in their community. There are many ways that you can be helpful in introducing them to their local senior center, nutrition site, or other senior activity programs.

We recommend several resources that explore these techniques in detail. One that is particularly helpful is a publication titled *The Wit to Win (How to Integrate Older Persons with Developmental Disabilities into Community Aging Programs)*, which is available for download from www.uic.edu/orgs/rrtcamr/families.

Other resources include a publication titled *Building the Future - Planning and Community Development in Aging and Developmental Disabilities,* and a compilation of helping activities, titled, *Casebook of Integration Experiences - Program Ideas in Aging and Developmental Disabilities.* These were available from the New York State Office of Mental Retardation and Developmental Disabilities (c/o "Aging Services," 44 Holland Avenue, Albany, New York 12229-1000) but are now out-of-print. They may be available at the offices of your state's developmental disabilities planning council.

The "Reading Resources" page in the Appendix contains a listing of these and other useful publications. ▲

Chapter 4

Organizing Your Community

> ***"We found that as we began to receive referrals, we did not have a network to use for passing on the referrals."***

In this section we provide some practical insights on the first steps in undertaking an initiative targeting older families or other carers of someone with a lifelong disability.

Starting a carer assistance initiative requires creativity and considerable thought. Funding for new programs, especially those which duplicate services for other populations, is a luxury of the past.

Today, the focus is on reducing service duplication while increasing service integration. Network development and coalition building are key ways to shape human service delivery programs in the 90s. Working together can prove to be a more productive way of getting something done.

However, the critical first step is to sit back and consider your main goals and concerns. You need to define the issue in your own terms and in a manner appropriate for your situation.

Defining the Issue

You are concerned that there are a number of older families or other carers in your community with an adult with a developmental disability at home. They either need help now or will shortly. These carers are growing older and are people who have up to now been managing on their own. As they age, things are changing. Now you are getting more calls from families or neighbors about what help you can provide for them.

You are concerned enough to want to start some type of initiative or program to help them. You might begin by trying to determine how many such families in need are in your community. However, this may be difficult to measure when starting out. So, alternatively, assume that some number are out there, and then, consider the following

- what are their needs and which are most immediate?
- what resources currently exist in your community to help these families?
- what are the disability and social services networks doing to help such families and carers?
- what would happen if you did nothing to help them?
- what do you want to do?

Now that you have a sense of the issue, some background on the aging and disabilities networks is timely.

Coordination Between the Aging and Disabilities Systems

In many local communities, older adults with disabilities are participating in services provided by the aging network. The Older Americans Act, as amended in 1987 and 1992, has been instrumental in providing legislative support to include older persons with disabilities in the services provided under the Act. Some of the specific requirements of the Act which have helped this cooperation include

- encouraging the state unit on aging and the area agencies on aging and state and local disabilities agencies to cooperatively plan and develop services for older persons with a disability
- allowing disabled, dependent adults under the age of 60 to be served at congregate meal sites when accompanying their eligible parent or carer
- establishing a linkage between the long-term care ombudsman program within the state unit on aging and the protection and advocacy agency within the state
- authorizing the Assistant Secretary for the Administration on Aging to undertake initiatives, and call upon the state units on aging and area agencies on aging, to target carers for special assistance (such as permanency planning, respite, in-home assistance, and other activities) who provide uncompensated care for adults with

developmental disabilities

- authorizing the Assistant Secretary to explore how senior centers can improve social and physical accessibility of persons with disabilities

Next to the Older Americans Act, the most important piece of legislation affecting the participation of older people with disabilities in aging network programs is the Americans with Disabilities Act (ADA). Title II of the Act prohibits discrimination in the provision of state and local government services for qualified people with disabilities. Title III bans discrimination in public accommodations, such as senior citizen centers, adult day program sites and social services centers.

Under the ADA, reasonable modifications must be made to policies, practices or procedures to avoid discrimination. Auxiliary aids and services must be provided to ensure effective communication, and physical barriers must be removed if readily achievable. These accommodations are not required if they would fundamentally alter the nature of the goods or services or would result in undue burden to the public entity. All of these mandates together provide considerable support for linking the aging and disability networks.

You can get a copy of either of these Acts by calling your Senator or Representative. Your state unit on aging may also have copies of the Older Americans Act. A good source for information on the ADA is your local independent living center.

Who Should Do It?

Aging network agencies generally are the primary source of formal assistance for older people. The aging network is composed of a number of components. For example, in each state there is *state unit on aging*, known under a variety of names, such as the office for the aging or elderly, council for aging, department of aging or elder affairs, or some other variation.

Within the state, there are regional bodies called *area agencies on aging* which are responsible for local planning and service delivery. In some sparsely populated or smaller states, the state unit on aging and the area agency on aging are the same entity. These are mostly governmental or quasi-governmental bodies. However, some are not-for-profit agencies accountable to local or regional government.

Within the local aging network there may be a number of agencies that provide generic or specialized services for older people. These may include senior centers, nutrition sites, adult day care, home maker assistance, and the like. Local aging agencies also provide supports for older people and their relatives who may be their carers. They can provide legal counseling, help with straightening out finances, and access weatherization or other support services.

Developmental disability agencies are generally found in each community. They may provide a variety of day services, residential programs, individualized supports, and aid to families. They may be governmental or voluntary, not-for-profit agencies. How they are financed and what they do varies from community to community, depending upon how each state's developmental disabilities services are organized. In some localities the service providers or vendors work in concert with a regional or state developmental disabilities agency, which provides their funding.

Generally, these two major networks intersect when it comes to aiding older adults with a developmental disability. In some communities, this may also be true when it comes to providing aid to older carers.

In some localities, one network may be more developed or prominent than the other. A key question is which network would be best suited to take the initiative to develop a local program that will reach out and help older carers? Obviously, there are arguments that can be made for either or both systems taking on this responsibility.

Should an Aging Agency Take the Lead?

Some argue that when it comes to reaching out and helping older families, area agencies on aging are better prepared to do outreach because, they

❖ have more of a focus on family issues

❖ have more information and resources related to issues for older people

❖ provide more generic aging services, so their outreach may be more effective

Some also hold the belief that aging agencies have a more neutral status in their community, thus older families may perceive less of a stigma attached to getting aid from an aging agency. There is also the belief that many older and potentially vulnerable families will be less fearful that their child or relative may be taken away by an aging agency. In addition, aging agencies may be better positioned to help, because many carers need aging related services.

Conversely, some argue that disability agencies often don't understand what aging agencies do and what aging related services may be available. Some think that disability agencies are more likely to hold a "dysfunctional perspective" of families and not be sympathetic to the needs of older carers because they are concentrating on those of the adult with a developmental disability.

Should a Disability Agency Take the Lead?

Despite these concerns, some argue that when it comes to finding people with a developmental disability, the locality's disability agencies may be better prepared because they

- ❖ focus more on the individual needs of the person with a lifelong disability
- ❖ have more information and resources related to lifelong caring issues
- ❖ know how to work with people with special needs and disabilities

Some also argue that disability agencies are in a better position to aid families and other carers because the issue is to address the needs of someone with a developmental disability. For example, disability agencies

- ❖ are better at diagnostic and behavioral intervention issues
- ❖ know disability issues and are tied to rehabilitation systems
- ❖ are familiar with the barriers that families face when they have a member with a disability

Also, some aging agencies don't understand what disability agencies do and what disability related services may be available. In addition, aging agencies may have difficulty determining eligibility for disability services.

How to Make the Decision?

As you weigh the merits of using either aging or disability agencies, consider who is most capable of undertaking and following-through on this type of an effort. We certainly recommend working together -- combining the efforts of the aging and disability networks to meet family needs. However, someone has to take the lead. Thus, we'd advise giving thought to the following

- ❖ who has the best outreach program?
- ❖ who has the best support system?
- ❖ who has the best history of networking and working with your locality's agencies?
- ❖ who is perceived most favorably by families in your community?

- who is willing to do it?

You've given some thought to which network may be able to take the lead, now you are ready to get the initiative going. On the assumption that you are working from a broad community development perspective, the remaining sections in this chapter will explore the factors you need to consider or will encounter as you attempt to get your community to respond.

To help move the process along, some advice in offered on how to define the issue and how to get your community mobilized to react. In the next chapter, we'll explore what you may need to consider as you attempt to formally set up such an initiative.

Building Consensus on the Issue

Now it's time to get agreement. You have done some thinking about this within your own group. You have probably decided that there is a need to pursue this issue. You have also decided that your *main goal will be to aid such families to help keep them intact and viable for as long as possible or practical.*

Your other goals may be to help them arrange and plan for the future and to help the adult with a disability decide what he or she will want to do when his or her parents or other carers are no longer around.

Thus, one of the first things to do is to contact and discuss this concern with others in your area. You may want to reach out to specific networks, such as those represented by disability agencies, adult protective agencies, social and family services agencies, and others who might come in contact with such families. Don't forget to make contact with consumer advocacy groups and parent associations.

You can do this by making some quick telephone calls or calling a group meeting to help identify the issues that are pertinent to your area, the degree of involvement by community agencies, and what help each can bring to the problem.

If you work within local or regional government, it would be helpful to confer with the administrators of your agency, as well as other government agencies to work out territorial issues and divisions of labor.

Consider that getting everyone behind such an initiative may not be easy. Others may not share your concerns. They will be suspicious of your entry into this area.

In a time of scarce resources, many of the agencies you contact will want to know who will pay for this effort and if you begin something like this, will it detract from the funds they are getting for other purposes.

Getting everyone on board, as much as possible, can help ensure that, at least in the beginning, things will run smoothly. Also, remember your main goals - *keeping the family intact for as long as possible and helping families to meet their needs.*

Organizing a Network

There are a number of ways to organize support for a carer assistance initiative in your community. In the following sections, we will cover networking, coalition building, and participation on committees or task forces.

Network Building

What is network building? Networking is an informal means of connecting with people or agencies with similar interests or agenda. It means talking with friends, colleagues and people inside and outside of your discipline or interests and linking these folks with each other. Network building can help you to

- identify a critical mass of interest
- build a constituency which will be able to lend support, influence and help when necessary
- open "the door to opportunity"
- make things happen

Once you have had those informal discussions, it's time to bring people together. Here are some suggestions

- *identify a core group* of people who share your interest in developing a carer assistance initiative. The group should include
    - people from the aging network
    - people from the developmental disabilities network
    - family carers

To be inclusive, ask participants to refer you to others who should also be involved in the initial discussions.

- *meet informally* as a small group
    - discuss the need for a carer assistance initiative
    - identify the barriers to getting such an initiative off the ground
    - identify solutions and goals
    - identify next steps
    - identify other people to invite

into the network

- *expand the group* by bringing in others who can help with solutions and next steps. Consider involving persons in the health and social services arena.
- *identify one person* who will be the lead for moving the effort along. Continue to problem solve and to bring in people who can help with overcoming any barriers you may encounter**.**
- *draw in key officials* from the developmental disabilities, aging, social services, health and community supports networks.

Once you have gotten this far, you can begin to formalize your network. One way is to call a larger group meeting to promote a dialogue among networks. The meeting can also be used to chart future directions for your efforts. Try to come out of the meeting with the following

- agree to share information on what each is doing
- agree to exchange referrals
- agree to form an coalition that would work toward furthering a specific goal (for example, advocating for one of the local government agencies to develop a carer assistance program, agreeing to establish a local coalition, or setting up a clearinghouse for information exchange)

> *"Our experience with the local developmental disability agencies was generally positive. There was a demonstrated willingness to work together. In fact, as things progressed, we evolved into a coalition. One thing that seem to come out of this was a better understanding of each other's workings. My staff told me that during the initial phases of the project they found that our local developmental disabilities agencies lacked an understanding of what we did. I must say that we were guilty of not knowing what they did as well. Each of us did not understand the limits of what the other could do and did not understand each other's policies and regulations. Yet, as we worked together in the coalition, I think we overcame these obstacles."*
>
> An aging agency director

Coalition Building

Another approach involves building a coalition. A coalition is an alliance of persons, agencies and/or organizations coming together for some joint action on a common goal, with identifiable outcomes and specific tasks defined to achieve the outcomes.

Coalition building differs from networking in several key ways: it is more formalized, key participants may be specifically named or assigned, and it is generally identified with a specific function.

Coalition members should include agency or service networks which are affected by the problem or have the resources to address the goal. You might think about including representatives from the aging and developmental disabilities services such as

- hospitals and health agencies
- social service agencies
- mental health programs
- local and regional Alzheimer chapters
- public and private agencies
- local aging agencies
- adult day services programs
- local disability agencies
- city, town, and county government officials

Who in these agencies should be invited to join? We have found that a balance of providers, decision makers, and key advocates is helpful.

Some Thoughts on Developing Coalitions

What seems to work best when developing a coalition? It is helpful to have

- one leadership person - a “spark” - identified with the project who has a vision of where things should go
- your planning effort attached to a recognized agency in your community to give it an “official stamp;” people need to know who you are and that what you are doing is sanctioned
- coalition leaders who believe that the coalition is a forum for agencies to plan for an integrated service, not to duplicate existing services.
- participants that are not overly concerned about jurisdictions and boundaries

Some Practical Tips for Holding Meetings

At the first meeting, both administrative and “nicety” things should be dealt with. Make sure everyone gets to meet everyone else and that they know what role they or their agencies play in the community. Then run the meeting with the following in mind

- have open discussions that focus on identified needs, goals and general outcomes, and define the types of tasks to be undertaken
- determine whether you may need subcommittees to attain the goals
- determine the roles and responsibilities of members and who will be accountable for work group activities

The first and all subsequent meetings should be task oriented with reports of subcommittee activities. At the end of all meetings, be sure to have agreed upon the agenda for the next meeting.

Subcommittees

Subcommittees should be formed around tasks and assigned responsibility for task completion. In working through subcommittees, try to

- establish a specific sub-committee membership
- determine frequency of meetings
- provide a description of expected outcomes
- determine the steps or processes to

> *"Here's what I would recommend to anyone interested in starting up such a project. First, define what is it you want to do. Second, call together all the people in your network and get them to agree to help. Third, identify any gaps in helping the families and then agree on what can be done to fill the gaps. Fourth, see what impediments exist to getting this project off the ground. If there are any, find ways to get around them.*
>
> *Be sure to define the target population in clear terms. For example, who are you targeting? People with intellectual disability age 40 and older? Those age 50 and older? How young can the parents or families be? Do you include parents only over age 60? Also, think about developing some common referral forms or a even a common assessment instrument.*
>
> *Be sure to have a direct line of communication by holding regular meetings. Get everyone to agree to participate in cross-training on what each of the members of the networks does. Be sure to set up agreements on how to handle casework or follow-up with families who are referred. Agree beforehand who will be the gatekeeper of the system. That's what I recommend!"*
>
> An area agency director

attain the outcomes

- develop a time line for completion
- be structured to provide information on how needs are met

- determine types of resources to be shared

- report your activities at all coalition meetings

Using Existing Coalitions or Structures

You will generally find that coalitions made up of human service agencies and organizations are found in almost every community.

By tapping into an existing aging, disabilities or community service coalition, it is possible to amplify your effort in raising support for a carer program.

Committees and Task Forces

Another way of getting a program established is to form a carer task force as part of some larger committee. Look for a committee already in place, possibly under the formal auspice of any of the following

- a local government mental health or developmental disabilities department

- the area agency on aging or local aging office or department

- a university center on developmental disabilities or gerontology/ geriatrics

- a foundation

- a community planning body or interagency council

- a health systems agency or similar planning group

As a carer task force, your committee has the advantage of being in the official loop. This eases the task of sharing information, tapping resources, and building the support you need for a program in your community.

▲

Chapter 5

Developing Your Agency’s Initiative

> ***“Be careful not to characterize the families as `the problem’ -- it is the lack of services that is the problem.”***

Now that you have explored organizing your community, you may want to implement an initiative within your agency. You have defined the issues, met with the key people in your area, and “talked-up” the need to help older carers.

You have done your fact finding, local assessment, and planning. The results show that there is a need for some type of initiative, that there are a number of families who need help, and that you have support from others about going ahead.

To proceed, you need support within your own agency to get the initiative off the ground. Consider what arguments you could make in your own agency (or if you are responsible to local government, then to the legislative oversight committee) to get approval to undertake an initiative to help older carers of adults with developmental disabilities in your area.

To begin, remember that *“nothing happens without a problem . . .”* That is, you need to clearly state what the problem is for your agency and what the pressures are within the community. Something must catch the attention of key decision makers. Perhaps it may be presented as a need for a mandated service, a pressing social problem, some critical incident, a response to community pressure, or the result of a planning endeavor.

Sometimes you may have an

advisory committee or council that is interested in this topic. Getting the members to advocate for this type of project is helpful. Getting them to adopt this as their own idea and project is even more helpful.

In framing your argument, one notion to consider is that you are being responsive to an issue or problem in your community. Perhaps, start your discussion this way

- provide a synopsis of the problem using some talking points that can be quoted and illustrated
- arm yourself with some personal stories of families in crisis or who have been helped
- consider preparing and using a fact sheet on the problem for meetings, legislative hearings, and "policy sells"

You may also need to show how such an initiative or program can work in your agency, how it will be funded or how much it will cost (either in dollars or staff time), and what will be the outcome.

Some key tasks at this stage would include

- deciding that you want to do this
- getting your agency's administrative people to support the effort
- getting your leadership and legislative bodies and/or your board of directors to "buy into" doing it
- getting oversight bodies to understand why resources and time need to be devoted or diverted to do this
- getting clearance from other oversight bodies -- make sure they understand why you are targeting this population

In what follows, we have made the assumption that this initiative will be undertaken by an aging network aging. If you work for a disability or other agency, think in terms of how you would proceed within your own agency.

After the Approval - What's Next?

You got the "go-ahead," now what? Now it's time to work on the details and implementation. Some thoughts to consider as you proceed

- this is a significant problem and the response should not be an one-shot effort
- there should be a multi-year commitment to the initiative

- it should be designed to reduce service duplications and promote service integration

- it should be organized as a community response -- “coming together to solve a problem”

You have to decide on the best approach. One decision is whether to undertake this type of initiative within your agency or contract out. What you decide may be governed by whether your agency does direct work, normally contracts out, or works through other agencies.

If you have discretion in making this type of decision, ask

- how would families respond to outreach or other contacts from your agency?

- how would families respond to outreach or other contacts from a disability agency? an aging agency? another agency?

- what are your agency’s policies about contracting out or doing things in-house?

- what are the capabilities of external agencies or internal branches of your own agency?

- if your agency was to take this on, who would get the assignment?

The question boils down to “Do you do it yourself or have someone else do it?” First, let’s explore what you need to consider if you decide to contract out.

Contracting Out

If the decision is that you want to have this project done outside of your agency, then the first question is who should do it. Consider that whomever does it needs to understand the aging and disability system and the dynamics, character, and needs of the target families.

Sometimes you may have the flexibility to approach any agency you want, other times you may be restricted by your organization's or government's policies on contracting out. These policies may include prior approval, a competitive request for proposal (RFP) process, or other contract award procedures that have to be followed. If you are restricted to having to bid out the contract, be sure to carefully craft your award notice so as to attract the best agencies or providers.

Other times, you may have wider discretion on how to handle the selection process. So, in choosing an agency or provider to do this project, consider some of the following questions

- who has the best outreach program?

- who has the best support system?

- who has the staff that can relate to these families?

- who has the best history of networking and working with agencies?

- who is willing to do it?

Similar questions can be woven into the review criteria for an RFP (Request for Proposals).

When choosing an outside agency, you need to consider whether they have a *family focus*? A family focus is needed, because a *disability* or *aging* focus in not sufficient.

For all agencies that express an interest in doing the project, consider

- can they do a quality job with the funds you have allocated?

- will they be able to stay with the families for as long as needed?

- do they have the means to provide oversight and supervision? If not, who will do it?

- will they address the immediate problem (that is stabilize the family in crisis or need) or create a demand for new or extensive services that cannot be met?

- what funds will be used for the services that agency identifies as being needed by the families?

As you proceed, there may be other considerations in choosing and overseeing the contract agency - but you can handle these as you would any other contract situation.

Our experience showed that contracting out seemed to work better for large agencies in heavily populated areas. In contrast, in smaller geographic areas, having it done within the agency seemed to work best.

Now that we have explored contracting out, let's consider what it would take to do it within your agency.

Doing it Within

You may decide to undertake this type of initiative internally -- that is, do it within your agency. If you do, then you need to decide who inside the organization will be given this responsibility. If you work in a small agency, this may not be a major issue. You may take on this responsibility yourself or you may have to hire someone who will do it.

If you work for a large agency, with separate divisions or units, the decision of who will do it may not be as easy. Consider these thoughts

> *"Since my AAA is a county agency, I only needed to get prior approval from the county legislature to proceed with the project. Once approved, the legislature set up a revenue and appropriation account and we began work.*
>
> *To get the project started, I shifted some assignments in the Services Division and embellished some of the functions of one of my caseworkers. But this became a problem as the case worker had little contact with the developmental disabilities system. So I then moved the caseworker to the Day Care Division because it had more experience in this area. This division had already done a great deal of development with a group of adults with developmental disabilities in our community.*
>
> *After the caseworker gained familiarity with the developmental disabilities system, I had her reassigned back to the Services Division. Now she is in a program area by herself so she can focus on the developmental disabilities population."*
>
> An AAA Director

- which agency function or branch should do this -- that is, to what part of the organization does this get assigned.
- how do you allocate the project components (that is, outreach, information and referral, training and education, and casework, advocacy and brokering) and how will these be coordinated? Will they be under one branch of the agency or spread over several?
- which agency function or branch will get the information out to the community and then do the follow-up?
- how does the public get informed -- that is, how do you set up external notices and information on who to contact at your agency?

As we explored in the previous chapter, a carer initiative requires unique activities, such as

- building off natural networks to get started
- developing a coalition
- letting people in the disability system know about your project
- recognizing that there will be "turf" issues among the agencies in your or other networks and develop

strategies to address them

- reviewing the pros and cons of first organizing your community or attempting to build relationships across agencies
- getting representatives of families involved in the process

Who can best achieve these activities is an important criterion for selecting where in your agency to place the initiative.

Building Consensus

You've made some decisions within your own agency. As you proceed, remember also that you may need to get the community's disability agencies to be part of the effort. To do this, it might be best to hold some face-to-face meetings.

Two sets of meetings may need to be held. The first is with colleagues from the disability system. You need to decipher what constitutes the disability system - Who are the key players? Where is it located? What does it do? What is its language? What are its funding streams?

Unless you are already intimately involved with this system, you will need to find out what this system is like. You need to find out where the "power centers" are and who are the "key actors."

One area of concern that may emerge is "what are you doing in my territory," or the "turf issue." Let them know you are doing it to provide aid for families. Let them know that they can call you if they find older carers. Leave them with three clear messages

- you are not their competitor
- you are not trying to give them more work
- you are willing to share resources

The second set of meetings will be with your community. The general community needs to know what you are doing. Approach this by providing as much information as you can. You may consider holding some community workshops for older families or speaking to community groups.

Our experiences showed that local newspaper articles, presentations, and workshops that give out information are very useful. For example, information on energy assistance or weatherization can also include mention of issues of concern to carers.

Tell your audience that there may be some additional resources that may help them if they are caring for a son, daughter or other relative with a disability. If done in the context of a workshop, have one or more colleagues from the disability network available as speakers or resource people. Try anything that works.

What Will it Cost?

Our experience showed that, at minimum, you need a staff person who can take the lead within your agency, administrative support time, and non-personnel resources for travel, meeting attendance, supplies, telephones, office equipment, and other expenses. Be sure to allot costs for staff travel if your agency covers a large geographic area. The same applies if you decide to contract out.

To have the greatest impact assign a full-time person and appropriate resources to support the effort. Of course, the level of commitment will be determined by what resources you have, the size of the area you need to cover, and the number of families you will try to impact.

Our experience has shown that generally, as an initial investment, an assignment of a staff person for two days a week is sufficient to address the initial need. Our projects ran at about this level and were, on the average, able to aid some 20 to 30 families over the course of a year. A two day a week investment comes to about 12 to 16 hours weekly and it means that you have a person who is dedicated to the initiative.

In areas that serve a greater population base, and are thus served by larger organizations, there may be additional requirements. In our larger projects, supervisory time was also allocated. However, the amount of supervision needed varied.

So what will your costs run? Consider both the costs of personnel and supports. Personnel costs will include the daily cost of the salary and fringe of a caseworker or project person who does the direct assistance with families and provides the sup-port to other aspects of the project (such as networking, brokering referrals with other agencies, hand-ling publicity within the community, and the like). Personnel costs may also include secretarial and supervisory time.

Taking Charge

Who takes responsibility for the project can vary widely depending on the design and purpose of your program. Hiring someone who has experience as a carer may mean compromising on experience in providing services. However, when outreach is the top priority, direct service experience is not as important as an ability to find and connect with people in the community.

Often you may already have someone on staff who specializes in outreach and providing information and referral. Such staff can often refer families for more intensive services when more than information and referral is needed

An alternative might be to use a resident "expert" who follows up after carers are found. This person may contact the families after initial contact is made by another staff person and provide extensive and detailed information and counseling. They may also provide consultation to other staff who have found a family and are not sure what to tell them.

For example, the intake worker for a home delivered meals program may request the expert to call the family to determine what other needs they may have, or to ask them about planning for the future. All staff need to be aware of the role of the "expert" and how to use his or her services.

What's Important to Get the Job Done?

The people who work directly with the community and carers will ultimately determine the success of any project. If they are caring people, willing to listen and learn, and willing to work with others who may not have been viewed as traditional providers then the project is more likely to succeed.

Specifically, the person you choose to do either outreach or provide expert advice needs skills in the following areas.

- *First and most important are interviewing and counseling skills.*

Families who avoided services in the past may be very reticent about discussing their private lives with someone they don't know from an agency.

Making a connection and keeping people interested in remaining connected with service programs are difficult tasks requiring sensitive, optimistic individuals who are willing to keep working despite discouraging responses from families.

It may take several years of trying to convince a family to take actions to prevent a crisis.

- *Equally important is being able to work with families on service eligibility and application issues*

Area agencies on aging often have many workers with these types of skills, and have a variety of information available on such things as health insurance, energy assistance, housing, transportation, and income benefits. Sometimes a family will be willing to come in to ask for help regarding one of these issues, even though they are not willing to consider more extensive services.

Area agencies are required to provide basic legal services on a contribution only basis. The lawyers working in these programs can provide valuable information regarding financial planning, guardianship, and estate planning. The person who is hired to conduct the outreach program should be familiar with the legal program and assist the lawyer when necessary in addressing special needs of the families found.

- *Also important is knowing the local service system and having the capability to pursue information needed to get people to the service most appropriate for them.*

It is not enough to simply refer someone to the intake worker at a large developmental disability agency and expect the person to get what they need. Many phone calls may be needed to find the most receptive and reliable person. Understanding the subtle variations in approach between various programs may also be significant. One organization may be very oriented towards family counseling, while another is primarily interested in case management.

A lack of understanding about service providers may make a good outreach worker unable to follow through appropriately once a family has been found. Getting involved with a family can be very interesting, but if the worker is not skilled in facilitating access to needed services, time and money has been wasted.

Thus, the success or failure of such a project like this boils down to the person involved. When assigning the responsibility (or hiring a new person to lead the project) look for a person who

- has an entrepreneurial spirit - a self-starter who can “deliver the goods”
- is good at taking ownership of tasks and assuming responsibility
- is good at solving problems
- is creative
- likes people, relates well, and wants to help them

To organize and run the project you need someone who functions well in a generalist role. The person has to be comfortable with a role that enables him or her to interact with all sorts of people and in all sorts of situations.

The Start-up

Start the initiative by notifying agencies in your area who come in contact with the families you want to reach. You can do this by visiting the various agencies to introduce yourself and the initiative and thus establish a working relationship.

Another first step is to sponsor an invitational luncheon for all community agencies to announce the initiative. Work with local leadership agencies to get other agencies in your area to attend. You can also get their attention by placing announcements on TV and radio and in newsletters. Personal letters also work nicely.

Let your community know of the services being offered and how to reach you. You can do this in a variety of ways. Most of our projects used multiple methods to publicize their efforts. Some of these included the use of informational programs, such as

- workshops and forums for carers
- open community education meetings (for example, on legal and financial issues, planning for the future)

One thing that seemed to work well was advertising "workshops" in the local press. The registration list of attendees led to follow-up calls with the families who attended to see if they needed any assistance.

Some of our projects made extensive use of the media, such as

- presentations on local TV and radio talk shows
- press releases

> *"We used all kinds of efforts to publicize the project when we first started. We went around to practically all of the agencies in our town. We would introduce ourselves, explain what the project was all about, and make a contact. We also personally contacted all the human services agencies in the surrounding areas by telephone. We also made contact with local services clubs, such as the Elks and Rotary. We made up releases for local newspapers, developed brochures, conducted events, attended meetings to make our pitch, and put notices on the local cable TV bulletin boards. We also distributed pamphlets to physician's offices, schools, senior centers, and nutrition sites. We also attended local human services coalition meetings. We tried everything we could think of. We wanted people in our community to know what we were doing."*
>
> A project worker

- spots on local TV and radio

- notices on local cable TV bulletin boards

One of the techniques that was particularly useful was planting personal interest stories in the local press featuring a family in a caring role.

Community presentations were also helpful as a forum to get the message across. Such venues included

- hospitals and senior centers

- local human service coalition meetings

- local service clubs

- family support groups

- community agencies

Another means of publicizing the project was the use of printed materials, such as

- pamphlets and flyers sent to senior centers, churches, doctor's offices, schools, senior centers and nutrition sites

- announcements in local aging agency newsletters

- notices in local grocery stores, banks, beauty parlors, pharmacies

- letters to Realtors, police and fire companies, funeral directors, and clergy

Using the Media

This area deserves special mention since it can be very useful. At the same time there are pitfalls if you are not careful. Media resources to get your message across include

- news, in the form of a *news release* (something that is new, significant and of interest to the public)

- human interest, in the form of a *press release* (something that links to a specific situation or event)

- public service, in the form of a *public service announcement* (this a more formal production that is used over a longer period of time)

As your prepare your materials, consider how to structure what thoughts or messages you want to convey. Messages should include a focus on

- the issue of aging and carers

- the new program your agency is offering

Such messages should stress that you are embarking on a new community initiative and that you want the public to become involved (perhaps by volunteering or helping in some other way).

Consider the following when preparing your announcement or release

- cover your main points simply
- avoid jargon
- provide a list of priorities that the media can use
- give the reporters background information from which they can write

It is useful to prepare a "press kit" that contains the press or news release and fact sheets on the issue. Cover a few main points, give the name and contact information for the contact person, and provide definitions of terms or concepts unfamiliar to the general public

Program Design

Designs for agency outreach efforts can vary widely, from hiring of a worker to do specialized outreach and follow-up, to using the services of a consultant who insures that existing programs are capable of finding and providing services to carers and their families.

Your approach will depend on the size and complexity of the agency which houses the program. Key features of programs should include

- supervision of outreach contacts and separate follow-up to insure quality service
- continuity and backup if there is staff turnover
- a written structure describing how referrals and consultation will be handled within the agency
- designation of the location of the outreach program within the larger agency
- designation of a source for resources for the program, including funding for phones, printed materials, and space
- a record keeping system which is integrated into the larger agency record keeping system, with rules regarding information sharing and confidentiality
- a fee structure, if needed (area agencies usually cannot ask for anything but a contribution)

If your area agency covers a wide geographic area some of the outreach suggested here may be difficult. Here having a number of part time persons responsible for local programs is a feasible option.

Such an approach allows sharing of such things as training, case review, printing, and general mutual support. For larger agencies it would also be consistent with the federal mandates to subcontract where possible to existing community organizations.

Program Monitoring and Evaluation

Monitoring and supervising a carers outreach program is essential to ensuring quality and continued viability.

Outreach is quite difficult to monitor because the results of outreach are not always immediately obvious. You may spend a year driving around from place to place, distributing flyers, talking to people, and doing a wide variety of things which can only be recorded as activities rather than results. The number of families you have found is one measure of outcome. Other outcomes are more difficult to quantify.

Consider doing a thorough program evaluation after the first year of the program. Questions that could be asked include

- are the program design features mentioned above all developed? (written program policies, record keeping system, and the like)
- is a log of activities being kept and reviewed at least quarterly by the person running the branch within which the program is housed?
- are expenditures on track as planned?
- have extensive changes been made in program design, and have they been adequately justified?
- does a review of a few case records show any glaring simple deficiencies either in services or record keeping methods?
- are responses of families to the program being recorded to provide a source for suggestions to improve the program?
- was the original time line for activities adequate, or are certain activities delayed, necessitating a new time line?
- do other staff in the agency not directly involved in the program know as much as they need to know about it?
- how is the program viewed? Have any complaints been made? Have any negative attitudes regarding serving people with develop-mental

What Factors Outside of Your Control Can Help or Hinder Your Initiative?

Those that Help

- when the initiative is housed within your agency's specialized carer assistance unit
- when you have up-to-date program information
- when your agency is already involved in developmental disabilities activities
- when it is obvious that being an aging agency helps with "getting a foot in the door" with families
- when you hire a parent or carer who is knowledgeable, interested and readily accepted by families
- when you get support from local government officials which make the project a focal point

Those that Hinder

- when you have limited funds and it is difficult to hire someone for a part-time or temporary position
- when you have fragmentation of funding to support the initiative and you are confronted with multiple regulations

disabilities been changed?

❖ how successful has each discrete outreach approach been in reaching families?

These questions provide the data upon which an evaluation review can be based. Encourage advisory committees or coalitions to become involved in the review. Objectives of such a review might include

❖ determine whether the program should be continued

❖ develop major recommendations for program redesign

❖ look at the successes or failures in finding and serving carers and their families (through case review)

❖ develop long range plans, assuming the program will be continued

Not Getting the Response You Want

Sometimes, no matter how hard you plan, your efforts do not produce a response. Our experiences were often mixed using the techniques outlined above. Among AAAs, one agency's initial efforts generated a minimal response from the use of

What Factors Within Your Control Can Help or Hinder Your Initiative?

Those That Help

- when you have support from the state unit on aging and other key actors in the aging network
- when you have a good relationship with local or state disability providers and they have a well-developed community network
- when your office is physically located in an easily accessible area of your community
- when your agency has a positive image in the community - this in turn gives your project a positive image
- when your agency is viewed as family oriented (with neither a heavy bias toward aging or disability)
- when you have a supportive and positive climate at the government disability agency which helps fund services
- when you have a strong relationship with local private disability agencies - such as cross board membership

Those That Hinder

- when you are obstructed by budgeting procedures that unnecessarily burden your subcontractor (for example, imposing on subcontractor an administrative charge and use of "units of services")
- when you get resistance and resentment from other agencies because they were not involved in running or developing the project
- when you have a low level of support from the local government disability agency because it does not see the value in the project
- when there is little understanding within the aging and disability networks of each other’s services
- when you have to account to multiple funding streams (sources of funding)
- when there is a history of a lack of collaboration in your community
- when your efforts are affected by major reorganizations or restructuring of local agencies during the course of project

newspaper notices, radio and TV announcements, meetings with local agencies, and personal calls.

However, they got a good response from several large community education meetings held at a local college for families on legal and financial issues and planning for future.

Another agency sent letters to disability and aging providers announcing the project and invited them to an orientation meeting, but got a low turnout. They told us they did not get much of a response from the local disability agencies, because these agencies felt they already knew all of the families in area. Only after it was demonstrated that the agency identified families unknown to the disability agencies did they get greater interest.

Don’t get discouraged!

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Taking care

What happens when family carers of people with disabilities confront their own mortality

By Stephen G. Landesman
Journal Staff

Ithaca, N.Y., February 19 -- Shirley Wright's trim, blue-and-white house sits in the middle of the block, indistinguishable from a dozen other neat-as-a-pin home on this quiet residential side street off Route 13 in Dryden.

Inside, bathed in a brilliant February sun, the living room is cheerful and bright. On a counter-top in the adjacent kitchen two pies sit cooling. What's different about this kitchen, however, is that along one wall there stands a five-foot-high apparatus equipped with wheels and pulleys that at first glance resembles a home exercise machine.

But it's not an exercise machine. It's a battery operated power lift and the only means by which the 66 year old widow can help her 31 year old son, Bruce, who has cerebral palsy, get in and out of a wheelchair. She also bathes him, takes him to the bathroom and helps him get into and out of bed.

"He needs lots of help. Some days it's a little bit demanding," says Wright whose husband died 25 years ago.

Wright, a retired teacher who taught in Dryden's elementary schools for 18 years, is one of an increasing number of older Americans who live alone and are carers for an adult family member with some form of developmental disability. It's a situation that's become more common as better living conditions and medical care have contributed to the longevity of both carers and those for whom they care. In the past...

Shirley Wright is better off than many carers. Despite physical limitations, Bruce is bright, perceptive and active. He's employed four hours a day at the Computer Center in Lansing where he maintains the firm's mailing list and enters reports on a computer, skills he acquired through courses at Tompkins-Cortland Community College. And the posters on his bedroom wall suggest he's as avid a baseball fan as any. "Bruce loves sports, especially baseball, says his mother, "and knows all about it.

She recalls that on one recent evening when she was away, an older friend came to keep Bruce company and the two of them watched the Winter Olympics on television. But the friend has a serious vision problem.

"So Bruce just narrated what was going on the whole time," said Wright.

Sometimes, when his older brother, Mark, comes to visit, he'll go to nearby professional games in Elmira, traveling in the family van that's also equipped with a power lift like the Gadabout van that takes him to work.

And it is Mark, two years older and a successful attorney with Eastman Kodak in Rochester, who has not only made a big difference in both their lives by accepting some of the responsibility for his brother, but who first began asking his mother aloud the unspoken question that has nagged them both in recent years.

"Have you thought about what will happen to Bruce when you're gone,"' he said to me one evening," recalls Wright.

That’s a profound question and one that many older carers of an adult child or close relative with even more serious disabilities have been reluctant to ask themselves, says Evelyn Kalish of Tompkins County’s Office for the Aging.

“Most older people aren’t afraid of dying,” says Kalish, “but they are afraid of leaving behind people whom they are caring for.”

Sometimes a carer, unwillingly to face his or her own mortality, doesn’t have time to ask the question.

“Typically, we’ll get a call from the hospital on a Friday afternoon telling us that an elderly person has just died.” said Kalish.

Then the caller will drop the bombshell.

“Did you know she was caring for a 50-year-old son?” the caller will ask Kalish.

“It’s a culturally difficult thing for many Americans to deal with the concept of death,” says Kalish, “so plans that may have been mentioned once are never discussed realistically again. Sometimes they’re never discussed at all.”

* * *

Ithaca Journal, February 19, 1994

Chapter 6

Finding Older Carers

"Touching one family opens the doors to other families."

Many older carers are unaware of the services that are potentially available to them or are reluctant to contact agencies and ask for help. Consequently, they may not respond to agency advertisements for a new program. Agencies that reach out to carers through others in their community are more likely to be successful.

A wide range of people who live and work in a community can help to identify families, give them information about your program or refer them for services. Because of the rapport and trust that they have built up with carers, often over a long period of time, these workers can encourage families to learn about and use your services.

Community leaders, agency staff, professional service providers, other carers and individuals who know and understand the local community are vital to successful outreach efforts.

Planning Your Outreach Strategy

Finding families can be a slow and lengthy process. It often requires considerable creativity. To develop an effective outreach strategy you need to

- prepare written materials such as handouts and announcements which describe the program and are easily understood by professionals and families
- identify people and organizations in the community who might know

carers and help to get information to them or refer them to the project

- identify places where carers are likely to be and can be approached directly

Also, you need to maintain an ongoing dialogue with staff of local agencies, such as the Alzheimer's Association or Heart Association who have used outreach tactics to find families for other projects. They know what works in your community.

How Can You Inform Families about Your Services?

There are different approaches that can be used to reach families who could benefit from your services. We offer some thoughts about two of them.

The first approach is to provide information about the program directly to families through a variety of activities which are aimed at the general public and to families. This can include

- creating public service announcements, arranging for newspaper articles, participating in television interviews
- planning, advertising and holding educational workshops on specific

"Last spring we held a public forum, "What the Future Holds."

It was a workshop for parents with a child with a developmental disability. Mrs. P., a woman in her late 60s, came and listened. When I introduced myself to her, Mrs. P. spoke only in a monotone and in words of one syllable.

When it was her turn to speak at the forum, she had little to say. However, what she did say had a very strong impact on the group. Mrs. P. had become severely 'burned out' caring for her twin daughters in their early thirties, both dual diagnosed with a developmental disability and mental illness.

But just three months after the workshop, Mrs. P. came into the area agency with her husband to get a senior discount card. She cheerfully introduced her husband, remembering my name, and said how wonderful the workshop was. She was talkative and animated and thanked me for offering the workshop. Mrs. P. said it gave her and her husband the strength to look for options for their daughters. She said they needed to 'cut the strings,' because they wouldn't be around forever."

A project coordinator

topics of interest to carers

- visiting public places where families are likely to be, such as shopping malls or community expos

- attending public hearings on concerns related to disability

The second approach is to enlist the aid of people who live and work in the community and know carers of persons with a developmental disability. Professionals, business and trades people can be recruited to distribute information directly to families, refer families to the project and encourage their use of services.

As example of a creative approach used by one of our projects, the coordinator worked with the county's association of pharmacists. Together, they designed a set of displays on the program for drugstores and a flyer that pharmacists agreed to place in prescription bags.

Such approaches require considerable effort and determination as you talk with and visit staff within your own agency network, health and human service providers and the business and public service community. However, with creativity and perseverance, they can be productive.

Look Within Your Own System and Service Network

A logical first step in finding families is to contact staff within your own agency or service network. Talk with the administrators and staff of various programs with whom you are in close contact such as

- intake and information and referral personnel

- senior centers and nutrition programs

- energy assistance and weatherization programs

You might also want to highlight the carer initiative in your aging or disability office newsletter.

Contact Other Human Service and Health Providers

Agency staff and independent providers of health and social services come in contact with family members of persons with developmental disabilities.

Some health care providers may have a longstanding relationship with carers and be well aware of their difficulties. They may have tried to help them with their concerns in providing care.

Many would welcome the additional assistance you can offer. Thus, you might call and personally visit

- doctors
- nurses
- hospital social workers and discharge planners
- home health nurses

If these health professionals are alerted to your project, they can refer families in need or distribute information about the project in the course of their daily work.

You might even suggest that they incorporate questions into their routine assessment procedures which would help to identify carers.

The staff of Social Security, social services and other social agencies may also count carers among their clientele and may have helped them through family crises or at least be aware of some of their difficulties.

Reach Out Through the Business and Public Service Community

Others who work in the community may also be aware of carers and their families who need your services. In the course of routine business or social contacts, carers may share their concerns or difficulties with one or more of the following

- beauticians
- pharmacists
- postmasters
- police
- volunteer fire and rescue squads
- Realtors
- clergy
- funeral directors
- bank officials
- lawyers

In addition, various business and social organizations in the community may know families who might need help. Some of these are

- social and cultural clubs
- Alzheimer’s Association
- Chamber of Commerce
- local AARP chapters
- veteran's groups

If these individuals or groups know about the program, they will be able to provide information to families, including outreach telephone numbers, and suggest that they call. They can also distribute written information to their members.

Religious organizations, in particular, are excellent vehicles for finding families. Carers tend to stay in contact with clergy and church members even if they are unable to attend services.

We found that lay people have a growing role in the service programs offered by churches and temples. They are often asked to visit families who cannot attend regular services, especially when the clergy are occupied with administrative duties.

Some churches have programs in which lay people, who have received special training, provide support for carers. We found that such lay volunteers were a great help in finding families.

Working Through Organized Groups

Working with and through organized groups has many additional benefits. Although working with individuals can be very effective, going through groups is more efficient in reaching large numbers of people.

Enlisting the assistance of a professional organization as a sponsor for your project may

- lend credibility to the effort within the community
- open avenues for oral presentations at regular meetings of the organization
- provide access to membership lists for individual contacts or mailings

Consider attending routine meetings of professional, service and business organizations to discuss the project. At the meetings, be focused when you make your presentation to make the most of your opportunity to get your message across.

When targeting specific public services or professional groups, seek their input on the format and content of any written materials which you would like to distribute to the membership.

Ask the providers for their ideas about the most effective way to disseminate information about the program to their colleagues and to carers with whom they have contact.

Each group will have their own ideas. After asking for its advice about written materials, follow it! Brochures, posters for bulletin boards or offices and articles or announcements for newsletters for any organized group should reflect its input.

Some Thoughts about Creating and Distributing Written Materials

Developing a useful and

informative brochure requires careful thought. You must identify the key information to be conveyed in a clear and concise manner and avoid the use of certain colors that are difficult to photocopy as well as to read.

Older persons may have difficulty reading materials that printed on low contrast colored paper (for example, black print on red paper), or when the text is printed in a small size or the presentation is too busy.

It is important to have a good sense of the languages spoken in your community. Have materials translated into these languages or at least have speakers of these languages available to answer questions when there are telephone inquiries.

Hand deliver brochures to offices and set up displays yourself. In busy offices or places of business, materials can easily get misplaced and never displayed.

Devise an easy way for materials to be reordered, such as having the last sheet in pads of resources contain a mail order or contact form. Be sure your telephone number is on everything you give out.

Examples of brochures and other written materials used in our project are found in the Appendix.

"Overall, we met with our local clergy three times.

In the first meeting the clergy present told us what resources they thought they would need to help inform their parishioners. They agreed that written materials, not a workshop in which the program was discussed, would be best.

Specifically, they suggested we develop laminated cards listing the community agencies and specifying the services each provided; bright, eye-catching posters to be placed on bulletin boards; and text and information for their church bulletins.

At the second meeting, which was held about three weeks after the first, we reviewed drafts of the materials we had developed.

Two months after that, we met again and presented them with the final versions."

A project worker

Tips for Insuring Successful Outreach

To make the most of your efforts

- follow-up on referrals quickly and show your appreciation
- listen to the advice given to you by people in your community
- once you have made personal contact with groups or individuals within your community, return monthly to find out if they have identified any families who need assistance

Examples of Outreach Strategies From Our Projects

Here are some examples of strategies which were used in our projects and may help you to find families. Not all of these strategies were universally successful. Some worked well in one community, but not in another. Some examples

- a local newspaper wrote a story on an older carer who was assisted by the project
- questions were added to the evaluation form for a financial planning workshop to learn about carers' needs for more information or services
- information was distributed to carers on a waiting list for disability agency services
- a local "advocate" passed out, by word of mouth, information about the initiative
- campaigning politicians going door to door gave out project brochures to families they thought might want them
- municipal officials were alerted to watch for families and handed out brochures when appropriate
- project staff visited walking programs at local malls

  "In addition to joining organized programs, older carers often walk at malls with family members with a disability -- since malls are convenient and wheel chair accessible."

- key community leaders were asked to endorse the outreach effort
- persons with a disability were asked if they had friends with older parents in need

Remember touching one family opens the door to other families.

Outreach Takes Time, Don't Get Discouraged

It takes a lot of time and work to devise successful outreach strategies and carry them out. Don't get discouraged when your efforts at first do not result in identifying many carers.

Instead, reexamine your strategies and how they were implemented. There is no magic way to find families which works equally well in all communities. You might want to

- look at who is doing the outreach and under what conditions
- talk with a different set of providers or organizations
- review your written materials
- talk with families and get their feedback on what works

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Chapter 7

Working With Older Carers

> ***"My daughter and I are a team. I just need a little help to keep us as a team."***

Working with older carers means working with families, not just working with one individual. It also means working with families over an extended period of time as carers age and family circumstances change.

Initial Contacts With Families

When you first contact families you will generally find that

- some do not have a current need, but are interested in learning about services which might be needed at a later time
- some are in crisis and need immediate help
- some will ask for help for a specific concern which they have identified

Families Without Immediate Needs

Some families will agree to meet with you, although perhaps a little reluctantly, but are not interested in receiving any services at that moment.

This often happens during outreach efforts in public places, such as shopping malls, when you talk with families informally about your program and various services in general terms.

This type of interaction is an ideal

way to establish a relationship with a family. While you provide information about the program and other services, families do not feel pressured to either explain their situations in detail or to accept services.

Later, when services are needed, families are more likely to contact a worker who is known to them and to use services. In addition, the worker is more prepared to work with them.

Families in Crisis

When older carers of persons with a developmental disability begin to experience difficulties in providing care, you may receive an emergency referral. This often occurs when the older carer dies or becomes too infirm to provide care, or when the needs of the person with a disability increase and the carer is no longer able to cope.

Referrals may be made by carers or by other family members, friends, or agency staff (such as workers in adult protective services) who are concerned that the carer is no longer able to provide adequate care or that the carer needs assistance.

Upon receipt of referrals such as this, the worker is often faced with the immediate need to find alternative

What the workers said . . .

- *Carers are most adamant about not losing their son or daughter to an institution.*
- *Carers may avoid "long range planning" when there are no good alternatives.*
- *Many carers do informal "long range planning" but because it does not usually include the formal system, it is not recognized as "long range planning."*
- *From the perspective of some older carers, the developmental disabilities system has not changed as much as we may think it has.*
- *Diagnosis is a system issue - not a family issue. How a person is diagnosed is not as significant to the carers as it is to service providers. Many carers do every-thing they can to avoid being labeled.*
- *Carers do not view themselves as problems, yet we keep referring to families and people with disabilities as problems.*
- *Carers want as little intrusion into their lives as possible. For parents who avoided the service system, to have to ask for or accept help is very difficult - and often may mean that they have to give up control over some aspect of their lives.*

living arrangements, sometimes for both the carer and the person receiving care, to determine guardianship of the person with a disability, and to create long term financial and residential arrangements for all of the people involved.

Situations like this call for a rapid response and are most effectively handled when agencies work together to serve all family members. An interagency agreement which involves the area agency on aging, the local developmental disabilities services agency and adult protective services can be very useful. Such agreements can address a number of issues, including

- ❖ sharing of confidential information about families
- ❖ responsibility for initiating guardianship proceedings in specific types of situations
- ❖ availability of financial management assistance and services, such as representative payee
- ❖ procedures for emergency services, such as
  - housing
  - relocation assistance
  - in-home assistance
  - brief respite
- ❖ plans for ongoing and additional services

> *Mrs. J., in her mid-sixties, was showing signs of Alzheimer's disease. She was the sole provider for her 42 year-old daughter, whose disabilities included a seizure disorder. She had refused offers of help from her other children and wouldn't let them into the house. Frustrated and concerned that her sister was no longer regularly receiving her medications, one of the siblings called the local adult protective services. The worker established that the health care needs for both mother and daughter were not being met and that Mrs. J. was no longer able to manage her household or finances.*

Families with Specific Concerns

Most families will identify one or more specific concerns during your first contact. They may need help with a variety of concerns or issues, or they made need help with just one, for now. You can help families by providing information, brokering and advocating for services, and offering emotional support.

In our project, carers often requested information about the following programs and services

- housekeeping, laundry, transportation, and meal preparation and nutrition services
- home health aid and personal care attendant services, day programs
- brief respite services to go to a doctor's appointment or to visit a sick relative
- assistance with medical bills, Medicare and Medicaid eligibility and procedures, and pharmacy programs
- programs for persons with developmental disabilities, including recreational activities
- housing programs and alternatives

As you give carers information to address their specific concerns, you have the opportunity to apprize them of other services including legal, financial planning or special benefits to which they maybe entitled. Although carers may not need these services immediately, they might in the future.

Information

Carers often need and request information about available resources, benefits, and entitlements which can alleviate a number of difficulties. Just learning about services will be enough help for many carers who are able to follow up on their own.

Consider developing a brief resource manual which describes services and benefits, eligibility criteria and telephone numbers for easy reference. This can be left with the family or household for their use.

Brokering

Older carers sometimes need more than information. For many reasons, carers may be reluctant or unable to investigate possible resources or complete agency eligibility processes on their own.

Telephoning agencies for appointments or to discuss possible services, explaining your situation, and filling out forms can be time consuming, frustrating and difficult for many persons given the complexity of our service systems.

Carers who have limited free time, no transportation, or who do not speak English fluently may have a particularly difficult experience.

> *"Some of the easy situations that occurred were when the carers did not want anything for themselves, but were looking for help for their son or daughter, or when all they needed was help with interpreting a letter from SSI or when they had problems with bills or money.*
>
> *On the other hand, some of hard situations are typified by the following family: A mother, age 71, who had serious medical problems including breast cancer, is taking care of a 49-year-old daughter with intellectual disability who is also severely overweight. The father died six years ago and the family's condition has since progressively deteriorated. During the initial contacts she expressed a deep rooted fear that our worker would take her daughter from her."*
>
> A project supervisor

You can assist carers with these tasks by contacting service providers to determine possible eligibility, alerting providers to the carers' needs, insuring that carers keep appointments, completing applications or by helping carers to tell their story to providers. Accompanying a carer to an appointment can be a tremendous help.

Advocacy

Occasionally carers will have difficulty in communicating with agency staff or will be rejected for services. In these situations, a carer might need someone to advocate on their behalf or to resolve conflicts with agency personnel.

Support

Sometimes just talking to someone who understands your situation is helpful in easing worries and fears. Emotional support can help to reduce the sense of isolation which carers often feel and might help to strengthen their ability to cope with problems.

Often this type of support is best offered by other carers through face-to-face meetings or more formal support groups. The process of sharing similar experiences, thoughts and feelings is especially effective in reducing a sense of isolation.

In addition to emotional support these groups can be very useful in helping carers learn about community resources and solve care related problems, including planning for the future. Such groups can become

What Carers Said . . .

- *Some carers asked - "Are you calling to take my child away?"*
- *Some asked about respite - they wanted to know about it even thought they were not ready to use it.*
- *Some confided - "It scares me that my son will outlive me."*
- *Some said, when asked about what they wanted, "How can I ask if I don't know what to ask?"*
- *Some wanted help in going to the doctor and sitting in with the doctor to later explain the doctor's remarks about their son or daughter.*
- *Some said they were surprised that their son or daughter could also receive a home delivered meal.*
- *Some told us that the home delivered meal was okay for them, but not for their son or daughter - They said they often cooked a separate and different meal for their offspring.*

effective advocates for themselves and the persons for whom they provide care.

However, getting carers to attend a support group meeting is often difficult. Some support groups are often not well attended for a number of reasons, including

- ❖ lack of time
- ❖ inability to leave the person for whom they provide care
- ❖ discomfort with attending group meetings

In planning a support group for carers these considerations should be taken into account. Although support groups can be very effective for many carers, others may not want to participate. Support groups are not for everyone.

The previous page contains some tips for planning a support group. An example of a six session group model is included in the Appendix.

Guidelines for Working with Families

To work effectively with families, it is necessary to understand their needs. Only families can tell us their story. Listen and you will hear it.

Some Tips for Planning a Support Group

❖ Offer the group under the auspices of an AAA, religious organization, college or neighborhood center or some other agency not identified with developmental disabilities. Carers may be more receptive to attending a program with a neutral focus.

❖ Collaborate with several agencies on recruiting carers, running the groups, providing space, making mailings and staff. By working with the local AAA, colleges, private and public agencies expenses can be cut. Local foundations may be willing to provide a small financial grant for expenses.

❖ Make sure the group leaders and presenters are qualified and have credibility with carers. They must be knowledgeable about current community resources for persons with developmental disabilities, as well as residential, financial and legal planning.

❖ Advertise the group repeatedly using brochures, flyers, presentations, articles in agency and public newsletters, free community bulletin board services of radio stations, talk shows, and public interest stories in the newspaper.

❖ Contact many different sources for referrals.

❖ Invite many more carers to the group than you plan for and expect half of the carers who initially express interest in the group to actually attend. Be delighted with eight to ten parents, an ideal number for the group.

❖ Respond in a timely way to carers who express initial interest in the program and be prepared to spend time talking with them about their previous experiences, their situation, and if the group will be worthwhile to them.

❖ Ask carers about when and where to have the meeting and if they need transportation and respite. Providing care for the person with a disability may enable some people to come.

❖ Arrange for a meeting place which is handicap-accessible and convenient, comfortable, homey and private.

❖ Offer simple refreshments and on-site respite during the group meeting. Refreshments, which carers may want to bring, are appreciated and help the participants to open up.

Anne Botsford
Marist College

One worker spoke of the frustration she felt when a mother would not permit her son to attend programs at a local recreation center. The worker felt that the son would benefit from getting out of the house more and socializing with people of his own age. The mother was concerned about how people would treat her son and wanted to protect him. The worker acknowledged, however, that this was a loving home and overall the son seemed very content.

Build Trust, The Key Ingredient

Take the time to build trust with families. If families do not trust you they will not be receptive to the help that you can offer. Many families have been alienated from the service community and may feel that you have no understanding of their situation. You might want to review Chapter 2 where this issue is more fully discussed.

You can begin to build a trusting relationship by responding to the issues which the family wishes to discuss. In addition, taking the time to talk with family members about their past and current experiences and getting to know the family members will convey your interest in them as individuals and as a family.

The gender, age and ethnic background of household members may affect their attitudes and expectations. However, you cannot assume that you understand how a family thinks and feels only by virtue of these characteristics.

Each family and caring situation is unique. You can help carers best by listening to and learning from each person.

Listen to the Family

Let the family members tell you about themselves, the impact of their cultural heritage, and the way they are most comfortable accessing services

Recognize that families may have been traumatized in the past. Families are not looking for sympathy but want information that will assist them in deciding options for the present or future.

Acknowledge a Job"Well-Done"

Even though you are involved in

helping carers through difficult situations, it is important to recognize the great job that these families have done and are doing in caring for a person with a disability. It is unlikely that any other service providers have taken the time to say this.

In general, we do not give sufficient credit to the success of families in maintaining someone with a disability in their own home. Often the goal of agency services is to offer persons with disabilities the greatest level of independence possible, in as "normal" a manner as possible, and the family as a provider is over-looked.

Too often our words and actions indicate that feel that for someone to live with parents or other relatives for their entire life is not normal.

Yet, this is something that is a family decision and needs to be respected as such.

Skip the Jargon

When you use professional jargon and abbreviations families will be confused at best. At worst, they may wonder if you are trying to impress them or to make them feel inadequate. They won't be impressed and you will be perceived as not helpful.

Such terms as "IHP" or "Individual Habilitation Plan," as well as "case management," are unlikely to be part of the family's regular conversation. Instead, talk about "developing a plan for the present or future" and promise to work together toward achieving it.

A relationship that begins with correcting the family's language is unlikely to be one that the family will want to continue. Try to use words and explanations that are generally familiar to the lay person.

In the Appendix we have included a glossary of terms and acronyms that you may find helpful.

Help and Support, Don't Control

Listen. Listen. Listen. Let families decide their present and future with your assistance.

Families have been making decisions independently for years and will resent being told what is best for them. Your role is to help them think through their concerns, provide information about available services, and help them arrive at informed decisions.

Begin with Pressing Concerns but Recognize Deeper Concerns

You may feel that a family's needs are greater than the immediate concerns which they discuss with you. However, you need to address the family's priorities.

Also, remember that basic needs such as housing and food need to be addressed before the family can consider recreation and long range planning.

Successful resolution of a simple problem will build trust and a willingness to work on larger and more complicated issues.

Respect Cultural Values and Traditions But Don't Stereotype

As you work with families from diverse cultural groups, it is important to respect their beliefs and customs. However, you must be vigilant not to stereotype families or individual family members into rigid cultural profiles. Family members vary in the extent to which they share family and cultural group beliefs.

In the same vein, don't assume that the attitudes or beliefs of all men and all women are the same, or that the needs of older and younger families are the same (or are always different). Families and their members are unique regardless of age, gender, cultural, or ethnic background.

Working with families with a strong cultural identification is discussed further in Chapter 9.

Work with the Family

Agencies often have a need to identify "a central client." However, families think in terms of the household and may resent such a limited perspective.

A singular focus on the person with a disability often obscures the existence of other family members who also have disabilities or other problems.

Older family members who receive care from others in the family, including the person with a developmental disability, may have needs as well.

Ask How Families Make Decisions

Take time to understand the way in which families make decisions. This includes learning about which family members are involved in decisions and their concerns and goals.

Sometimes family members who

do not live in the same household or who may live some distance away play an important role in family decisions. Never assume that only family members who live with or near the person with a disability or provide hands-on care are the only ones influencing decisions.

Mrs. P., who provided care for her grandson, John, explained why she always rejected the idea of John attending a day program. Her daughter, John's mother, lives in another state. When Mrs., P. talks with her daughter about John attending a day program, her daughter gets upset and threatens to take John back with her. Mrs. P. said: "I can't let that happen. She's too ill to take care of him. I'll do without the program."

Often, the person with a disability is overlooked as a participant in decisions which affect him or her and the household. Make a special effort to insure that the person is included in decisions as you work with the family, especially around issues of alternative living arrangements. Be very careful not to assume that separation and independence from the family is in everyone's best interest.

Values, Yours and Theirs

In working with a family, it is critically important to distinguish between your values and beliefs and those of the family.

Families, especially those from cultures which are markedly different from your own, may make decisions or plans with which you may disagree. You may feel that you have a better solution to their problems or that your expectations or goals are not met by their solutions.

However, be open to discovering approaches which are different from yours and be willing to help families find solutions in their own way.

Don't Give Up

Be available on a long range basis to listen. Many families may only contact you years after you first met them, perhaps when a crisis occurs.

▲

Chapter 8

Key Issues In Working With Carers

"I never thought my son would outlive me."

Few families have made plans for what will happen when the primary carer is no longer available to provide care for the person with a disability.

When their child with a disability was born, most parents expected that they would outlive their daughter or son and so they would be providing lifetime care. However, rapid increases in the life expectancy of persons with disabilities means this may no longer be true.

The process of asking other family members to commit to greater levels of caring, of considering out-of-home situations and establishing legal arrangements that require acknowledging one's own mortality, often evoke strong emotions.

For example, one mother whose own infirmity was likely to result in admission to a nursing facility still resisted planning when faced with this major life change. Yet, in the end she acknowledged feeling tremendous guilt that despite caring for her son with a disability for 50 years she was about to fail him.

In working with families caring for a person with a developmental disability, you probably will be involved in helping them resolve at least one of several difficult and complex problems.

They may have difficulty in

- proving their eligibility for disability agency services
- finding appropriate, viable housing options

- planning for guardianship and financial security

Determining Eligibility for Disability Services

The developmental disability service system provides a range of services which may benefit the older person with a disability as well as his or her carers.

Some older persons with a developmental disability have difficulty gaining access to those services because they cannot offer proof that they have a developmental disability.

Eligibility for disability services is usually based upon federal or state statute, rules and regulations, or policy. Most state agencies use a broad, functional definition of developmental disability such as the one defined by the federal Developmental Disabilities Bill of Rights and Assistance Act (PL 100-142).

Generally, for a condition to be a developmental disability, it must have

- occurred before the person's twenty-second birthday
- must impede independent functioning in a variety of life activity areas
- be expected to continue into old age

States may define "developmental disabilities" using different criteria or restrict their definition of developmental disabilities to specific conditions.

Check with your state and local agencies for the criteria used in your state.

What Are Some Difficulties in Documenting That an Older Person Has a Developmental Disability?

Usually, developmental disabilities are documented in childhood by medical doctors, psychologists or psychiatrists. Schools and clinic records often contain documentation of a disability for children and young adults.

When this type of documentation is not available, other information can be substituted, such as descriptions of the person as a child as remembered by family members and previous use of disability services.

Unfortunately, for some older adults, this information may not be readily available because

- some older adults may never

have been enrolled in a school or participated in a service or program

- formal documentation of the history of the disability may not be available as clinic and school records may be lost or inaccessible, or the documentation may be unacceptable in today's service environment

- there may be no family members who can reliably provide a thorough history of the person's early years. Parents and other members of older generations may have impaired memory or have died When this happens, one option is to refer the person to a psychologist or physician for a clinical diagnostic evaluation. But often this may be intrusive, impractical or costly, or the person with a disability may be unwilling to be evaluated.

Under these circumstances, try to establish "presumptive eligibility." That is, show that the person has a developmental disability by collecting and summarizing past and present information about the person and his or her functioning. This information can be used to develop a justification that the person has a developmental disability and, therefore, is eligible for services.

Helping to establish eligibility for disability services is an important service to families. Working closely with a developmental disabilities services agency will facilitate this process.

Guidelines for Determining Presumptive Eligibility

As part of our project, specific guidelines were developed for determining whether someone has a developmental disability and is therefore eligible for disability services. We suggest a three stage process.

One: Obtain Any Information about the Person Which is Relevant and Readily Available

Collect as much information as possible and create a clinical or a social summary which can be presented to the disability agency.

You can collect this information from interviews with

- personal sources, such as the individual, family members, a legal guardian (if any), carers, neighbors and friends

- formal sources, such as social workers, physicians, dentists, psychiatrists, psychologists, *Mr. L, age 61, became aware of the Haitian Family Assistance Project through a public service announcement on the local radio and requested help for his 33 year-old daughter who is severely handicapped. Mr. L and his family immigrated from Haiti several years ago and their primary language is a mixture of Haitian French and Creole. During the interview it was apparent that eligibility for disability services could not be established through records since their daughter had never attended school in Haiti. However, since many of the family's neighbors knew them when they lived in Haiti, the agency was able to collect collaborating information.*

podiatrists, pharmacists, home health care providers, "Meals on Wheels" providers, senior service centers, legal aid or personal attorneys

- informal sources, such as grocery store operators, beauticians, apartment superintendents, spiritual leaders and local community leaders

Two: Develop a "Clinical Picture"

Many areas of the past and current functioning of the person with a disability can be included in developing a "clinical picture."

Look for evidence of long term functional impairment, such as

- a history of delayed developmental milestones
- difficulties in performing personal care tasks, managing money, working and getting around the community, as well as deficits in basic educational skills such as reading, writing, and simple mathematics
- attendance at special schools or programs

Look for signs that lead you to think that "something is different" about the person.

Don't expect people to use terms such as "developmentally disabled" and "developmentally delayed." This is professional language not generally used by the public.

Instead, you will need to look for cues from your informants. Notice how they describe the person with a disability. They may describe the person as

slow
different
couldn't be left alone
always teased by the other kids
easily taken advantage of
didn't go to school

didn't finish school
never worked or got a job
had special help

Take into consideration any other terminology that may be appropriate for the particular culture and population group with whom you are working.

Remember that below normal intellectual functioning (i.e., intellectual disability [*mental retardation*]) is not the only factor that identifies a developmental disability.

Categorical conditions such as cerebral palsy, autism, neurological impairments, seizure disorders, sensory impairments and other similar conditions may also be considered developmental disabilities in your state.

Three: Justify Why You Think the Person Is Eligible for Services

When you have collected sufficient information, summarize your justification for the individual's eligibility for disability services. It should be based on your information and indicate that conditions other than a developmental disability were considered and ruled out.

Make sure that your conclusions address the eligibility criteria that your state or other governmental jurisdiction uses.

Sometimes Eligibility for Services Cannot Be Established

At times, you will be unable to establish that the person has a developmental disability and they therefore will not be eligible to use disability services. Your inability to document a developmental disability does not preclude your helping these families.

You can still provide a vital service to families by referring them to any services for which they are eligible.

Appropriate and Viable Housing Options

Aging carers and their families may find that their current living situation is no longer viable or they may anticipate the need to make a change in the near future.

Some of the families with whom you work will ask for help in exploring options. Families may be interested in housing for the entire family or only for the person with a disability.

Many options for living arrangements are available, but families are often unaware of the range, availability and cost of the housing options in their community. And even if they are knowledgeable, they may be uncertain about the best plan.

In helping families to address their housing concerns, it is important that you keep certain principles in mind

- involve the person with a disability in the decision-making
- consider alternatives that maintain the family unit when appropriate, such as supportive in-home assistance or merging households with other family members -- some families may be able to move in with siblings or other relatives
- present as many options as possible to the family

Because the range of housing alternatives varies in each community, you should take time to explore the options in your community.

The following sections briefly describe the range of alternatives.

Home Ownership

Ownership of a house, apartment or other situation gives any individual the most control over his or her living arrangement. To purchase a house, the family or a person with a dis-ability

Mrs. G., age 73, provided care for her 47 year-old daughter and her daughter's five children. Twenty years ago her daughter received a head injury during a robbery. Since then she had numerous broken and abusive relationships, an unstable work history, and multiple psychiatric hospitalizations.

After reading about the Carer Services Program, Mrs. G. called for help, explaining her diffi-culties: "I'm still raising my daughter, although she is an adult and I'm also raising her children. I'm overwhelmed!"

Since her daughter's injury, Mrs. G. has been seeking help for her family. As her daughter did not have a developmental disability, she had been frustrated in getting assistance.

However, the worker knew of a head injury victim's assistance program and referred her to it. The program aided by getting some needed relief for Mrs. G.

Mrs. G called later with thanks. "All these years they kept treating my daughter as though she was crazy and just gave her psychiatric medicine. You're the first one to help me get her the right kind of help."

might use family savings, investments, or property and first time home ownership programs. The use of a special needs trust may be appropriate to help the person or the family handle the financial details.

More information about trusts is included in the financial planning section.

Family members might also develop plans to donate their existing home to the individual with a disability.

Sometimes we don't consider the home ownership option because we believe that the person with a disability will need many supportive services. However, in-home services may be provided through a home health care agency, an agency that serves persons with disabilities, a roommate, or other community and family supports.

Families should contact Realtors, banks, affordable housing corporations, other families, first time home buyer groups, municipal and county governments, trust attorneys, pooled trust organizations, and state and local human services agencies for further information.

Renting or Leasing

Another option is to rent or lease a place to live. In most communities, market rent or subsidized apartments are available. In-home services may be arranged to help people in these settings.

Information about rental subsidies can be obtained from state or federal governments. Subsidized units may have waiting lists, but in many areas housing managers are interested in filling some apartments with persons with a disability. As a result, persons with a disability may move to the top of the waiting list.

Specific information about rentals in your community can be obtained by contacting public housing authorities, local affordable housing agencies, municipal and county government, housing advocacy organizations, human service agencies, friends, relatives, landlords, and Realtors.

Home Sharing

Sometimes two or more unrelated persons might share their housing and expenses. In some communities, a local agency may serve as matching brokers and help people to find compatible roommates.

In some living situations one roommate may provide services to the other in exchange for free or reduced rent.

A person with a disability may be either a housing seeker or a housing provider. In other words, they may be able to find someone to come and live in their home or may want to move in with someone else.

If families are interested in this option, they should contact one of the local human service agencies which runs a home sharing program.

However, talking with friends and relatives or checking the newspaper may be the best way to find a roommate.

Also refer to the guide on home sharing listed in the "Reading Resources" section in the Appendix (see page 133).

Family Care or Foster Care

Some families may be willing to consider having their son or daughter live with another family. In this type of housing option the host family receives funds for clothing, food, shelter, other living expenses and in some situations funds for personal care services.

Information about foster or family care can be obtained through state, county, or local human service agencies. Many underwrite or operate family care programs in their locality.

Group Homes

In most communities, there are group living programs for persons with developmental disabilities. In these a small group of adults live together in a home which is either owned or leased by a public, private or non-profit agency. These homes provide varying amounts of supervision and assistance for the residents.

Group homes generally are certified by a government agency. Generally, state regulations deter-mine much of how homes are run, who lives there, and the staffing pattern.

If a family is interested in a group home, arrangements can be made for the person with a disability to visit on a short term or trial basis, before a final decision is made to relocate. For instance, they can be invited to have dinner with the residents or stay overnight or for a weekend.

Many adults live in group homes for an extended period of time. The group home becomes their permanent residence. Others stay for shorter amounts of time, on a temporary or interim basis, while they look for an apartment or other setting. Group homes may also be used as respite opportunities for families.

Disability agencies are usually aware of the availability of group homes in your community. There may be waiting lists. To learn more about a specific group home, carers can visit a group home, and talk with staff and the residents and their families.

Supervised Apartments

In many communities, disability agencies help adults set up their own apartments or match adults who want to live in a supervised apartment. In these situations, two or more adults with a developmental disability or someone else (sometimes the other person may be a college student) share an apartment.

In some situations, an adult may live on his or her own. In others, the adult may live with some minimal staff supervision or oversight.

Apartment living situations vary in the amounts of supervision and assistance they provide for their residents.

Such apartments may be certified by the state disability agency and owned or rented by a host agency. Other times, the rental or lease agreement may be in the name of the persons living in the apartment.

If a family is interested in an apartment situation, they should be placed in contact with local agencies that either operate or provide funding and supports for them.

Helen:	*"Has your son always stayed at home?"*
Anna:	*"Yes."*
Helen:	*"Have you considered another situation for him?"*
Anna:	*"No . . . He's okay at home."*
Helen:	*"Yeah . . . but why not let him live on his own or in a group home? He's never lived anywhere but home! We're not going to live for ever, you know! The time to consider our children is when they are younger, when the separation may not be as critical . . ."*
Anna:	*"I've considered that . . . but, my son will always be home."*
Helen:	*"Okay, fine. But, are you going to help him so he can manage when you're not around any more?"*
Anna:	*"I'll be around until I'm 106 . . ."*

Two parents

Guardianship

In your work with older carers, the issue of legal guardianship of the person with a disability will need to be addressed. In most families legal guardianship has not been determined, especially when the person with a disability lives with their family.

What is Guardianship?

Guardianship is a legally defined situation where one or more persons or an agency is given the right and duty to make decisions for another person. The person or agency given this right is the "guardian." The person being looked after is the "ward."

Guardianship, when properly exercised, can be an important support for persons who are unable, for any of a variety of reasons, to make personal and/or financial decisions for themselves.

Issues in Guardianship

Historically, a guardian was given very broad authority to make almost all decisions for the ward concerning personal care and/or financial matters.

More recently, however, many states have adopted statutes providing for "tailored" or "limited" guardianships where the authority of the guardian is limited to those areas of decision making where it is demonstrated to the court that the disabled person does not have the capacity to make decisions for him or herself.

Families are unlikely to be aware of the ways in which guardianship laws have changed. They may also assume that they are and have always been the guardian for the person with a developmental disability. You need to explain what legal guardianship means to all family members, including the person with a disability.

In some cases, the improper use of guardianship can lead to the loss of all autonomy by the person with a disability.

In others, it may have positive aspects, as it may make the difference between the individual being able to maintain himself or herself in the community, possibly with their family, or requiring out-of-home care.

The proper exercise of guardianship allows the carer to

- ❖ assist the individual in exercising the greatest degree of decision making of which he/she is capable
- ❖ provide assistance and make those decisions for which the individual does not have capacity

The challenge is to strike a careful

balance between maintaining the individual's autonomy and providing the needed surrogate decision making, help, and protection.

A guardian can be appointed to make medical decisions, thus insuring the delivery of needed health care, but the individual can retain the authority to make other personal or financial decisions.

A guardian could be given the authority to enroll a person in day programming and to give consent to necessary medical care, but leave residential decisions up to the individual. Thus, the adult decision making rights of the individual can be respected without giving up the use of guardianship.

Who Can Serve as a Guardian?

Anyone who is being considered as a guardian or standby guardian of a person should have the individual's best interest at heart and understand the nature and degree of the person's disability and special needs.

Additional factors that are considered include the geographical distance and availability of the guardian to make visits and decisions.

How to Obtain Guardianship

The procedures for becoming a guardian, the standards governing the appointment of the guardian, the authority given the guardian, and the reporting and educational requirements for the guardian differ from state to state.

In addition, several states have more than one guardianship statute, often having a statute governing the appointment of a guardian for persons with a developmental disability and one governing the appointment of a guardian for persons with other types of disabilities.

Because state statutes differ and because several states have more then one statute governing guardianship, it is important to check with legal authorities in your state and inform yourself about your state's procedures.

Information about guardianship can be obtained from your state's Arc chapter, local family services agencies, or the state's protection and advocacy agency.

Also, contact the National Association for Protection and Advocacy System (NAPAS - 900 Second Street, N.E., Suite 211 Washington, DC 20002; ☎ 1-202-408-9514) for the name and number of your state's protection and advocacy agency. NAPAS's website is: www.protectionandadvocacy.com and the contact email address is: info@napas.org

In addition, in the Appendix we have listed a number of national associations that might be a resource to you.

Other Forms of Surrogate Decision Making

In the course of your work with families you may find that some families use other forms of surrogate decision making.

Two of the most common are "representative payee" and "health care agent."

Representative Payee

A person who has been appointed as a representative payee receives and manages the financial benefits of a person with a disability on their behalf.

Social Security, the Veteran's Administration, and other government agencies have procedures by which a person may be appointed as representative payee. The appointment only applies to the specific benefit program.

Health Care Proxy/Advanced Directives

Most states have provisions for the appointment of a health care proxy or agent for the purpose of making health care decisions for a person lacking capacity to make such decisions for themselves.

In many cases such an appointment must be made by the individual while he or she is still competent to understand the nature of the delegation of health care decision making authority.

Persons with a developmental disability can often understand that they are delegating health care decision making authority to a carer while not, at the same time, having the capacity to make health care decisions for themselves.

Most states also have statutes covering specific medical care decisions, such as "do not resuscitate orders," providing for surrogate decision making authority under very specific circumstances.

There may also be situations where an adult with a developmental disability may be suspected of having or is diagnosed with early stage dementia of the Alzheimer type. In such circumstances, planning for future health care decisions might be undertaken by an "advance directive."

For more information on the effects of dementia and the use of such devices, refer to the AAMR practice guidelines on care management of adults with dementia and intellectual disabilities [*mental retardation*] noted in the "Reading Resources" section of the Appendix (see page 133).

Financial Planning

Families often ask for help in securing or saving money to insure that their relative will have funds for the future. Some carers may decide to leave money to other family members to care for the person with a disability and make an informal arrangement with them.

Others may not have available family or may wish to create a more formal plan. They may be interested in establishing a trust.

Using Trusts

A trust is a legal relationship created by a person (referred to as the *settlor*), in which another individual (the *trustee)* owns and manages assets for the benefit of a third party (the *beneficiary*).

In most cases, the purpose of trust is to provide a higher quality of life to the person with a disability than would be provided by government programs. A higher quality of life might include extra education, training, recreation, vacations, gifts or personal amenities.

A trust is a way to set part of an estate aside for the use and benefit of the individual with a disability without making the beneficiary the owner of the estate. Setting up a trust is useful because assets or trusts in the name of an individual with a disability may disqualify him or her from federal or state assistance, such as SSI and Medicaid.

In addition, some states require persons with a disability who have assets to pay for their own care in residential homes or settings funded through public funds.

It is helpful to have some degree of familiarity with these issues and how they are treated in your state for people with disabilities. Find out what information is available on the laws around trusts in your state and their implications for the future of the person with a disability.

In some states, an improperly set up

trust may result in the denial of future services. Some of our projects reported that they were able to get expert help in this area through their network of agencies.

Since each state's laws on trusts, estates, and wills may differ, you may wish to check with your agency's attorney for help on this matter.

Alternatively, a good source of information can be your state's developmental disabilities planning council, the state chapter of the National Arc, or any organization established to aid in advocacy for people with disabilities.

Obtaining Federal Benefits

Another area of financial planning is ensuring that the carers and the adults with a disability are enrolled in federal benefit programs, such as Social Security and Medicaid. Parents are often unaware that their son or daughter may be eligible for federal assistance because of their disability.

Social Security Disability and Supplemental Security Income programs are a major source of income for adults with a disability. Often parents are unaware of how to enroll their adult child in one or both of these programs.

Thus, being familiar with the quirks in these federal programs and knowing how to help families apply for benefits under them can be a great advantage.

For example, to receive maximum benefits, parents must view their adult child as financially separate from themselves. Yet, parents are often reluctant to do this for they make substantial contributions to their adult child's upkeep and do not wish to place a monetary value on these contributions.

However, these contributions have to be considered in monetary terms and a value placed on the room and board costs. Consider

- if they are, then the adult becomes eligible for a higher level of benefit, as much as $160 more a month.

- if they aren't, the adult will only be eligible for a non-contributing rate, which is the lowest.

Older parents are also often unaware that when they file a Medicaid application on behalf of their son or daughter, it is not their income that should be reported, but their son's or daughter's. They must make this "descriptive separation" to access the entitlements.

Many parents, however, are reluctant or unwilling to not identify themselves as a family and as a result inadvertently jeopardize their adult child's potential benefits. This is another example where families need accurate information on how to secure benefits for their adult relative with a disability.

Knowing how to advocate on behalf of families for such benefits is a very useful tool. Consider getting trained by the Social Security and Medicaid programs in completing enrollment applications.

Make a point of learning the "in's and out's" of these federal programs. It is also helpful to get to know the federal program intake workers in your area.

Your knowing how to "work the system" can save families immeasurable time and effort!

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Chapter 9

Cultural Aspects to Working with Carers

> ***"When my son was born with his condition, I never felt alone. I always knew that there were people around who would help me."***

American society is comprised of people of many different nationalities, including people with roots in African, Asian, European, and American countries. The cultures and languages vary broadly and contribute to the richness of the North American experience.

Caring for a person with a disability is integrally related to cultural attitudes and personal experiences. Some people, specially recent immigrants and those who are trying to retain the customs and language of their heritage, may hold views about caring for a person with a disability that may differ from prevailing values and attitudes across the United States.

Consequently, you cannot make assumptions about how any individual or family approaches caring for a member with a disability. In our project, we found that it was very important to gain an under-standing of the values underlying caring of all families with whom you work.

Families with strong ties to non-European or non-English language cultures consistently do not access or use services to the same degree as those with European heritage. In addition, some service providers fail to consider the influence of values and beliefs of persons from non-European cultures in the design of services or service related materials.

Therefore this chapter offers some

thoughts about working with persons with cultural identities different from those generally seen as American-European or linked to English speaking backgrounds.[1]

Staff in aging and disability services report that families with strong cultural ties may refuse services for a number of reasons. These may include

- ❖ the belief that one generation has a moral responsibility to take care of another (sociologists call this "filial piety"). For example, *"Just as my parents cared for me when I was a child, now I must and will take care of them in their aged years"*
- ❖ the availability of extended family supports in multi-generational households
- ❖ suspicion of or being uncomfortable with formal agencies
- ❖ beliefs that "one takes care of one's own"
- ❖ language barriers

Not everyone agrees with this perspective. Some point out that the experiences of these groups in American society strongly influences their use of services. Consider the following

- ❖ historic experiences of discrimination may make cultural groups wary of formal services, even when needed, and uninformed of the availability of services
- ❖ migration away from countries or areas of origin may mean that extended family members are not readily available to help with care
- ❖ acculturation may mean that numbers of persons from diverse cultures no longer believe in *filial piety* and extended family obligations and support
- ❖ employment demands, economic pressures and caregiving needs of other family members may mean that caring for a person with a developmental disability is beyond the resources of the family

We learned some important lessons in working with families from diverse cultures. One is that each family is unique and has its own patterns of caring and decision-making. Thus, we should not make assumptions but rather need to keep an

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[1] Our project was concerned with four specific cultural and ethnic groups: African American, Haitian American, Chinese American, and Native Americans. Also our association with the NYS OMRDD's Multicultural Professional Development Institute has brought us into contact with Asian American, Caribbean American, and Hispanic American families and agencies.

open mind.

In the following pages we pose and discuss a series of important questions that can be used to guide you in your work with families from diverse cultures. Consider these questions as you plan services and interact with these families.

Who is the Family?

Who makes up a particular family may not always be obvious to workers but may be very clear to members of the family. We often think of family as being those people who either live in the household or are a part of the immediate family. Often we think of family as the "nuclear family;" that is, two parents and the children.

However, families may consider others, including friends or in-laws, to be a part of their family and may include three or four generations in the same household.

Sometimes family members who assist with caring may not live in the same household, but live near by or some distance away. And don't forget, some families may not have relatives available at all, or available relatives may not be willing to provide care.

As you may not recognize some family members or friends as being critical to the care of a family member with a developmental disability, it is important to ask the family about who helps.

Consider some of these "family" members who we encountered in our project. They all played an important role in providing care.

- a friend who immigrated to the United States at the same time and from the same area as the family
- a sister-in-law from a marriage that had ended
- a friend who moved into the family's household

Who Provides Care?

In every cultural group with whom we worked, the primary carer was usually the mother of the person with the disability. However, other family members provided significant levels of support or influenced decisions. Let the family tell you who are the carers of the person with a disability.

For example, in multi-generational households it is not unusual for the majority of caring responsibility to have been transferred to a sibling or another younger relative, and yet the aging mother still receives the respect and recognition of the primary carer.

Mrs. K., a woman of African American heritage, who was caring for her mother, her sister with a disability and two children, died suddenly. Various agencies in New York City, her home community, were involved in relocating the mother to a nursing home, her sister to a group home, and the two children to foster care. Meanwhile, members of her extended family in South Carolina learned of her death via word of mouth. They contacted a cousin in Chicago who agreed to assume the responsibility of caring for all of the family members. So she moved to New York City and then spent three months working to reunite the traumatized family.

We also found that grand-parents and other family members often assumed caring responsibilities.

It is not unusual for there to be others in the household with chronic illnesses and related disabilities who also need care. In such households, the person with a developmental disability may be someone who provides care rather than someone who receives it.

If you focus exclusively on one or two family members, or make assumptions about roles and needs of family members, you risk disrupting important family relationships. Consequently, your help will be rejected, even by the family members you have targeted for help.

How is Disability Perceived?

Disability may be viewed differently by various cultural groups and by individual families within those groups. Many families in our project struggled not only with their own beliefs about disability but also about how others in the community perceived the disability and the family. For example, one mother said that her son with a disability was “God's special gift,” but another saw her son as “God's punishment.”

In some cultures, disability is perceived so negatively and shamefully that the family hides a person with a disability from the community. As one family member explained, *“It then appears that the community has no persons with disabilities!”*

In other cultures, the opposite occurs. Everyone in the community has "a soft spot" for a person with a disability and they are active participants in family and community life.

The way in which disability is perceived is likely to influence both the level of services needed and a family's willingness to accept those services.

What do Family Members Expect of Each Other?

All cultural groups value family support and expect their members to help with caring. However, the reality may be quite different in individual families for many reasons. The difficulties faced by many families were discussed openly by families in our project.

Native American families expected their other sons and daughters to take over caring, but acknowledged that economic realities forced their children to leave their community and traditional ways.

Chinese American families talked of expectations of family support being compromised by acculturation of younger family members, and reduced availability of extended family members.

One Asian couple with two adult children, both with severe mental retardation, were from a cultural group that highly valued kin involvement. They lamented that no other family members were available to assist with care of their daughters or of them when they needed assistance.

Haitian families talked about how important it is to support other family members even in the face of acculturation and scattered family networks.

What Support do Families Receive from Friends and Community?

How families feel about receiving help from friends and neighbors varies widely by cultural group and individual family within cultural groups. The actual amount of help they receive also varies.

Many families have friends and neighbors who assist them. Help from churches and culturally based social and service organizations is particularly valued by families of some cultural groups. Indeed, families in our project expressed disappointment when they did not receive the help they expected from these sources.

In contrast, other families may not seek or even accept help from the

"A worker was helping Mrs. H., a widow, to make plans for the future of her 35 year-old daughter with intellectual disability. Suddenly Mrs. H. changed her mind because her parents objected to the plan.

The worker was surprised as Mrs. H.'s parents lived some miles away, in their own household, and seemed to have no role in caring for their granddaughter. When the worker asked Mrs. H. why she had complied with her parents' wishes, she learned that Mrs.

H.'s parents had cared for their granddaughter on a daily basis throughout her childhood while Mrs. H. worked. Mrs. H. felt a debt of gratitude to her parents and that their opinions about the care of her daughter, even now, were very important.

After the worker and Mrs. H. encouraged her parents to get involved, they voiced their concerns and felt reassured about their importance to the planning process. Mrs. H.'s parents became part of the decision-making and eventually supported the original plan."

An agency social worker

In contrast, other families may not seek or even accept help from the community. Instead, they may try to hide the person with the disability because of the shame they feel. This happened in a variety of cultures.

How Does the Family Make Decisions?

Families may make decisions about caring and other matters in ways that are different than our own. And we may not be happy with the outcome of their decisions, especially when families refuse services or do not want to plan for the future. However, families have the right to make their own decisions.

Our project found that many workers had to re-examine their own beliefs and expectations particularly about the caring roles of mothers and fathers. This was true when both parents were present in the household, or when they continued to participate in the life of the person with a disability, even if in separate households.

Why Did the Family Move?

Why do people come from another country to the United States, why do people in small towns or rural areas move to large cities, and why do people living in urban areas move to the suburbs or rural areas?

Some reasons that a family with a member with a disability might move may be to

- find greater tolerance
- escape shame and labeling
- find more appropriate services
- "hide" the person with a disability

Understanding the reasons for a move can help to clarify a family's willingness to accept services as well as their fears and concerns.

How Important Are Cultural Values to Family Members?

The importance of cultural traditions and values should never be assumed or undervalued for any family or for any family member. This applies to people who enter the United States from other countries as well as African Americans, Hispanic Americans, and Native Americans and others who emigrate across the country from their regions of origin.

Adherence to traditional cultural values has both positive and negative effects on families. For example, if

An agency worker was excited about the success of her outreach effort to one family. In addition to receiving services, the mother had been helping the agency with outreach, trying to locate other families who needed assistance, and had been featured in the agency's newsletter. However, the father, who felt that these events led to his being ridiculed by others in his community, insisted that his wife and daughter stop contact with the agency.

When the worker understood the disastrous effect of not involving the father, she told him about the agency's services and explained how they might help the mother and daughter.

Once the father was part of the decision making, he agreed to the services and became an advocate and volunteer for the agency's efforts.

An outreach worker

family participation in caring is strongly valued, families may be more likely to receive informal support.

On the other hand, if receiving services from agencies is not valued, families may be reluctant to accept services. And if some family members do not share traditional values but others do, conflict and disappointment may result.

Traditional cultural values and beliefs may be modified by the experience of migration. Migration creates geographic distance between family members and may

- reduce the number of family members available for caring
- reduce contact between family members
- create tension between maintaining traditional values and living in new circumstances

Traditional values may hold different meanings for different generations. Older generations, particularly those who emigrated late in life, may be more likely to retain the values and traditions of their culture. Individuals or families of diverse cultures who appear to be, or who are assumed to be, acculturated to mainstream American ways of life may still be influenced by past traditions.

First generation individuals born in the United States and those who emigrated at a younger age often feel the most pressure to "fit in" so that they may support their families economically. They are more likely to acculturate, even while claiming to support traditional cultural values.

Second and third generations of families often selectively reclaim traditions as a way of defining themselves, while still resisting other cultural traditions that they see as too restrictive. Consider the differences in the perspectives of these two recent immigrants from Haiti

> *An older Haitian man explained that helping a mother care for a son or daughter with a developmental disability demonstrates respect for older family members and helps families take care of their own. These are traditional Haitian values and an important part of being Haitian.*
>
> *A younger Haitian man said that he would always support his mother in providing care but felt that the traditional ideas about respect for the authority of elders and the family were too restrictive to be held onto in America.*

Cultural groups also experience

strains as they try to maintain their own identity while challenging barriers to equal participation in society by their group.

A Chinese American leader explained that every time a family accepts services from an agency, they and their culture are changed. But not accepting services often places family members at a disadvantage, especially in the work world.

Workers who reach out to families without understanding the role of culture run the risk of

- offending families
- missing important informal resources that may maintain persons in the community
- assuming that refusal of standard forms of help means that no help is wanted or needed
- misunderstanding family behaviors, and misinterpreting the information families provide

How Willing Are Families to Accept Services Outside of Their Own Cultural Community?

In our project we found that most families with a strong cultural identity preferred to receive services within their own community. These are some of the advantages which families might experience in using culturally based services

- fewer problems with language and access
- less fear of formal service providers
- more familiarity with services
- more respect for their traditions

Some families who "hide" the person with a disability from friends and neighbors preferred to use agencies from outside their community. Others sought out workers who were familiar with their culture and understood their feelings and concerns. One such parent expressed the feeling that she hoped this involvement with the agency might open up dialogue and greater acceptance within her own community.

What Is the Family's Native Language?

In addition to the barriers posed by workers' use of professional jargon and abbreviations, many families have increased difficulty in accessing services because English is not their first language. Many information or registration materials are only in English, and many workers are only English-speakers.

Older families in general know little about available services and difficulties in language complicate their situation. Few agencies have translator services available. Instead, many rely on neighbors, family, and even children as mediators for non-English speaking family members. Many families are uncomfortable with using interpreters, particularly since so much personal information is often shared.

Language difficulties also create additional costs in accessing services. For example

> *Mrs. S, a non-English speaking Guatemalan mother, spoke of the difficulty in accessing medical services for her daughter with a disability. A relatively routine medical concern required six doctor visits before medical clinic staff understood what had to be done and took care of it. Each visit required a taxicab ride to the clinic and the mother pointed out that even free and low cost services become expensive when these additional costs and the frustrations involved are added in.*

One suggestion we received while conducting this project was that aging and developmental disabilities service agencies need to reach out to the public schools in their regions to access their translator networks.

However, families indicated to us that, despite laws mandating that educational planning be conducted in the language of the child and family, language accessibility in many schools also needs improvement.

Is the Family Concerned About Service Providers?

Many families have concerns about dealing with formal service providers. They may wonder

- will they provide the services they need?
- what will the quality of those services be?
- if they ask for one service that they feel they need, will they be required to accept other services they don’t want?
- will a request for services be considered as justification for removing the person with a disability from the home?

> *"A Korean father explained that he approached a service agency for assistance caring for his daughter with a developmental disability, when he and his wife were both out at work.*
>
> *The agency offered a personal care attendant, but could not guarantee that the attendant would be Korean.*
>
> *He explained that it was not acceptable to him and his wife to have non-Koreans in their home. The agency's response was that this was the only service that they could offer him.*
>
> *He thus refused the service and contacted his own parents still living in Korea. Since that time his father and mother have alternated coming from Korea for six month periods to care for his daughter.*
>
> *Another Korean parent said that for her this was an old fashioned view and in some ways she preferred to receive services from outside her community."*
>
> A project worker

For cultures that place value on extended family and community support, the use of services also may result in carers feeling a sense of failure for having to turn to "strangers." They may have a profound sense that they have not fulfilled their obligations to their family.

Agency offices are often not easily accessed and difficult or unsatisfactory interactions between the agency and family may have occurred in the past.

Families may feel judged by professionals, particularly those from another culture, regardless of the amount of support offered by the worker.

Families may also be concerned that information given to the agency will be used for other purposes. Some of these concerns include

- all cultural groups believe that abuse of persons with disabilities is wrong, but not everyone agrees that all use of corporal punishment is abuse -- families have expressed concerns that traditional practices in their homes may be misinterpreted and reported to other agencies

- family living arrangements which might include large numbers of people in the household, involving several generations or other extended relationships, may be interpreted negatively by agency staff, resulting in reports to housing code agencies, and allegations of improper care

- use of formal agencies may attract attention from other agencies such as the Immigration and Naturalization Service, independent of their actual legal status

How to Proceed

The process of building trust and communication with families of diverse cultures requires first building a trusting relationship with the family, and taking the time to understand the unique meaning of the issues raised for that family.

Our experiences suggest that the agency leading the outreach effort should include in its network agencies run by specific cultural groups found in its catchment area. In addition, resources should be directed to those agencies so that they can initiate outreach within their community.

Some examples of the initiatives successfully undertaken by community agencies include

- development and dissemination of own-language materials on family caring issues and concerns

> A recommended publication is *Best Practices: Outreach Strategies in Multicultural Communities.* Copies may be obtained from Dr. Lucinda Grant-Griffin, c/o NYS OMRDD, 44 Holland Avenue, Albany, New York 12229-1000.
>
> To develop guidelines for individuals not of their culture planning to work with families in a variety of communities, the Multicultural Professional Development Institute gathered agency staff and family members from five different cultural groupings: Asian Americans, Caribbean Americans, Native Americans, Hispanic Americans, and African Americans.
>
> This publication, which they developed, contains guidelines and basic orientation materials for accessing the community and aiding both family carers and persons with a develop-mental disability.

- recruitment and training of a group of peer outreach volunteers from an existing grandparent support program

- engagement of community leaders in discussion of the needs of families in communities often reluctant to acknowledge the existence of persons with disabilities

By increasing cultural sensitivity and awareness, agencies will benefit from providing services more responsive to a variety of groups within their midst. This will also benefit the greater community by removing barriers to accessing services by some sectors of the community.

What are ways in which this can be done?

- channel resources to agencies representing the cultural group you are trying to reach, and encourage those agencies to pursue strategies that *the*y know will work

- provide for cultural sensitivity training and experiences for all outreach and information and referral staff

- use community leaders to examine how agency policies may pose barriers to building trust with diverse cultural groups, and how agency practices may conflict with prevailing values of the cultural groups in your area.

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Chapter 10

New York Caregiver Assistance Project

> ***"...older families need time to become acquainted and comfortable with services."***

The New York Caregiver Assistance Project was a multi-year demonstration funded by the Administration on Aging and supported by the New York State Developmental Disabilities Planning Council, the New York State Office of Mental Retardation and Developmental Disabilities and the New York State Office for the Aging. Collaborating organizations included the University of Rochester, Utica College, the State University of New York at Albany, and NYSARC, Inc.

The project had two goals. The *first* was to test the feasibility of incorporating into daily practice at local area agencies on aging, low-cost and low-tech outreach, linkages with developmental disabilities agencies, and supports for households with an adult member who has a developmental disability.

The *second* was to see how private not-for-profit service agencies, run by different cultural groups, could carry out outreach, identify older carers, and provide assistance to households within the context of their culture.

There were several reasons for undertaking this project

- the 1992 revision to the Older Americans Act had targeted older non-paid carers of adults with developmental disabilities and we wanted to test the feasibility of a state unit on aging response to this targeting

- we had discerned that there were a number of older families within our communities, with whom we had no contact and who were at risk due to their own aging and the aging of their son or daughter with a developmental disability

- we had information that some of the area agencies on aging were encountering such older families and were uncertain as to how to respond

- state and national reviews of individuals receiving services indicated that families from diverse cultures are under- reported among formal service recipients.

The demonstration sites included area agencies on aging and local not-for-profit agencies aiding specific cultural groups.

The Project

There were two projects that ran in parallel, both designed to achieve similar ends. The differences between the two were the funding sources and the area agencies on aging (AAAs) involved in the demonstrations.

- Project A, funded by the state's developmental disabilities planning council and managed by the New York State Office for the Aging[2], focused on AAAs that also have a "caregiver resource center." These centers were established in 17 of the state's 59 AAAs and were to aid households and other carers helping older persons who needed special assistance. Eight of the overall 13 demonstration projects were associated with these centers.

- Project B, funded by a grant from the federal Administration on Aging and the OMRDD's Multicultural Professional Development Institute (MPDI), focused on AAAs that did not have a "caregiver resource center." Six AAAs participated in this project, one of which was also a member of the first project. This project also drew upon four not-for-profit agencies serving four distinct cultural populations. Two of these agencies were part of the original project. Funding provided by the MPDI enabled us to incorporate two additional agencies within the project.

Since Projects A and B were inextricably linked, what follows concerns both of them.

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[2] Philip LePore of the New York State Office for the Aging was the project director.

The Carer Assistance Model

The combined projects operated from a model which had at its core the assignment of an older carer outreach and assistance function residing within a host agency. Requisite components included a needs assessment, a call to target special households, and a program of promoting community awareness. Incorporated within this core were several complementary functions

- bridging the disability and aging networks
- promoting agency awareness
- conducting outreach
- providing casework or brokering referrals

The project design was based upon three core assumptions. The first assumption was that if an agency targeted carers of adults with a developmental disability they could *(a)* increase the success rate of their outreach resulting in an increased level of preventive or ameliorative supports provided, and *(b)* decrease the calls for emergency requests for services and precipitous out-of-home residential need referrals, because of more responsive and effective services.

The second assumption was that these core efforts could be modestly funded and carried out without necessarily increasing the reliance on "high tech" or costly supports. In other words, the operation could be cost-effective and efficient, as well as practical and satisfactory.

The third assumption was that the core function could be carried out by assigning a specific person primary responsibility for carrying out the activities.

What Were the Projects Asked to Do?

We selected the demonstration sites following a review of the responses to a "request for proposals" announcement that was sent to all of the area agencies on aging in the state. They were informed that a small annual stipend (between $14,000 and $18,000) was available and were invited to apply.

The applicants were asked to describe what they planned to do and to identify the manner in which they would go about doing it. In the RFP, we defined who was to be served, identified some of the activities to be performed, and targeted specific needs of families to be addressed.

The project developed a standardized carer intake form for use by the demonstration sites for identifying the demographics and needs of the households identified (a copy of the intake form is available from the authors).

A second instrument, a household assessment form, was developed but not used. Originally designed to identify basic household concerns and futures planning of the primary carers, the instrument proved to be too intrusive and following advice from the local site people we chose not to use it.

In our specifications for the demonstration sites, we asked that they

- *conduct outreach* or identify some determined number of new households caring for a family member with a developmental disability. The emphasis was on finding carers not generally known to or already receiving services from the formal developmental disability system.
- *establish working relationships* with the community's developmental disability provider agencies (such as chapters of The Arc and United Cerebral Palsy Association) as well as advocacy and self-groups (such as independent living centers and self-advocacy groups).
- *work with the regional developmental disability office* of the state developmental disabilities authority and assist it in providing support to families on waiting lists for services.
- *provide supports* for carers, such as counseling and/or group support assistance.
- *assist carers* in getting linked to appropriate aging network and other community service agencies.
- *participate in training* offered by the state aging and developmental disabilities agencies to become familiar with the needs of families caring for an adult with a developmental disability.
- *employ a parent or grandparent* (if applicable) who has an adult relative with a developmental disability as a "parent peer model" to assist with the outreach and identification effort.
- *develop and test materials* which could be used during outreach to households with an adult with a developmental disability

Who Did We Target?

Participating AAAs were asked to target the following carers

- parents caring for an adult with a

developmental disability

- siblings caring for a brother or sister with a developmental disability

- children, other relatives and close friends who are carers to older adults (age 60 and older) with a developmental disability

- adult sons/daughters with a developmental disability who are the primary carer for an aging parent or parents

Who Were Our Participants?

Our participants included both area agencies on aging (AAAs) and cultural organization provider agencies.

The Area Agencies on Aging

Thirteen of the state's 59 area agencies on aging participated in the project. The demonstration site AAAs represented both urban and rural populations and varying complexity in terms of agency organization.

The population of the AAA catchment areas ranged from around 55,000 to close to one million inhabitants. Population densities varied greatly as well. We had several rural AAAs where about 100 persons per square mile was the norm and we had several high density areas of between 1,000 to 2,000 persons per square mile. Most, however, fell in between.

Our other AAA demographics were typical of those of AAAs around the nation. Per capita income ranged from the low $20,000s to the mid-$40,000s. The percentage of persons age 60 or older ranged from 12% to 21%, with a state average of about 17%. The average annual budget, from all sources, for the AAAs was about $3.0 million, with a $1.0 million at the low end and $8.4 million at the high end. Included in the Appendix is a list of the participating AAAs.

Cultural Organization Agencies

Since part of the design of the project was to assess how cultural variations affected outreach, family contacts, and the design of services to assist families, four agencies serving distinct cultural groups participated in the project. A brief description of each of these four agencies follows.

Miracle Makers, Inc. is a large agency serving persons of African-American heritage in the Bedford-Styvesant area of Brooklyn, New York. The agency, predominantly a foster care and social services provider, operates a network of developmental disabilities group homes and supportive housing programs, as well as providing casework, recreation and social services for a largely African American clientele.

The *Chinese American Planning Council, Inc.*, (CAPC) is a large multi-faceted agency in New York City which serves a mixed Asian population. The agency, predominantly a social and senior services agency, operates a network of senior centers, meal sites, and housing programs in Manhattan and Queens. It also provides social services.

Haitian-American Cultural and Social Organization, Inc. (HACSO) is a small multipurpose social services agency operating in a three county area of southeastern New York which has become the home for many persons of Haitian heritage.

Native-American Community Services of Erie and Niagara Counties, Inc., a social services agency in the two-county Niagara region of Western New York, specifically aids Native Americans from the Seneca Nation.

What Did We Find?

The project provided a wealth of information both about households in which an adult with a developmental disability lived and the approaches and experiences of the participating agencies.

Findings About Households

Over the course of the two years of the project, the 13 participating area agencies on aging and four not-for-profit cultural organization agencies identified over 300 families in a variety of situations.

Interestingly, less than half of these families were already linked to the state's registry system, meaning that over half of the families "found" were unknown to developmental disabilities providers.

The statedevelopmental disabilities agency's registry system showed that there are about 3900 families statewide for-mally known to "the system" caring for an adult age 35 or older (the criterion group for this project). Of these families, about 63% were caring for a member between 35 and 44 years of age, 33% were caring for someone between 45 and 64 years of age, and about 3% were caring for someone age 65 and older.

Among the households we identified, typically the primary carers were elderly women who had a son or daughter still at home and who were isolated or divorced from any formal connection with the developmental disabilities system. Yet, we also found fathers, siblings, and other relatives who were functioning as primary carers. In addition, neighbors and members of extended families frequently served as major supports. All had one thing in common - they were in a caring role and because of some problem, issue, or situation, needed some type of help.

Many of the families were wary of becoming involved with the State's developmental disabilities offices or other developmental disabilities providers. They expressed fear that if they did, the State may interfere with their lives, and even come and take their son or daughter away from them. Some still harbored resentment over a lack of supports from the State when they were younger age parents. Yet, we found that these families were often willing, to accept services from the AAAs -- a resource not identified with the disability system.

We also found instances when families previously unknown to the system wanted disability agency services, they experienced great difficulty getting them because their aging son or daughter had no documentation of a developmental disability. Thus, this disengagement from formal services proved to be an additional barrier to the receipt of wanted services.

The amount of assistance required by families varied. Many families were faced with serious problems stemming from some crisis or series of crises that engulfed them. Some of these crises threatened their housing or financial resources. Others had to do with diminishing health or illnesses that disrupted the family's equilibrium. Not all of these crises were linked directly to the adult with a disability - they were often just part of the family dynamics and the family's difficulties were their difficulties.

We also found families who were having difficulties providing continual care for members who were now an adult child - some of whom were multiply handicapped. These families were becoming overwhelmed by the combination of continual care and problems associated with their own aging.

Outcomes

It became increasingly apparent during our project that maintaining the "family" or household represented an important safety net for the person with a disability *and* for the other family members. Without the intervention of the AAAs, we would have seen many more referrals for crisis care and residential services to the local developmental disabilities system.

Findings About AAAs

The project gave us new insights into approaches that can be undertaken by AAAs to reach out and serve households caring for someone with a disability, as well as the mechanisms that they need to employ to carry out such initiatives.

The most important findings were that *(a)* AAAs could be called upon to successfully undertake initiatives targeting older carers of adults with a developmental disability; *(b)* to be successful at such an effort requires close cooperation between the AAA and its local disability agencies; and *(c)* some families require a degree of casework that most AAAs are not prepared to provide without additional resources.

Unequivocally we could say that when the effort was given the full attention of the AAA and a staff person was assigned to the initiative, the AAA could undertake and successfully carry out initiatives targeting such older families.

Where we observed difficulties in AAA undertakings, we could attribute them to a misassignment of staff or inattention to the initiative by staff assigned. We also observed varying degrees of involvement in terms of outreach and casework, but this was usually a function of how the AAA invested itself in other activities.

Some participating AAAs reported difficulties in building cooperative relationships with local disability agencies. Staff reported to us that they hadn't done any networking with their local disability agencies. Others noted a strong sense of competition and territoriality from the disability agencies in spite of their efforts.

Still others were told by their local disability agencies that there were no more older people to be "found" and that they saw no reason to cooperate. AAA staff reported that in retrospect they would have done much more initial bridge building and would have worked harder to draw the disability agencies into the planning and execution of their local projects before they began the initiative.

We found major variations in how involved the AAAs were in providing casework. Some of the AAAs had excellent working relationships with their state district developmental disabilities offices. They passed most of their referrals on to these offices. Others, while connecting with their local developmental disabilities offices, found that they ended up doing all the casework and providing all of the supports themselves.

Most area agencies on aging added or reassigned someone on their staff to perform a variety of functions, such as outreach, community education, information and referral and casework. Generally the support grants we awarded bought about two days a week of someone's time to be solely dedicated this effort. Most of the funds were used for salaries and non-personnel expenses (such as travel, printing, workshops, supplies and the like).

The approaches taken by the participating AAAs to find and aid household members could be categorized into three main designs. The first is a direct operation approach, the second is a contract operation approach, and the third is a multi-organizational approach.

Direct Operation Approach

Here, the AAAs essentially undertook the initiative within the operational capacities of their own organization - they did it themselves. With one exception, all were branches of their county government. The exception was a contract agency in the county specifically chartered to be the county's AAA. These AAAs were mostly located in rural or less densely populated areas of the state.

The following AAAs used a direct operation design: Cattaraugus, Dutchess, Fulton, Madison, Niagara, Orange, Tompkins, and Westchester Counties.

Contract Operation Approach

Here, the AAAs contracted out the function to a not-for-profit service agency or coalition. Both the Monroe County Office for the Aging and the Onondaga County Department of Aging and Youth are large government organizations that traditionally contract out AAA activities. They are located in densely populated counties, each with a major city.

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The AAA in Monroe county contracted with Lifespan, Inc., a local aging services agency with extensive experience serving families and older adults with developmental disabilities. The AAA in Onondaga county contracted with Exceptional Family Resources, Inc., a general family services agency. The Oneida County Office for the Aging, located in a mostly rural area, contracted out the function of outreach and information dissemination to a local aging and developmental disabilities coalition.

Multi-organizational Approach

Here, the AAAs participated in a cooperative multi-AAA endeavor that was organized and coordinated by the regional developmental disabilities authority. The "Tri-County Project" used an interventionist model with the Letchworth Developmental Services Office of the OMRDD as its central organizing component.

The regional developmental disabilities agency donated a quarter-time senior clinical administrator to coordinate the activities of the three AAAs with relation to this project. The coordinator relied upon several graduate level social work interns to help in the regional effort. The students were placed in the participating agencies and functioned as ancillary staff.

The three participating AAAs worked cooperatively to share outreach and information and referral resources, while each did its own casework or household assistance. One AAA, the Orange County Office for the Aging was also part of the state funded project which began before the federal project and thus started its project under an direct operation approach, but later became incorporated within the multi-organizational design.

Two of the counties did their own household follow-ups when they became part of the federally funded project. The third (Orange County) had previously contracted out its casework to an independent caseworker and continued to do so. It did this because it had a carer resource center that was already doing casework and it felt that by going outside, it could devote more casework time to the households identified.

These AAAs conducted efforts within this approach: Orange County Office the Aging, Rockland County Office for the Aging, and the Sullivan County Office for the Aging.

Outcomes

We observed that the AAAs generally chose the approaches that best fit their organization style or population base. The direct operation approaches were successful in rural or small AAA operations where a small number of personnel were present, yet all were quite familiar with the area's population and resources.

In larger areas the contract operation approach worked well as it both conformed to the organizational style of the AAA and permitted specialized agencies to undertake the functions with which they were more familiar. In the one large AAA where a direct operation approach was tried, it was not successful.

In retrospect, the AAA staff told us they would have undertaken a contract operation approach if they could have anticipated the problems they eventually encountered.

Findings About Cultural Organization Agency Approaches

The approaches adopted by the participating cultural organization provider agencies could be characterized as a combination of outreach and case assistance. All of these agencies undertook efforts to let their constituent community know of their project, conducted targeted outreach among older families in their immediate community, and when a family connected with them, attempted to provide casework and other assistance.

The degree of casework varied depending on the extent that they normally provided such casework or family assistance to other families.

Miracle Makers, Inc., the agency serving in large part African Americans, used an age-peer model approach to find households. They assigned two grandparent volunteers the responsibility for outreach, case finding and counseling for about a dozen households.

Many of the carers these outreach workers found were grandparents or great-grandparents, some of whom were caring for several generations of children and adults with a developmental disability in their home.

The CAPC, Inc. used various media to locate Chinese American households in the Flushing section of Queens, New York. Linked to their senior center in Flushing, this agency focused its efforts on case-finding and direct casework with a group of Chinese households.

The CAPC, Inc. used Chinese language media, such a local radio station and newspaper, as well as broadsheets from the local senior center to inform the Chinese families in their area of their services. They were successful in locating a significant number of families and eventually incorporated the older carer component as a permanent part of their agency.

HACSO, Inc. targeted households of Haitian heritage. It sought out a number of households within the area of the “Tri-County Project” and developed and conducted a needs assessment for Haitian households through word-of-month and a community involvement process. HACSO, Inc. also provided needed casework and brokered services for the Haitian families in its network.

The agency serving Native Americans, NACSENC, Inc., used a number of techniques. These included outreach in local beadwork classes, their food pantry, and a monthly elders dinner program, to identify older families in which the carers needs could be met by supports pro-vided through its social services component.

Outcomes

We observed a great deal of enthusiasm and receptivity by the cultural organization provider agencies to the initiative. They were pleased that they could undertake a project that was directed at some of their older clientele and to do it in a way that was consistent with their cultural norms.

What was most telling was the variety of caring situations we uncovered. The participating agencies quickly validated the contention that there were many older parents or other kin members in caring roles for both children and adults with a disability. In many instances, these carers were previously unknown to the agencies as caring for someone with a disability.

We observed that when they did find members of their culture who needed assistance because of care responsibilities, these carers usually wanted the services delivered in the context of their cultural values and attitudes. Among some of the parents, there was also concern about the use of services that were provided outside the context of their culture.

For example, when it was suggested to one community group that a day services program for seniors with a developmental disability was available not too far from their neighborhood, they very quickly pointed out to us that it was not of their culture and that their older parents would never consent to using it for their adult sons or daughters. They are now developing their own seniors program, which has the full support of the families.

Commentary on Key Findings

Our primary research question was whether it was feasible for AAAs to undertake an initiative targeting older carers of adults with a develop-mental disability. Our secondary research question was whether we could identify sufficient diversity in culture-dependent outreach approaches that would warrant special efforts by AAAs to support direct outreach and casework by cultural organization agencies.

With regard to the primary question, we found that the area agencies on aging could, for very little money, provide a safety valve for potential crises that otherwise would have resulted in immediate placement demands and referral to potentially more costly day and residential programs within the developmental disabilities system.

Thus, we found that it was feasible for AAAs to incorporate targeting older families caring for an adult with a developmental disability into their day-to-day activities and that this effort was fiscally productive for the area as a whole.

This lead us to recommend to AAAs that they consider initiating such targeted efforts with the cooperation (both fiscally and programmatically) of the area's disability system administration and provider agencies.

With regard to the secondary question, we found that the manner of approach and entry into households around the issue of disability was culture-dependent and that workers from the same cultural group had greater ease of access and assurance of family responsiveness.

This lead us to recommend to AAAs that targeting of outreach and casework toward cultural groups found within the AAA might be made more effective by sub-contracting such activities to cultural organization agencies.

General Commentary

Among the diverse cultural communities the project included, there have historically been low levels of utilization of formal services. Yet a most striking finding among the cultural organization projects was that pressing needs did exist for many families and, when services were offered by agencies in their own communities, they were willingly accepted.

This increased willingness to accept services appears to be attributable to *(a)* greater ease of access - local agencies were often open on evenings and weekends; *(b)* services were offered in a culturally sensitive manner, in one's own language and on one's own terms; and *(c)* local agencies were more likely to respond to the needs of the family rather than specific individuals.

Among the outcomes of the AAAs' efforts, we found lessons in *organiza-tional responses*, *networking efforts*, *family issues*, and *system effects*.

First, in terms of organizational responses, we observed a strong commitment to this effort on the part of the AAA officials. They recognized that the older parents they were finding were an integral part of their natural constituency, but they also recognized that they did not have sufficient resources, without additional help, to do the extensive type of outreach and casework they found these families needed.

Yet, we found that for very little investment the return proved to be sizable. Not only did this effort get about two days a week of a staff person's time (on the average), but also it also got all the other services the area agency on aging was offering to other older people.

When the AAAs got involved with direct aid to households, most of their assistance was centered on help with securing federal assistance (many families were ignorant of their eligibility for SSI and Medicaid), help with getting respite or transportation, or help dealing with needs related to home weatherization, heating assistance, or obtaining access to meals programs, legal aid, or other senior services.

Second, in terms networking, we observed that in some communities, well-oiled networking had taken place, yet in others there was a seeming lack of communication or networking. This was true even *among* local developmental disabilities agencies and *between* the develop-mental disabilities and social services agencies. Because of this, agencies helping a carer were not always able to refer the carer to the most appro-priate services.

Third, with regard to the families, we observed that the AAAs identified a significant number of families heretofore "unknown" to the disability agencies. The fact that such an unknown population exists is something that needs to be taken into consideration by AAA planners and administrators when developing local AAA plans and developing new initiatives.

Another lesson is the nature of the problems faced by the families that were identified and the investment necessary to provide an adequate level of help. In some cases, the outreach worker's willingness to work with families was not enough. Some problem situations were so complex that the worker became overloaded.

In others, we found that external factors impinged on the worker's ability to help the families. When the projects began the state was making available funds for family support efforts. In the final stages of the project, state budget difficulties meant there were more restrictions on the use of funds and less availability. This, coupled with the complexity of some of the problems faced by certain families, lead to unrealized assistance in some cases.

We observed that most of the families wanted to remain in place and most of the adults wanted to remain with their families. Both wanted some help to make their lives that much better. We also found that many of these families had not planned for the future. We found this to be an area needing further atten-tion. Indeed, several of our projects locally run “parents workshops” on financial planning drew the biggest response.

If planning did occur, it was more of the day-to-day variety. Yet, we couldn’t help but think that some of this “lack of longterm planning” may have been influenced by the fragmentation of case management services and the waiting lists that have confronted older carers. Many had not been seen in years and were not getting information about their options. Thus, they were not getting help with making informed decisions.

One concern many raised was that the “system” now is much different than the one they knew many years ago. To navigate this new “system” was frightening and off-putting.

Fourth, in terms of system effects we observed that AAAs often ran into difficulties when referring some older adults with a disability because the adults had not undergone a diagnostic evaluation at some point in their life, and thus had no documentation of a developmental disability. Consequently, the AAAs often had to do their own investigations into the individual’s past to assemble the documentation that would satisfy the developmental services agency.

As a result of this project, the state developmental disabilities agency accepted the notion of “presumptive eligibility,” acknowledging that many older adults seemingly lacked formal documentation of a developmental disability and accepted *ad hoc* case summaries prepared by AAA workers as sufficient basis for eligibility.

We also observed other system-type problems, not easily rectified. In several of the project sites, workers encountered situations where older parents could not live at the residence they chose because the residence’s administrator would not permit them to bring along a daughter or son who depended upon them. Conversely, we found a lack of willingness or inability for residential programs for adults with a developmental disability to permit a parent to come and live with their son or daughter.

We also observed "turf" problems. In the developmental disabilities system funds are normally tied to persons. Therefore some disability agencies were reluctant to support more open referral approaches because they feared losing their fiscal resource base. This type of “hoarding behavior” is problematic because it indicates that decisions about people in service may be made on the basis of retention of fiscal resources and not on the welfare and betterment of the individual. While this type of agency behavior was not pervasive, it did occur.

It was evident from our interviews that many of the local developmental disabilities offices did not have the resources to provide for families in caring situations, and when they did get involved, they focussed primarily on the older adult with a developmental disability. While this addressed one need, it did little to support the whole family.

Lastly, of all the observations we made, probably the most valuable one was that older families needed time to become acquainted and comfortable with services. Workers talked about the importance of "making time" for these families, but acknowledged that most agencies usually couldn't dedicate that time. Yet, what we heard over and over was

> *"listen to the families, be there when they need help, and don't promise what you can't deliver."*

Impact of Future Trends

A number of system factors will effect how many more families will be in need of or desire aid with the support or transitioning of their son, daughter or other relative. These factors will include

- more families aging while caring for a family member with a developmental disability
- more multigenerational caring (for example, grandparents caring for grandchildren with a developmental disability) and more household caring (where not only the mother bears the responsi-bility for caring, but others in the household do so as well)
- more families from diverse cultures who will continue to challenge providers to design services useful for them
- more aged carers experiencing health problems, loss of helping spouse, and cognitive dysfunction
- more families who have experienced a richer array of services and supports over their lifetime, and who, as they age, will be much more sophisticated and demanding in their requests for assistance

Given that waiting lists already exist, expectations that the numbers of households with an older adult with a developmental disability will continue to grow has encouraged a perception in the developmental disabilities system that outreach to families and carers will adversely impact caseloads that already can't be managed.

Our carer project found the opposite to be true. Outreach and assistance to families and carers may instead prevent adverse impacts on caseloads for a number of reasons, including

- most aging carers are not looking for the developmental disabilities system to take over caring -- we found that many older carers want to keep their son or daughter with them for as long as they can
- most of the older carers we encountered needed only a little help from time to time, to continue the care they want to provide
- most carers are willing to become involved in planning for the eventuality that their son or daughter will be living elsewhere and thus, if offered viable and realistic alternatives, will participate in the "launching" process
- most families from "minority cultures" are more than willing to be helped by local cultural provider organization agencies rather than mainstream agencies and thus will not impact generic services

In the end, we strongly believe that when you assist an aging carer, everyone benefits. The help provided can avert crises and keep the family intact. It can also help adults with a lifelong disability plan their own future and make a planful transition from their family home, if they so chose to do so.

We found that staff resources can be conserved and monetary resources can be preserved for when they are most needed. Contact now with families will permit timely consideration of more independent and therefore less costly options for services in the future.

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Appendix

Essay - The Lost Generation

by Nancy Breitenbach

Sample Outreach Materials

- Demonstration sites
- From the sites

Tear Sheets

- Reading resources
- Environmental modifications
- Some common terms and acronyms
- Model carer support group
- National associations & organizations

Note to Readers: These appendices have been abridged since some of the original matter was dated and some was not saved in electronic format. Copies of the original appendices can be obtained from The NFCSP Project, Richardson 280, 135 Western Avenue, University at Albany, Albany, NY 12222.

The Lost Generation

By Nancy Breitenbach[1]

In every country where people with developmental and psychiatric disabilities are enjoying a longer lifespan, this new phenomenon is generating a number of consequences:

- a certain perplexity among professionals with regard to the aging process itself, since service providers working with people who are disabled have had little experience with older adults;

- a progressive realization that services designed for younger people may not be adequate or appropriate for older individuals;

- a growing concern with the type and quality of services offered to elderly citizens in general, brought to light especially when integration into services for the aged is suggested for older people with mental or physical disabilities.

These issues are essentially related to the field of organized services. Greater longevity of people with developmental disability has also spotlighted other situations, in particular that of elderly caregivers (primarily mothers) who, after providing care for up to twice the normal childraising cycle, continue to provide it on a daily basis. Women who are great-grandmothers are still responsible for "children" they brought into the world shortly after World War II. Moreover, they expect to carry on until they drop.

Planning for the future of these caregivers as well as that of their offspring is a growing concern in a number of countries, where the needs expressed may be influenced by cultural factors. But these variations are secondary to some universal issues. Despite the fact that often they have ensured their child's survival singlehandedly (perhaps because they have assumed this task singlehandedly), elderly caregivers and the middle-aged adults with developmental disability who have remained with them at home, have been largely forgotten. Only recently have we begun to rediscover what the lives of those who belong to this *"Lost Generation"* are like.

Early awareness of the problem goes back to the 80's, when several American articles on elderly caregivers were published and the film *"Best Boy"* won an Oscar. In Europe, I first described in 1989 the inextricable psychological dilemmas of parents who, after providing years of affection and home care to an adult with a developmental disability, find themselves faced with the prospect of residential placement. Jacques Rio, in his longterm study of the parallel aging process in employees of a sheltered workshop employees and their parents, also referred to deepset parental resistance, suggesting that some elderly caregivers were compromising their offspring's future by not accepting residential placement when offered.

Since then, other studies have come out and a French video tape on the subject has been produced.

An urgent concern

This growing interest is becoming an urgent concern because the Lost Generation is fast running out of time. Each year makes it harder and harder for elderly parents to cope. Each year probably makes it harder and harder for their adult offspring to find appropriate services or adapt to a new lifestyle. The everpresent specter of an aged caregiver's sudden disappearance makes it necessary to plan now for the imminent future. And yet, if and when approached with offers of support, these families express ambivalent if not negative attitudes towards what social services have to offer.

From observing behaviors to understanding them

The challenges faced by elderly caregivers and their coping strategies can vary considerably. There appear to be a number of basic human responses which crop up consistently, regardless of the country or the culture where researchers have sought to make contact with the Lost Generation. Diane Serneels, for instance, has described different levels of parental behavior in terms of active and passive response: those who overtly seek solutions; those who think about the future but can't bear to talk about it though this may be necessary for their plans to materialize; and those who totally avoid the issue.

Such responses are important to recognize. However we must dig a bit deeper, if we want to help caregivers take concrete action, if we hope to defuse unconstructive reactions. Practitioners need to concern themselves not only with

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how elderly caregivers act, but with the motivations behind their actions. Policy-makers need more than figures on how many families avoid future planning. In order to implement effective policies, they need to know what has caused, and continues to cause, the particular attitudes adopted by the members of the Lost Generation.

Why have these families gone underground? Why do elderly caregivers find it so difficult to let go before the situation degenerates? What prevents them from ensuring against crisis placement by designing alternatives in a timely manner?
To find out, we need to go back in time.

The visible tip and the rest of an iceberg

Until recently, the caregiver problem which caught the attention of social services and advocacy associations, has been that of unmet demands for children and young adults with disabilities as expressed by their parents. These militants tend to be educated people who know how support systems work and have insisted on accessing available services or getting new ones created.
In response to their repeated requests, public agencies have tended to increase the number and size of standardized services, aimed at those who already know the ropes.[2]

In contrast most elderly caregivers, whose career in disability began before the advocacy movement got off the ground, have rarely benefited from it. They have not kept up with the System as it has evolved over the past 30 years. They may lack the education necessary to understanding how it works, or the confidence needed to knock on the door. Thus those who did not gain early entry into the network, or who have remained on the fringes, have considerable trouble getting in at the end of their lifetime. They and their offspring have never been at the right place at the right time.

This situation of "haves" and "have nots" has finally revealed the numerous and acute problems confronting older caregivers who, throughout their lifetimes, have been on the outside of the service network, looking in, and who tend to remain there. Those who have asked but never received, may have had no choice in the matter. But others appear to hold back, deliberately remaining silent. So the problem is not simply one of short supply. It's also a question of non-demand.

Ambivalent attitudes

Apparently a significant number of elderly caregivers are unaware of contemporary support opportunities. But their attitudes towards services are just as important in determining their behavior, for example those who do not feel right about requesting services, those who do not want them, and those who can't quite make up their minds.

Elderly caregivers may have very mixed feelings about their future and that of their adult child. A number of older parents formulate frank requests for services and then back off at the last minute. Others hedge their bets, calculating how long their strength will hold out, assuming that they can send their dependant child to a good residential service at any time. Some elderly caregivers push their ambivalence to great lengths, for instance parents who have pioneered the creation of advocacy associations and residential homes for other peoples' children, but have insisted on keeping their own adult son or daughter at home.

Ambivalent attitudes are testimony to caregivers' internal conflicts, conscious and unconscious, about what could or should be done for their offspring, and what is nevertheless best for themselves. Separation is not necessarily their ideal.

Familiar environments, intertwined relationships and interdependence

When given the choice, most older caregivers prefer in fact to keep the disabled adult within the family environment. Diane Serneels' work shows that passive responses were present in 50% of the families interviewed, despite the fact that age and frailty were gaining on them all. This may say something about their perception of service provision and their ability to plan ahead. But it also says a great deal about the strength of family ties.
The lifetimes which elderly caregivers and their dependant children spend together may mean that they have become locked into set relationships, leaving little room for growth or exterior investment for any of the parties involved. Despite their restrictive aspects, these set relationships provide security.

Families who have survived the birth and infancy of an individual with a developmental disability, and developed the strategies for living which have allowed them to function without a break for years and years, have also developed the art of self-maintenance. They don't let each other go that easily. However cramped it may be, any nest occupied for an entire generation or more is hard to leave.

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[2] For example, every year in France brings new and glossier sheltered workshops and group homes, including a small but growing number of special retirement homes for older people with developmental and chronic psychiatric disabilities. But few have been able to obtain this type of placement. Those who gained admission 10-20 years earlier age in place, rather than give up their place to someone else. Moreover, access to specialized retirement homes is generally offered to individuals who have been clients of the service network for a number of years and whose new needs, due to age, require adapted services.

Moreover, the relationship may have evolved in such a way that letting go becomes extremely complicated.

Just as the shape of the nuclear family (father, mother, children) has evolved in many countries, families which have consolidated around an individual with developmental disability, have probably modified the standard configuration. The classical scheme of adults who provide and dependants who receive, has gradually grown into something else which is not always easy to define. For a number of years the person with a disability leaned on the caregiver who was able. In general this continues to be the case. But with time, the balance between strengths and weaknesses in each member of the family is likely to have shifted. At some point in time, the grown son or daughter has become more than a child.

Whether or not they head single-parent families, mothers remain the primary caregivers. Their longterm relationship with the disabled adult sitting at the kitchen table may have turned into something resembling that of an old couple: two people who rely on each other for company, each providing someone to talk to, someone with whom meals and activities can be shared on a regular basis. They are "odd couples", experiencing together the aging process (old age on the one hand, middle age on the other). Such dyads are particularly visible when a widowed mother finds herself alone with her middle-aged son. What woman wants to be widowed a second time?

Some elderly parents' identities are still tied up in the satisfying rôle of nurturer, but increasing age can bring about rôle confusion. Frail parents may find themselves physically less capable than their "dependant", in which case the family hierarchy becomes blurred. Rôle reversal may occur if the dependent individual turns out to be the breadwinner[3], especially if he/she knows it.

Some isolated caregivers may even require their offspring's presence in order to keep going. Having the person there everyday provides a reason for living, emotional support, social interaction, even indispensable household assistance if the adult child helps with arduous tasks or shopping. It is even suspected that in some cases, yet to be numbered, the "dependent" person becomes a caregiver in his/her own right, providing personal care to an elderly parent who cannot function alone either.

In another scheme, intense personal attachment, concentrated on only a few individuals over many years, may generate relationships reminiscent of the life-threatening ties joining Siamese twins.

To sum up, complex family relationships can result in a more or less advanced state of mutual dependence. Outsiders may judge these situations as being less than ideal. But no matter how problematic or tenuous these strategies for living may appear to others, they have proven to be functional within the given family ecology.

Each party involved, parent and child, has something important to lose if the tight-knit structure is threatened. The sudden disappearance of one member or the other, due to death or brutal decisions made by third parties, can be a devastating experience. Awkward or aggressive attempts to pull apart the intricate ties may make the knots draw even tighter. If the family unit is sliced open like a Gordian knot, only shreds remain.

The challenge, then, is to discover where the ties lie, to recognize exactly what they hold together, and to find out how to ease the way open.

Fundamental distrust due to past experience

Another level of reticence, best defined as cultural and historical, can add to elderly caregivers' apprehensions.

The Lost Generation is a cultural group in itself. It is represented not only by elderly caregivers tucked away in rural areas and working class neighborhoods, but also by caregivers living in homes where people sit on Louis XIV chairs. What characterizes this group, beyond their age-group and the presence of a disabled person in the home, are memories of a certain era and a particular set of references.

Most elderly caregivers are not in touch with contemporary channels of information concerning disability. They actively resist the idea of placement because of a fundamental distrust of social services, having assimilated and retained the predominant ideas of their culture and/or generation, when:

- the presence of a child with mental retardation probably meant a stain on the family, someone to be kept out of the public eye;

- religious affiliation may have meant specific attitudes towards the disabled child, who represented an Innocent Lamb to be cherished or a Cross to bear;

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[3] It is important to remember that the Lost Generation is largely comprised of retirees, whose set income may have lost ground because of inflation. Widows who never pursued careers beyond that of wife and mother, may be living at the subsistence level since their allotments are based on what their husband earned decades earlier (a significant proportion of the people living under the poverty line are elderly women). In such cases, the disabled person's contribution is essential to the overall budget. Thus the caregiver becomes financially dependant on the person cared for, and he/she may plunge into a state of destitution if ever this income disappears.

- living conditions in special institutions of 50 or 60 years ago were rather poor, meaning that less than perfect children were better off (if not more likely to survive) if discreetly guarded at home. Parents who lived through the Nazi era learned particularly well not to trust loved ones to social services.

- parents may have paid dearly for contacts with social services in the early years of special education, when professionals' attachment to certain theories made them quick to denigrate or dismiss;

- or caregivers may have tried to obtain services and been told too often that their child was still on the waiting list (the ultimate irony comes when they are told after 20 years of requesting services that their adult child has become too old to adjust to a new lifestyle). Longterm discouragement and scepticism have set in;

- and in any case, expectations for the disabled person's lifespan were short when the child was growing up so planning for the future has probably always appeared absurd.

The Lost Generation has also probably retained value systems which are out of sync with modern times, not to speak of contemporary bureaucratic techniques. Unlike the "Me Generation" of the 80's which looks out for Number 1, unlike the baby-boom generation whose vision of the world is determined by their experience of the prosperous 1960s-1970s, this generation lived through the Great Depression and several world conflicts.

Having grown up themselves and raised their children during an age when the values of family, devotion, self-reliance and frugality were considered supremely valid, their positive self-image may continue to require respect for these same values. Inviting elderly caregivers to surrender their offspring to strangers who "know better" and to accept public "charity", can mean asking them to abandon their values as worthless and to consider their years of commitment and self-sacrifice as wasted effort.

The fact that professionals are not aware of demanding that elderly caregivers give up the ideals which have given meaning to their entire lives, the fact that attitudes with regard to disability and the quality of services have generally improved, does not reduce older carers' deepest convictions. The historical attitudes and impressions they absorbed 40-50 years earlier still carry enormous weight. The past experienced by the Lost Generation continues to determine the present.

Conclusion

When considering the challenges confronting elderly caregivers, we should remember that we have challenges of our own to meet. We need to:

1) Learn to recognize and deal with the characteristic responses of older caregivers, when significant changes in lifestyle are proposed:

  - those who actively seek or await solutions saying, "What took you so long?"
  - those who plead, "Not just yet."
  - and those, unconvinced that what we have to offer is any better than what they already have, who answer, "Not on your life."

2) Learn to think in terms of human ecosystems rather than individuals, and to acknowledge the needs of all those who have managed to function together for so long.

3) Conceive of and provide responses which meet these various needs: flexible services which structure positive transitions, but also approach techniques which take into account the fact that whether caregiver or recipient of care, older persons find it difficult adapting to new, unfamiliar situations.

In other words, when reaching out to the Lost Generation, we need to care as much for the elderly caregivers' feelings and well-being, as we care for the older adults with a developmental disability.

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Videos

White Hair, Grey Hair - For information contact Ms. Nancy Breitenbach, Head of Programs for the Disabled, Fondation de France, 40, avenue Hoche, 75008 Paris, France

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