

Aiding Older Caregivers of Persons with Intellectual and Developmental Disabilities



**a Tool Kit for state and
local aging agencies**

Introduction

This tool kit has been designed as a result of three years of collaboration building workshops in 33 different states. It was made possible through a grant from the Administration on Aging to The Arc of the United States, in collaboration with the Center on Intellectual Disabilities, University at Albany, NY, and the Rehabilitation Research and Training Center on Aging with Developmental Disabilities at the University of Illinois at Chicago. Attendees at these workshops included: state and local aging agencies, state and local developmental disability agencies, family caregivers of individuals with intellectual and developmental disabilities, advocacy agencies, medical professionals and others who play a role in assisting caregivers and individuals with disabilities. The impetus of the workshops arose from the need to disseminate the latest information on aging and intellectual or developmental disabilities (I/DD) and to find ways in which agencies can collaborate to assist caregivers and care recipients maintain their family unit for as long as possible.

Although the workshops took place in very disparate geographic and political environments, there was consensus that agencies want new or enhanced collaborations, but require guidance about how to do so. This tool kit is an accumulation of the materials presented at the workshops along with a compilation of specific concerns and suggestions made by workshop participants. It is the authors' hope that the information provided within these pages will provide state and local aging agencies with the tools to reach out to form new, or enhance existing, partnerships with state and local developmental disability agencies.

Good reading!

The authors:

DiAnn L. Baxley¹, Matthew P. Janicki², Philip McCallion¹, Anna Zendell¹.

Contact information: Center on Intellectual Disabilities, University at Albany, Richardson Hall, 135 Western Avenue, Albany, NY 12222. Email: dbaxley@albany.edu Phone: 518.442.3791

Note ~ In this Tool Kit we use the preferred term “intellectual disability” (ID) rather than the historical term “mental retardation,” which many families and people with disabilities find offensive and which has fallen into disfavor. The term “developmental disabilities” (DD) refers to a number of conditions that first occur prior to or at birth, or at some time during the developmental period (until age 22), which result in a lifelong impairment in some life activity area, may continue into old age, and which often impede full independent function. Some, but certainly not all, of individuals with an intellectual disability may also be considered to have a developmental disability.

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1. University at Albany (New York)

2. The Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago.

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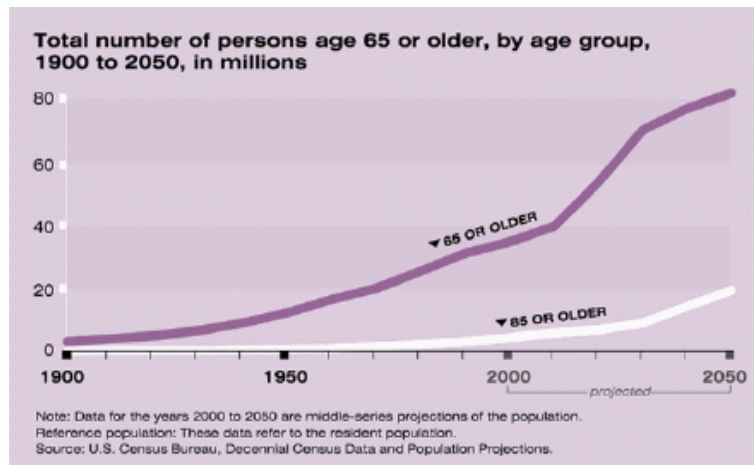
- I. Demographics, age-related health changes and other information about adults with developmental disabilities and their caregivers
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I. DEMOGRAPHICS AND OTHER INFORMATION ABOUT PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

DEMOGRAPHICS OF AGING POPULATION

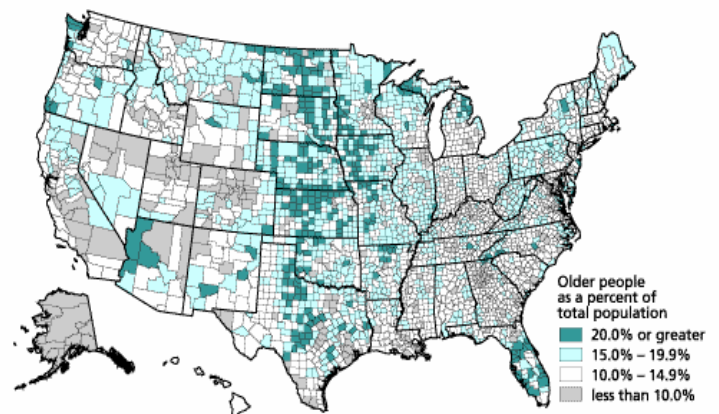
A growing number of statistics on aging support the premise that aging and developmental disabilities agencies need to be planning for collaborative efforts to support both the aging caregiver and the aging person with I/DD. The next several pages will provide an overview of the demographic characteristics and related phenomena of aging caregivers and care recipients.

1. There are 78 million “baby boomers.” (Baby boomers consist of individuals born between 1946 and 1964).
2. The number of persons age 65 to 74 will grow by 107% by 2030 – **65+ will be the fastest-growing age group.**
3. By 2020, 7 million persons will be 85+ and this number will double by 2040.
4. Boomers’ life expectancy has increased to over 70 – that’s 6 years more than their parent’s generation.
5. “Rule of thumb” estimates are that for every 1000 older adults age 60+, 4 to 5 adults have an intellectual or developmental disability.
6. Estimates are that there are some 9,000 adults with I/DD affected by dementia in the United States.



SURVIVING TO OLD AGE

Survival to very old age – living to 100 – depends a great deal on family genetics and environmental influences. Other factors include sex, income, physical activity, race and lifestyle (diet, etc.) *but up to a point*. If a sibling survives to old age, you will most likely also. Longevity is linked to absence of genes creating vulnerability for aging-related diseases (e.g., Alzheimer’s and cardiovascular disease) and presence of genes that slow the aging process at a basic level.



As the map indicates, the distribution of older people within the population shows great geographic variation. The same applies to older families or carers. **To find out about the numbers of older people in your area, contact the unit within your agency whose task it is to track statistical data.** Data is also available on the following web site: <http://www.aoa.gov/aoa/STATS/2000pop/default.htm>

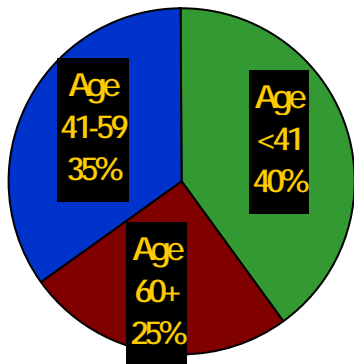
DISTINGUISHING CHARACTERISTICS OF PEOPLE WITH DEVELOPMENTAL DISABILITIES

The self-determination movement has helped de-myth beliefs regarding the abilities of people with disabilities. Understanding a person's abilities also requires knowledge of the areas in which they need supports. A person with a developmental disability may need very different types of supports, depending on the type and degree of the disability. It is important when working with individuals that support systems be highly individualized and designed to allow for the greatest amount of autonomy. Below is a brief overview of the characteristics of people with developmental disabilities. Also, highlighted below are topics important to supporting a person in the community.

DEVELOPMENTAL DISABILITIES (DD)

1. Are conditions originating at birth, infancy, early childhood, or during developmental period.
2. Pose hindrance to typical growth and development, impairing social, vocational & economic functioning
3. Are lifelong in nature, lasting through to old age.
4. Some 1.9 million persons with DD are estimated to live in their own homes or with family caregivers.
 - a. Some 25% of these caregivers, or 676,492, are age 60 or older (Braddock, et al., 2001; Fujiura, 1998).
 - b. A significant portion of in-home supports are being provided by family caregivers, who will be aging beyond their capacity to provide care over the next 10 to 20 years.
 - c. Estimates from studies show that approximately 50% of individuals with I/DD and their caregivers are unknown to either the aging or the DD service system (Janicki et al., 1998).
5. Expectations are that the 60+ age group with I/DD will increase threefold over the next 20 years.

People with DD living with family carers:



Estimates are that there are some 480,000 adults age 60+ living with family.

Some 665,000 are age 41–59 and their parents are 60+ .

Source: Braddock (1999)

PEOPLE WITH INTELLECTUAL DISABILITIES (ID)

1. Show below-normative intellectual functioning, due to cognitive impairment (organic or functional) present since birth or infancy.
2. Vary in degree and co-impairment.
3. Compensate by training, education, remediation, habilitation, supports for life activities.
4. Currently about 75% of all older adults with intellectual disabilities are in the 40-to-60 age group.

DEMENCIA VS. INTELLECTUAL DISABILITIES

1. Intellectual disabilities involve undeveloped or underdeveloped mental or intellectual skills and abilities.
2. Dementia is a widespread loss of mental or intellectual skills and abilities from previous level of ability.
3. Key – behavioral presentation may be similar, but it is the loss from previous level of function that differentiates the two.

CARERS OF PERSONS WITH I/DD VS CARERS OF AGING PARENTS - SOME THINGS TO CONSIDER

1. Families may be two-generation elderly families (this is where both the caregiver and the care recipient are 60 or over).
2. Parental roles may change due to retirement, illness, death.
3. Due to parent's declining health, caregiver roles may reverse with the adult with I/DD taking over as carer for the parent/s.
4. Succession planning is important. Will a sibling or another "key person" take over as carer for the person with I/DD, and perhaps even the aging parent or family member.
5. Self-determination (who's in charge?).
6. Families often face such complex problems as succession planning, lack of ability to retire as peers do, loss of social life because of continued caregiving role, own declining health interfering with caregiving ability..
7. Vagaries of financial resources- that is, the unreliability or unpredictability of public funds underpinning any support effort.
8. Household composition and carer relationships. In many cases a caregiver of a person with I/DD may also be caring for a spouse or a grandchild as well. In some cultures you may also find multiple family households living under the same roof and sharing caregiving roles. It is important to be sensitive to, and honor, these family compositions.
9. As the caregivers are aging, they will need gentle yet specific guidance on how to cope with and plan for the inevitable end of their caregiving role. Helping them plan will make all the difference in peace of mind and successful transitions for all involved.

COMMUNITY SUPPORTS - WHAT CAN AGENCIES PROVIDE?

1. Services that meet immediate needs (respite, housekeeping assistance, transportation, and emotional supports).
2. Help with getting financial supports or determinations of eligibility.
3. Help with obtaining financial planning information (such as information on entitlements, guardianships, and trusts).
4. Help with negotiating various service systems and advocacy for obtaining services for which they are eligible – including senior services.
5. Assistance with obtaining Medicaid and resolving problems with social services agencies.
6. Help with making decisions about their lives or the lives of the person for whom they are caring.
7. Environmental modifications to improve accessibility.
8. Counseling/support groups.

II. UNDERSTANDING THE STATE'S DEVELOPMENTAL DISABILITIES SERVICE SYSTEM

List adapted from New York State Office of Mental Retardation and Developmental Disabilities website:

www.omr.ny.state.us

I/DD Services

To understand your state's I/DD (known by mental retardation and/or developmental disabilities, *MR/DD*, in most states) service system it would be helpful to first understand some of the services that are offered. The following is a list of the services that state I/DD offices may offer through a variety of Federal and State funded programs.

After School Programs - are daily programs that provide time-limited, temporary care for individuals with disabilities after their school programs.

Ageing Services - is an extensive network of supports for senior citizens with intellectual or developmental disabilities (I/DD) that allow them to receive typical aging services as well as developmental disabilities services. Your state's I/DD system and its voluntary agencies provide senior day care, caregiver supports, and specialized residential supports. Service coordinators/case managers within the I/DD system can provide referrals to aging network services.

Autism Services - are person centered supports and services, in either day or residential settings, for persons who have been diagnosed with autism.

Camp/Recreation Services - are day, evening, weekend and/or overnight programs, which provide recreation, social activities, and needed care for persons with I/DD.

Case Management - which may also be referred to as "Service Coordination", provides for the development, implementation, and monitoring of a person's individualized service plan. This includes assessment, service planning, service referral, coordination, evaluation and advocacy.

Children's Services - includes caregiver respite on an overnight basis, after school, or school vacation basis; parent and sibling counseling; transportation; parent training; social work; advocacy services; recreation; and nutritional services.

Clinical Treatment Services - provide long-term habilitative services, such as outpatient medical, dental, nursing, physical therapy, speech therapy, rehabilitation counseling, social work, psychological, and psychiatric services.

Community Residences - provide a residential living experience. Many states may have 3 or more types of Community Residences (CR's) including:

1. Supervised: provide housing with staffing available 24 hours.
2. Supportive: provides assistance in independent living under varying amounts of oversight provided in accordance with the individual's needs. Supportive housing may be provided in a variety of independent housing choices offered to individuals with I/DD.
3. Individual Residential Alternatives (IRAs): provide a living experience including room, board, and individualized protective oversight.



Counseling – includes face-to-face, individual, group or family counseling or therapy in a planned, structured session intended to help an individual or family gain insight, resolve problems, develop adaptive behaviors or address other issues of concern.

Crisis Intervention - provides emergency intervention for people with developmental disabilities when they experience specific and time-limited problems that threaten to disrupt their residential or habilitation (services received that help with activities of daily living) situation.

Day Programs/Day Habilitation - include daytime activities that provide a combination of diagnostic, active therapeutic treatment, habilitative, and prevocational services to persons with a developmental disability. Such programs may vary in the services they offer based on the level of the individual's needs and his/her interests and preferences. A range of available day programs focus on providing the individual with developmental disabilities with the necessary personal, social and vocational supports needed to live a typical life in the community.

Environmental Modifications (E-Mods)/Adaptive Equipment Services - provide consultation and specialized equipment to enable individuals with physical disabilities or limitations to lead more productive lives (i.e., wheelchair ramps, lifts, handrails, etc.) This may require actual changes in the design or structure of an individual's place of residence to make it accessible to meet their physical needs. Environmental modifications to the home can often maintain the family unit for many years.

Education - provides information about various aspects of programs, services and/or diagnoses and treatment for people with I/DD.

Employment Services - are job-related supports for the individual, such as vocational training, job coaching, travel training, technological aids, counseling, job placement and any other support needed to meet the person's unique circumstances.

Evaluation, Intake and Referrals for Service - Individuals with I/DD and their families can apply for supports and services by contacting their state or regional I/DD office or voluntary agency that provides services through any of the state's funding sources. A staff person responsible for intake will then assist the person seeking services in identifying needs and service options. Linkages can be made to diagnostic, residential, habilitative, educational, vocational, medical and recreational services, and to entitlement programs such as Medicaid, SSI, HEAP, and Food Stamps.

Family Care - is a licensed residential program, which provides a family living experience through a structured and stable home environment, including the support, guidance and companionship found within a family unit. Family Care Providers receive a monthly stipend to provide services within their home or apartment. In many states these family care providers are often the individuals' own family thus helping to alleviate precipitous housing situations caused by financial burdens.

Family Support Services - is a family-directed, statewide system of comprehensive services such as After School Programs, Camp/Recreation Services and Respite Care which help the family's ability to provide in-home care to their family members with a developmental disability.

Financial Assistance – is assistance to families and individuals in accessing necessary aid from MR/DD and generic funding, benefits, entitlements, and other sources. It can also mean assistance to a family or individual in dealing with practical concerns, such as ability to handle budgeting, bill paying, major purchases, working with banking and checking accounts, and other monetary matters.

Forensic Services – Many MR/DD offices provide direct case consultation and assistance to both criminal justice and human services staff regarding persons with I/DD who are identified through the criminal justice system.

Some states may provide residential and treatment programs for people committed to MR/DD custody on an availability basis after being deemed by the courts as not competent to stand trial or not criminally responsible due to their I/DD.

Health Care - Although health care for people with I/DD is primarily provided by generic health care systems, many of these providers have health care professionals on staff with knowledge about working with individuals with I/DD. Some health care organizations may even have clinics that specialize in serving people with I/DD. Care at these clinics may include primary health, dental and vision care. Many have specialized equipment, such as adaptive chairs, to accommodate a variety of physical disabilities. These clinics and medical professionals specialize in working with persons who have a variety of disabilities. They may also provide an opportunity for care provision to the general aging system where there is a shortage of primary care physicians, or when there is a need for specialized care due to age related disabilities.

Housing - includes services that assist persons with developmental disabilities to locate, lease or buy, and access residential arrangements as alternatives to traditional congregate living situations. Such living situations may include shared or matched home-sharing, independent living, HUD rental subsidy programs (Section 8 vouchers), low income home ownership programs and other leasing and ownership initiatives. For a list of the various types of living situations available and their impact on the individual with I/DD and their carers see *Housing Choices* in the Resources Section of this manual.



Parent Advocacy and Training - provide support and education for parents of people with developmental disabilities.

Residential Service Options - are programs to provide housing and services and, when appropriate, overnight supports to individuals living in group homes. Either the state MR/DD or not-for-profit provider agencies operate these community residential programs.

Respite Care - these services provide relief for families or other caregivers of persons with developmental disabilities. Respite is time-limited and temporary, allowing families the needed time for errands, vacations and other planned activities.

Self Advocacy - enables individuals with disabilities to speak and plan for themselves regarding services offered to them. Many states have a state-wide self-advocacy association.

Transportation – many states have funding to provide an individual with the appropriate mode of transportation to and from his/her residence and day program services.

Volunteer Opportunities - help support the system of care for people with developmental disabilities in most states. Many state MR/DD not-for-profit agencies have collaborations with community businesses and organizations for volunteer services.

Waiver Services - provides a flexible funding system through the use of Medicaid dollars to make the following services accessible to eligible individuals: service coordination, residential habilitation, day habilitation, prevocational services, supported employment, respite services, environmental modifications, and adaptive technologies.

Negotiating the System

In the MR/DD system in the United States it is common practice for all individuals entering the system to be assigned a case manager. This case manager may be assigned at the state level, through a local state agency office, a not-for-profit provider, or a combination of state and provider agencies. Ask to speak to the director of the Case Management or Service Coordination Department when contacting your State MR/ DD agency for the first time. This should put you in touch with an individual knowledgeable of the services available to individuals with intellectual or developmental disabilities (I/DD) and their family carers.

Most State MR/DD agencies now have websites too. This is another good place to look for a listing of available services and programs. Should you not be successful locating the information you need by contacting a state staff representative, try any of the local not-for-profit provider agencies that offer services and programs for individuals with I/DD. Again, you want to ask to speak to the director of case management or service coordination. There are many such agencies in every state.

There are many good agencies out there that will be able to provide you with answers and assistance. Some of these are affiliates of The Arc of the United States, United Cerebral Palsy, Goodwill Industries, Catholic Charities, and Easter Seals, to name a few.

NOTE: If you are still having difficulty, contact your State Council on Developmental Disability. They should have the name and number of the contact person you need to speak with from your state MR/DD agency. You can find the contact information for your state at the following website:

<http://www.acf.dhhs.gov/programs/add/states/ddcouncils.htm>

III. OLDER FAMILIES' CAREGIVING AND FUTURE PLANNING NEEDS

Helping the Family Plan

Parents need to plan for their own future needs first. Many older carers have focused on their son or daughter's needs for so long that they have had little time to think about their own future health or retirement needs. Without proper planning for their own needs, these families will lack the time and resources to adequately plan for the future needs of their son or daughter with I/DD. The following steps can assist families and their relative with a disability in the planning process. There are many good resources out there to help parents in the planning process. See the *Future Planning Resources* section.

- Begin by having the parents write down their personal goals for retirement and long-term care. For many, this will be the first time they will give serious thought to these subjects.
- Estimate the cost of attaining their goals
- Have parents plan for their family member's future. They need to address at a minimum these questions:
 - Who will be there to carry out my and my relative's wishes?
 - Who has the competency to implement my plan?
 - Who has the information needed to perpetuate the activities in my plan?
 - Who will listen to and act upon my family member's wishes?
- Have parents develop a "wish list" for future care and quality of life for their son or daughter. Some examples for this wish list are:
 - A good place to live
 - Reliable & compassionate caretakers
 - Adequate private financial resources
 - Adequate government resources
 - Good medical & dental care
 - Friends
 - A healthy diet
 - Meaningful daytime activities
 - Opportunity to practice religious beliefs
 - Daily leisure activities
 - Appropriate transportation
 - Visits and contacts with relatives
 - Spending money
 - Holiday & birthday celebrations
 - Entertainment
 - Vacations
- Have parents prioritize both their needs and the needs of their son or daughter.
- Refer the parent and/or their son or daughter to the appropriate MR/DD service agency or local Department of Social Services.



A complete plan should cover the many aspects of an individual's life including residential, financial, life transitions, guardian or trust succession, social and family interactions, and hobbies or special interest groups. The plan is very much an asset management model and should look in-depth at all the support resources in an individual's life. The five key areas of support are 1) the person with I/DD, 2) the person's immediate and

extended family, 3) the state disability services agency and the not-for-profit providers, 4) other government agencies, and 5) community and natural supports, such as local businesses, and faith based communities or social clubs to which the parents or individual with I/DD may belong.

Some thoughts

Whether you have a lot of time to spend helping the older carer plan for the future needs of their son or daughter with I/DD or you are just a brief liaison stop for them, the important thing is to emphasize the importance of planning. If the family has not made contact with an agency that specializes in working with individuals with I/DD, then you, the agency providing senior services, may find yourself receiving the unfortunate "Friday afternoon crisis call" from another family member looking for an immediate residential placement for the individual with I/DD because the older parent has been hospitalized or has died. These crises are always more costly than the services provided through long term planning. To help alleviate many of these calls, work with your state or local I/DD agencies to design collaborative outreach strategies and activities to help older carers plan. *After all, GOOD planning will bring quality of life to all parties involved!*

IV. COLLABORATIONS -- THE KEY TO KEEPING FAMILIES TOGETHER

Older Carers whose Child or Older Adult with a Developmental Disability is Living at Home

Why form collaborations?

- The National Family Caregiver Support Program (NFCSP) mandates it. According to the Older Americans Act, states must give "priority for services to ... older individuals providing care and support to persons with mental retardation and related developmental disabilities ..." SEC. 373(c)(2) of the NFCSP (OAA).
- Many older adults with intellectual or developmental disabilities (I/DD) could benefit from special services such as nutritional sites for older adults, senior day activities, respite, in-home assistance, individual counseling, support groups, caregiver training and other activities.
- Many older carers could use the help of case management coordination, permanency planning, and assistance with access to services.
- Working together saves time, money and staff effort. For example: it can alleviate duplication of services or caregiver stress.
- Collaboration helps in planning for the future. For example: aging and MR/DD agencies could work together to facilitate pre-emptive planning strategies to avoid unnecessary hospitalization or institutional placement for individuals with I/DD in the event of sudden caregiver illness, establishing multi-use housing units, and sharing respite and transportation services.

Who should be the focus of your collaborations?

- Older caregivers caring for grandchildren or older adults with a developmental disability or related disability.
- Older individuals with developmental disabilities (collaborative focus of the I/DD agency).

What questions should you ask when collaborating to target older caregivers/grandparents and older individuals or grandchildren with I/DD?

- What are their needs and which are most immediate?
- What resources currently exist in your community to help people with I/DD?
- What are the disability and social services networks doing to help older adults with I/DD, their families, and carers?
- Can the Area Agency on Aging interface with existing collaborative efforts, or spearhead the initiation of a new effort?
- Are there areas within the two systems where resources could be blended to eliminate duplication of services and/or stretch resources so as to meet the needs of more families?

What information should you know before getting started?

- How many individuals with I/DD (and families) are in the catchment area?
- What are the most pressing needs of the adults/grandchildren and their families?
- What existing services are there and what are they doing for this group?
- What collaborations already exist?

Approaches to Collaboration

Informal approaches - Networking, Task Forces, and Coalitions

Networking

Why use informal approaches?

- Informal approaches can help
 - Identify a critical mass of interest.
 - Build a constituency that will be able to lend support, influence and help when necessary.
 - Open “the door to opportunity,” generating activity and results.



What things can be done together?

- Working together to target local services for age 60+ adults with I/DD.
- Shared outreach to locate and help older families.

Where to organize?

- Within locality.
- Within region (counties, administrative districts, catchment areas).
- State-wide.

How do we begin?

- Identify a critical mass of interest -
 - Who are all the agencies in your area that work with these populations?
 - Are there local businesses that offer special incentives or volunteer programs to help the target populations?
 - Are there resource materials already in existence to give out?
 - Are there strong advocacy groups in your region?
- Build a constituency that will be able to lend support, influence and help when necessary -
 - Acquire informal agreements with the above groups to work together or offer support on an as-needed basis.
- Open “the door to opportunity”; by dialoging with the above groups, many doors can be opened.

What is the difference between networking, task forces and coalition building?

Networking

- Is used when you need to gather information about each others' programs for referral purposes.
- Is a learning process that hopefully leads to task forces and coalitions.
- Is a great way to share resources (e.g. information and assistance).

Coalitions

- Building coalitions occurs when agencies share common concerns or needs and are unable to find resolution on their own, such as:

- The need for comprehensive information for families.
 - The need for an accurate services list in your community.
 - Concern over inadequate discharge planning from the hospital for the carer or the person they are caring for.
- Brainstorming is a frequently used tool during these meetings to generate ideas for activities that lead to results.
- To build a coalition you need to:
 - Define who should participate.
 - Call a meeting.
 - Gain consensus on needs, issues, and approaches.
 - Motivate participation and action.
 - Meet, follow-up, and encourage.
 - Lead and oversee.

Formal Approaches

Coalitions and task forces defined

Coalition - a temporary alliance of distinct parties, persons, or states for joint action.

Task Force - a temporary group under one leader convened for the purpose of accomplishing a definite objective.

Why build formal coalitions or task forces?

- Formal coalitions work best when there are policy, programmatic, or legislative changes to take place – some examples are:
 - Changes in state guidelines to allow for a blending of interagency service funding sources for older carers and their son/daughter with a developmental disability – this will help negate duplication of services in the same household.
 - Opening up senior day service programs to aging individuals with I/DD
 - Note: A formal agreement detailing the responsibilities of each agency is strongly advised.*
 - Shared transportation, home health care resources, casework, etc.
 - Shared housing & housing assistance.
- Building formal coalitions or task forces -
 - Define who is to be at the table.
 - Ensure that participant has the authority within the agency to make decisions and enter into agreements as a representative for the agency.
 - Define mission statement and goals for the task force.
 - Gain legitimate charge for the activities (agency directive, law, etc.).
 - Gain commitments for involvement (if executive director/commissioner not directly involved it is a good idea to obtain an MOU [memorandum of understanding] from the agency head as to their commitment to participate).
 - Establish, at a minimum, verbal agreements from participants.
 - Establish a time table for carrying out activities – this keeps everyone on the same page.
 - Carry out the activities; decide who will be responsible for what .
- Advocate for legislation, policy changes, etc.
- State initiatives -
 - Work at the state level for change.
 - Designing plans that involve policy changes vs. legislative changes are much easier to gain consensus on.

- Define terms of plan of action clearly – need for policy change, cost savings of plan, added costs of plan, implications for long term benefit for individuals and public and private entities.

How do we organize a formal effort?

- Step 1
 - Bring I/DD and aging providers together.
 - Gather data on prevalence of older carers.
 - Determine what services/systems are already in place.
- Step 2
 - Decide how to enhance efforts.
 - Divide up responsibilities.
 - Secure agreements.
 - Set timelines for work completion.
- Step 3
 - Follow-up
 - Designate one or two persons to lead the initiative and to “touch base” with participants’ progress on assignments.
 - Establish future meeting dates.

Local organizing - Formally

- Gain legitimate charge for activities (agency directive, law, etc.).
- Gather planning data.
- Define who is to be at the table.
- Gain commitments for involvement (stakeholders should include consumer...older adults with I/DD, older family carers, aging and I/DD agencies and providers, community government, oversight agencies, advocacy agencies, housing and transportation representatives and any other groups or individuals with a vested interest).
- Establish agreements among actors.
- Carry out activities.

Who Takes the Lead?

AAA's may be 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, which may result in their outreach being more effective.
- Have a more neutral status in their community.
- Older families may perceive less of a stigma attached to getting aid from an aging agency.
- Some believe that many older and potentially vulnerable families will be less fearful that their child or relative may be taken away by an aging agency.
- Aging agencies may be better positioned to help, because many carers need aging related services.

Developmental 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 I/DD.
- Some believe that MR/DD agencies are in a better position to aid families and other carers because their purpose is to address the needs of someone with a developmental disability.
- 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.

In deciding whether AAA's or I/DD agencies will assume the lead role consider the following points:

- 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?
- Whom do families in your community perceive most favorably?
- Who is willing to do it?
- Who is capable of sustaining this level of effort?

Caregivers Aged 60 + With Care Recipients age 19 - 59

What can you do to help older caregivers whose care recipient with I/DD falls into the 19 – 59 age group?

The NFCSP currently disallows Federal funds to be used to serve older caregivers whose care recipients fall into this age group; however, this group of caregivers should not be overlooked. Early planning can help alleviate a crises situation and help with transitions as these caregivers and recipients age into qualifying status. Many states have found ways to provide outreach services to this group. Below are a few ideas.

- Use state dollars to provide services.
- Collaborate with state I/DD agencies to conduct joint outreach and senior programs
 - Some individuals with I/DD age earlier than the general population so many senior center programs would be appropriate for both the individual with I/DD and their over-60 caregiver.
 - There may be funding available for the I/DD individual to attend aging programs through your state's I/DD waiver program.
- Conduct cross-training programs on services and regulation for aging and I/DD staff.
- Develop joint task forces to address mutual issues/concerns such as housing and transportation.

Planning an outreach strategy

1. Inform families about your services

Prepare easy to understand written materials such as handouts and announcements which describe program

- Convey key information in clear & concise manner.
- Reproduce in all languages spoken in the community.
- Set up displays with reordering forms, include contact phone numbe.
- Create public service announcements, newspaper articles, television interview.
- Plan, advertise, and hold educational workshops on specific topics of interest to carers.
- Visit public places where families are likely to be—shopping malls, banks, community expos.
- Attend public hearings on concerns related to disability.

2. Look for families within your own system and service network

- Use intake and information and referral personnel.
- Talk with senior centers, nutrition programs, energy assistance & weatherization programs.

3. Contact other human service and health providers.

4. Reach out through the business and public service community

Routine businesses are often point of first contact for older carers.

- Beauticians, pharmacists, police, Realtors, religious organizations, social & cultural clubs, Alzheimer's Association, VA groups, etc.

5. Work through organized groups

- Lends credibility to effort in the community.
- Opens avenues for oral presentations at regular meetings of the organization.
- Provides access to membership lists for individual contacts or mailings.

6. Tips for ensuring successful outreach

- Follow-up on referrals quickly and show your appreciation.
- Listen to the advice given to you by people in the community.
- Once personal contact is made with groups or individuals within the community, contact monthly to find out if they have identified any families in need of assistance

NOTE: Outreach takes time - don't get discouraged!



Working with Older Carers

1. Work with families not just individuals - Make initial contact with the understanding that some families:

- Do not have current need, but want information.
- Will attend public hearings on concerns related to disability.
 - This is a good way to establish contact, in order to provide information.
- Are in crisis and need immediate help.
 - Emergency referrals require a rapid response.

- Interagency collaboration most effective means to assist; develop an interagency agreement for crises between area agency on aging, local MR/DD services agency and adult protective services.
- Will ask for help for a specific concern they identify, such as housekeeping, transportation, meal preparation, home health aide, personal care attendant services, day programs, assistance with medical needs and billing.
- May want you to just provide them with:
 - Information.
 - Brokering - helping families contact agencies, filling out forms, making appointments.
 - Advocacy - helping families communicate needs.
 - Support - an understanding/listening ear, support groups.

2. Guidelines for working with families

- Build trust - the key ingredient.
- Listen to the family!
- Acknowledge a job well done.
- Skip the jargon.
- Help and support; don't control!
- Begin with pressing concerns but recognize deeper concerns.
- Respect cultural values and traditions.
- Work with the whole family.
- Ask how families make decisions.
- Evaluate values -- yours and theirs and how they interplay.



Don't Give Up!!!

Cultural Considerations When Working With Older Carers

Understanding the family

- Define the family on a case-by-case basis; family may go beyond immediate/extended family and include friends, in-laws.
- Define who the actual care provider is. For example, is a sibling providing care, while the elderly mother is being formally recognized as the caregiver?
- Define the expectations *all* family members have for each other.
- Define what supports the family receives from friends and community.
- Define how the family makes decisions - be careful not to impose your cultural beliefs on the family.
- Discern why the family came to this country - it may clarify the family's willingness to accept services.
- Understand the importance and effect of cultural values to family members - this applies to immigrants from other countries, as well as African Americans, Hispanic Americans, and Native Americans who relocate within the United States.
- Reaching out without understanding may offend families, result in missing important resources, and lead to inaccuracies about the need for help and information being provided.

The family's contact outside the cultural community

- Willingness to accept services outside their own cultural community - families with strong cultural ties often prefer to receive services within own community because of:
 - Fewer problems with language and access.
 - Less fear of formal service providers.
 - More familiarity with services.
 - More respect for their traditions.
- The family's native language -
 - May prevent family from learning about services - look to use existing translation services.
 - May prevent family from accessing services and medical care.
 - May impute additional expenses on families.
- The family's concern about service providers -
 - Will agencies provide needed services?
 - What will the quality of those services be?
 - If they ask for one service, will they be required to accept other services not wanted?
 - Will a request for services be considered as justification for removing the person with a disability from the home?

Building trust and communication with the family - how to proceed?

- Take time to understand unique meaning of the issues raised for that family.
- Network with agencies run by specific cultural groups in your catchment area; direct resources to those agencies.
- Look for existing successful initiatives or create them. Several best practice examples include:
 - Develop and disseminate own-language materials on family caring issues and concerns.
 - Recruit and train a group of peer outreach volunteers from an existing grandparent support program.
 - Channel resources to agencies representing the cultural group and encourage strategies they know will work.
 - Provide cultural sensitivity training and experiences for outreach, information and referral staff.
 - Work with community leaders to reexamine agency policies and practices that may pose barriers.

Supporting Older Adults with I/DD in Community Senior Activities

Senior Center Programs

Senior centers offer a wide range of services geared for the 60 and over population. They also focus on socialization and offer a myriad of programs very similar to those offered in adult day program activities for individuals with I/DD. However, the segregated programs for individuals with I/DD do not offer the opportunity to participate, grow, and be mentored by others in the general population who are dealing with similar aging concerns. Many aging individuals with I/DD have support services already in place, which may, depending on your state's funding regulations, continue to be provided in the senior center.

There may be the need for preplanning with the senior center to ensure that the older adult with I/DD does not become isolated. Creating a program that integrates individuals with I/DD involves outreach, networking and collaboration. Certain characteristics may better predict the ability of a person with I/DD to flourish in this setting. A few traits to look for are self-determination, openness to new people and activities, and the ability to



navigate in a less structured environment than the person may be used to. The following is a brief look at the steps that can be taken to ensure a smooth transition for both the current participants in the senior center and the individuals with developmental disabilities who wish to join. **For a detailed look at how to do this see the chapter on *Collaboration*.**

1. Conduct a preliminary meeting with staff from the I/DD agency and the Senior Center – discussion topics should include: the need for local aging and I/DD administration buy-in; similarities/differences in program activities and structure; familiarity of senior center staff to the needs of individuals with I/DD; senior center staffs' perception of the openness of current center's members to accepting new members from this population; any verbal or written agreements that both agencies may require or want; and based on the aforementioned discussion outcomes, the need for training and integration activities. Outcome goals will steer the group toward one or more of the following steps.
2. Establish a plan of action and goals. Establish future meeting dates and invite all necessary parties.
3. Conduct necessary trainings. Often the only barrier to blended community centers is training for both the staff and center members. I/DD provider agencies may be able to offer the necessary training through their own staff development/orientation programs. If this training is not available, your state I/DD agency or state council on developmental disabilities will be good sources for training programs. Every state has a council on developmental disabilities. For a list of state councils on DD visit the following website and choose your state.
<http://www.acf.dhhs.gov/programs/add/states/ddcouncils.htm>
4. Establish activities that will introduce senior center members to potential new members from the I/DD community. These activities may include mentoring programs (center members go to I/DD provider site to provide volunteer help) or have the individuals from the I/DD community participate in one or two activities at center.
5. Decide a time frame for transition for the individual and what supports, if any, the individual will need. This is an ideal opportunity to utilize the talents of current center members as natural supports for the individual.
6. Agree on the responsibilities of each agency toward supporting the individual.
7. Establish future collaborative meetings as necessary.

The benefits of collaboration between the aging and developmental disabilities networks

The benefits of a blended senior center are many for the aging and I/DD communities. LePore and Janicki (*The Wit to Win*, 1997, pp. 21-22), list the following:



Benefits to individuals with I/DD

- "Participation provides a link to the community" – an important step in self-determination and community integration.
- "Participation offers a break from routine."
- "Participation provides an entry into a normal community group which can have a stimulating and positive effect on the day-to-day behavior and feelings of the adult (with a I/DD)."

- “Participation provides exposure to a variety of experiences which tend to make life more interesting and pleasant.” It provides these individuals with opportunities for socialization rather than isolation, activities for retirement and recreational activities, and a chance to learn new skills that will increase self-confidence in a setting close to home.
- “For seniors with a developmental disability, as well as for the well-elderly, local senior citizen programs can and do forestall mental and physical deterioration that might otherwise occur.”

Other benefits:

- Maintenance of the family unit.
- Potential for alleviating transportation shortages through sharing of resources.
- Opportunities for shared housing situations, multi-use housing development through HUD or other revenue sources.
- Opportunity for agency collaboration and resource sharing for mutual concern and need areas.

Tips for integrating senior centers

The best success for integration starts with good collaboration! Familiarize yourself with the developmental disabilities system in your state or locality. Chances are, if you are reading this manual someone has already approached you regarding integration. If not, find out who in the I/DD system (state or not-for-profit) is the key person you should talk to. The more enthusiastic the individual is, the more likely integration will happen.

Flexibility and a willingness to negotiate staff-sharing relationships are key ingredients to the process. Another must is open and honest dialogue regarding the abilities and limitations of the participants, reticence some center members may experience about the participation of individuals with I/DD, and the needs of many participants for skills training prior to transitioning to the senior center.

For a complete downloadable copy of *The Wit to Win* go to the following website:

<http://www.uic.edu/orgs/rrtcamr/familya.html>. Click on the title at the left hand side of the web page to download.

V. SOME HELPFUL INFORMATION FOR OLDER FAMILY CAREGIVERS

GUARDIANSHIP

There are times when it may be necessary for a family to consider the possibility of legal guardianship for their son or daughter with a disability. Because guardianship is an extreme form of oversight in an individual's life, families should consider all alternatives of surrogate decision making before choosing. These other forms will be discussed later. Decision making vehicles should always be used to enhance a person's ability to live more independently in the community, not to prevent them from doing so.



Legal definition: One or more persons or an agency is given the right and duty to make personal and/or financial decisions for another person who has been shown to be lacking capacity in these areas.

- "Guardian" - person or agency given right.
- "Ward" - person being looked after.
- Properly exercised, it can be an important support toward maximum independence and decision making for the person.
- Families may be unaware of frequent changes in laws, also may assume that they automatically remain guardian of child with a DD after the age of 18— *an incorrect assumption*.
- Challenge is to find a balance between maintaining autonomy and providing needed surrogate decision making.

Who can serve as guardian?

- Someone who has the individual's best interest at heart.
- Someone who understands the nature and degree of the person's disability and special needs.
- Someone whose geographical location would allow them to make frequent visits and immediate decisions.

How to obtain guardianship

Issues

- Procedures for becoming, standards of governing appointment of, and authority given the guardian differ from state to state.
- Many states have more than one statute governing guardianship.
- It is important to become familiar with your state's procedures.
- Obtain information from your state's chapter of The Arc, local family services agencies, or the National Guardianship Association.

OTHER FORMS OF SURROGATE DECISION MAKING

1. Representative Payee

- A person appointed who receives and manages the financial benefits of persons with disabilities on their behalf.
- Social Security, the Veteran's Administration, and other government agencies have procedures for appointing representative payees.
- Appointment only applies to specific benefit programs.

2. Health Care Proxy

- Proxy or agent who makes health care decisions for a person lacking the capacity to make such decisions for self.
- A person with a DD can often understand the delegation of a health care proxy.
- Most states have statutes governing medical care authority.

3. Living Will

- Legal document often used in conjunction with health care proxy.
- Used to express wishes for medical decisions about withholding or withdrawing of life-sustaining treatment wherein the person lacks capacity to make decision.

4. Power of Attorney

- A contract between two individuals where one party (the principal) gives to the other (the agent) authority to make any number of decisions.
- A person may lack capacity for health care decisions, yet be competent to make an advance directive for power of attorney or other legal document.

FINANCIAL PLANNING

Proactive financial planning is critical for families who have a son, daughter or sibling with an intellectual or developmental disability. The process of future care planning can seem overwhelming for families. Sometimes the best way to overcome this anxiety is by taking steps that they know they can do. A good way for them to begin is to look at resources and monetary and natural support networks that are available. Doing this will help families to plan for providing those “out-of-pocket” expenses or supports they currently do for their family member. Many individuals are under the assumption that they cannot leave money to their family member with an I/DD. This is not the case. However, they must ensure that the proper legal vehicles are in place, as inadequate planning can have detrimental affects on their family member’s benefits. Families can also help by ensuring that their family member has applied for all benefits and entitlements due them. Below are some key points to remember.



1. Medicaid transfer penalties

- Individuals over age 65 can not transfer assets to *non-disabled* children without invoking a disqualification period for Medicaid.
- Transferring assets to an adult child with a disability may disqualify them for benefits. Assets, such as inheritances, can be left for the benefit of the family member with a disability through a vehicle known as a Special or Supplemental Needs Trust.

2. Special or Supplemental Needs Trusts - (SNT's)

- A trust is a legal relationship created by a person (the settlor), in which another individual (the trustee) manages assets for the benefit of a third party (the beneficiary).
- Provides for higher quality of life for the person with a disability.
- SNT's protect the beneficiary's government benefits as they state specifically that the individual has no legal authority to control spending of money.
- Must state that assets are to *supplement not supplant* government benefits.
- Consult an attorney well versed in SNT's.

3. Obtaining Federal Benefits - *be an educated advocate*

- Ensure carers and adults with a disability are enrolled in federal benefit and entitlement programs.
- Programs include: Supplemental Security Income, Medicaid, Social Security, Medicare, Veterans Benefits, Social Security Disability Income, Food Stamps, Section 8 vouchers for housing, and home

energy assistance programs (called different names depending on states but most use the acronym HEAP somewhere in the program title).

- Parents must view their adult child with a disability as financially separate from themselves.
- For children 18 and over it is the child's income, not the parent's income, that is reflected on a Medicaid application.

VI. LEGISLATION AND COURT DECISIONS

Recent legislation and Court decisions have affected services for people with developmental disabilities. The relevant programs and legislation that may impact on the National Family Caregiving Support Program are explored below.

Olmstead Decision

The landmark Supreme Court decision in *Olmstead v. L. C.*, 119 S.Ct. 2176 (1999), provided an important legal framework for state efforts to enable individuals with disabilities to live in the most integrated setting appropriate to their needs. The Court's decision provides the challenges to develop more opportunities for individuals with disabilities through more accessible systems of cost-effective community-based services. This decision confirmed what many in the advocacy community believe: that no one should have to live in an institution or a nursing home if they can live in the community with the right support. The goal is to integrate people with disabilities into the social mainstream, promote equality of opportunity and maximize individual choice.



The *Olmstead* case was brought by two women in a Georgia institution whose disabilities include “mental retardation” and mental illness. At the time the suit was filed, both plaintiffs lived in State-run institutions, despite the fact that treatment professionals had determined that they could be appropriately served in a community setting. The plaintiffs asserted that continued institutionalization was a violation of their right under the Americans with Disabilities Act (ADA) to live in the most integrated setting appropriate. The *Olmstead* decision interpreted Title II of the ADA and its implementing regulation, which oblige States to administer their services, programs, and activities “in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” (28 CFR 35.130(d)). In doing so, the Supreme Court answered the fundamental question of whether it is discrimination to deny people with disabilities services in the most integrated setting appropriate. The Court stated directly that “Unjustified isolation . . . is properly regarded as discrimination based on disability.” It observed that (a) “institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life,” and (b) “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”

Under the Court's decision, states are required to provide community-based services for persons with disabilities who would otherwise be entitled to institutional services when: (a) the state's treatment professionals reasonably determine that such placement is appropriate; (b) the affected persons do not oppose such treatment; and (c) the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others who are receiving state-supported disability services. The Court cautioned however, that nothing in the ADA condones termination of institutional settings for persons unable to handle or benefit from community settings. Moreover, the state's responsibility, once it provides community-based treatment to qualified persons with disabilities, is not unlimited.

How does the *Olmstead* Decision affect workers under the NFCSP? Under the ADA, States are obliged to undertake activities to help people currently institutionalized realize their potential by moving to community living settings. In most cases this will not directly affect the families involved as the child or adult is already living at home. It may, if the person has recently returned from an institutional setting and is eligible for special follow-along services from the state. However, given that states are attempting to comply with the Supreme Court

decision it may affect the allocation of resources to families as state funds and other resources are being directed to enable those adults in institutions who would benefit from returning to the community to do so.

Nursing Home Reform Act



In 1987, Congress passed the "Omnibus Budget Reconciliation Act of 1987" (P.L. 100-203), which is commonly referred to as OBRA-87. A segment of this encompassing legislation contained a series of provisions designed to reform the nursing home industry in the United States (it is often referred to as the "Nursing Home Reform Act"). The basic objective of the Nursing Home Reform Act is to ensure that residents of nursing homes receive quality care that will result in their achieving or maintaining their "highest practicable" physical, mental, and psychosocial well-being. To secure quality care in nursing homes, the Nursing Home Reform Act requires the provision of certain services to each resident and establishes a Residents' Bill of Rights.

The law adopted a two-step approach to address the problem of inappropriate placements of people with developmental disabilities in nursing homes. Section 1919(e)(7) of the Social Security Act was amended via OBRA-87 to institute new procedures for the admission and retention of persons with intellectual ("mental retardation") or developmental disabilities in nursing facilities. Specifically, it restricts new admissions and requires a screening of those who are already placed to determine whether they should be transferred to a more appropriate setting. The law established a requirement for a preadmission screening of every person with a developmental disability prior to admission to a nursing facility. It also established a requirement that persons with a developmental disability who were inappropriately placed into--and remaining in--nursing facilities be discharged into a community setting appropriate to meet their needs. It further stated that those who can remain, if not exempt for specific reasons, are to receive specialized services to address their particular needs related to their developmental disability.

A nursing facility that admits an adult with an intellectual or developmental disability without first having the state review and authorize the admission request, runs the risk of losing all of the federal payment received for that person's care and services while in the facility. Workers in the aging network facing the prospect of making a referral to a nursing facility of a person with a developmental disability should be always make a referral to the state's designated screening team. The headquarters or central office of the state's developmental disabilities agency can provide this information.

When faced with an adult who may appear to need the services of a nursing facility, the preferred practice is to find an alternate living arrangement in the community. Most adults with severe impediments will normally pass screenings for nursing facility admission because of low ADL [activities of daily living] scores. However, these low ADL scores are not usually indicative of a need for nursing facility care, but of a range of support services generally available from local developmental disabilities agencies.

As a rule of thumb, when faced with a request for nursing facility admission, question it and seek out an alternative care setting in the community.

Domestic Volunteer Service Act

The Domestic Volunteer Service Act [as amended by Public Law 106-170, approved December 17, 1999] was originally passed in 1973. The Act covers a number of older American volunteer programs including Foster Grandparents, RSVP, and Senior Companions. Although the primary purpose of the Act's Senior Companion component is to assist elderly persons who are homebound, the Act also authorizes senior companions to assist adults with a developmental disability in



any situation. Provisions allow any eligible agency or organization wishing to sponsor a Senior Companion Project without the Corporation for National and Community Service (CNCS) funding to enter into a Memorandum of Agreement with the CNCS. Such a memorandum would permit the sponsor to maintain a senior companion program and enable the seniors, who serve as volunteers in the program, to maintain a tax-exempt status for allowable federal benefits. The provisions also permit any public agency or private non-for-profit organizations wishing to sponsor a Senior Companion Project with CNCS funding to apply for CNCS grant funds. The law identifies eligible volunteers as persons, age 60 and older, who meet the income eligibility guidelines of CNCS (current regulations call for being within 125% of DHHS poverty income guidelines). For more information, go to <http://www.nationalservice.org/about/ogc>.

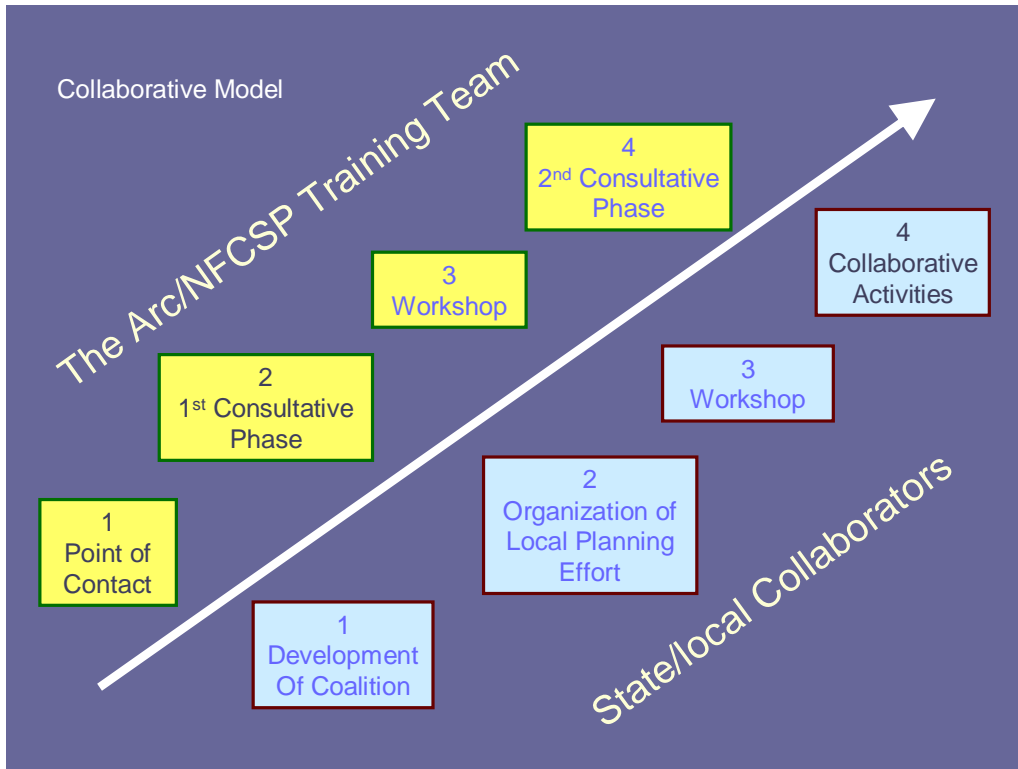
The implication of these provisions for NFSCP is the availability of a pool of senior volunteers who could serve as Senior Companions with persons (age 18 and older) with a developmental disability. Several state developmental disabilities agencies maintain their own Senior Companion Programs, affiliated with the federal government. Check with your state to see if such a program exists and if so, whether any Senior Companions might be available to aid the family with which you are working.

Americans with Disabilities Act

The 101st Congress passed the Americans with Disabilities Act of 1990 (P.L. 101-336). Title III of the Act prohibits discrimination against individuals with disabilities in the full and equal enjoyment of goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation. These provisions include a range of amenities or places of services, including senior citizen centers, day care sites and social services centers; and state that no places shall discriminate by the imposition of eligibility criteria for the use of services, failure to remove architectural barriers, maintenance of policies or practices that impede accessibility, and other aspects that demonstrate willful discrimination of person with disabilities. Obviously, the ADA can be helpful in ensuring that services, programs, and public amenities that you may wish to use to help with the family you are working with do not pose barriers to their use.




VII. SOME BEST PRACTICES AND CASE STUDIES

The model used for working with each state under this three year demonstration grant varied based on whether an aging or developmental disabilities agency was willing to take the lead. We were however able to develop an organizational model that successfully pulled all the players to the table. The model is highlighted below.



This section highlights different best practice models of collaboration used by five states. All states that participated in the training program worked with due diligence and enthusiasm to bring about the workshop and planned to continue collaborative efforts after the workshop was completed. We chose these five states as they provide examples of what can transpire within different political, geographic and demographic situations. The five states we will discuss are California, Florida, Maine, Washington, and New Mexico.

An overview:

	California	Florida	Maine
Structure	State/regional centers/vendors	State/vendors	State/vendors
Key actor	University	Regional provider agency	Regional provider agency/planning group
Process	Regional planning teams Workshops Network building by university	Technical aid Workshops State planning	Technical aid Network building by state planning group Workshop
Demographics	14% aged 60+	22.2% aged 60+	18.7% aged 60+
Impact	Regional attention to issue	Statewide initiative in development	Statewide network




	Washington	New Mexico
Structure	State/regional centers/vendors	
Key actor/s	State Unit on Aging The Arc State and local affiliate	State Unit on Aging State Development Disabilities Planning Council
Process	Regional planning teams Workshop Network building by State Unit on Aging mini-grants	State-wide planning teams Training MOU and guideline established
Demographics	15.3% aged 60+	16.3% aged 60+
Impact	Regional and state-wide attention to issue	MOU to develop Inclusion Programs state-wide

California

Prevailing Issues

- Large older population & competing demands on state eldercare resources.
- Significant number of immigrant parents aging with aging son/daughter.
- Agency structure present, but there is a decisive division of services and spending between the northern and southern half of the state. With the state being so large, state funding entities tend to focus regionally in a north and south division for provision of services. This system does not allow for collaboration or communication on services, programs or policy issues.
- Budget constraints due to fiscal situation.
- Large culturally diverse population.
- Many non-English speaking communities.

California Consultative Model

- Contact was made through a pre-existing working relationship with the University of Southern California.
- Provided Technical Aid (TA) and training to university to build capacity.
- University reached out to The Arc's local affiliates in both northern and southern regions, state I/DD authority the State Unit on Aging, and the State Association on Area Agencies on Aging to promote aging and I/DD workshop planning teams.
- Planning teams had an overlap of members to bring the two halves of the state together for future collaboration.
- Independent workshops held in Los Angeles and San Francisco.
- TA team aids state with building capacity.

Why this state chosen as a best practice and how was it successful:

California was chosen as a best practice state due to project staff's prior working relationship with key players and a verbal commitment at the state level to support collaboration efforts. The buy-in from the top down, found in California, is critical when collaboration efforts will be at the state level, or when policy changes may be needed in order to implement changes in services. The University of California, Los Angeles (UCLA) was the first point of contact in building the foundation for these workshops. UCLA in turn contacted and engaged with numerous other aging and I/DD agencies across the state. As a result of this intensive outreach, two workshops were held, one in Los Angeles and one in San Francisco. Representatives from San Francisco attended the LA workshop and visa versa in order to ensure consistency of strategic planning. After the second workshop a follow-up meeting was held to set the stage for the next steps. The state was already in the process of reactivating a statewide disabilities planning committee and it was decided that this group would be the logical forum for collaborating efforts. The results of the meeting are reflected below.

Expected Impact

- Setting up long-term situational response.
- Collaboration between I/DD and aging agencies to plan for state-wide vs regional service and program development.
- Reinstating a long-term state-wide steering committee to discuss ways in which to provide for better and non-overlapping of services to caregivers and care recipients.
- MOU's on which agency should have the lead for developing more streamlined and effective provision of information and services.

Florida

Prevailing Issues

- Large older population & competing demands on state eldercare resources.
- Significant number of immigrant parents aging with aging son/daughter.
- Agency structure present, but The Arc agencies mostly small and not a large presence.
- Budget constraints due to fiscal situation.

Florida Consultative Model

- Established contact with a significant player among the state's I/DD agencies (UPARC, The Upper Pinellas County ARC).
- Provide TA and training to agency to build capacity.
- Agency reached out to state I/DD authority to promote aging and I/DD.
- TA team aids state with building capacity.
- State uses the target agency as the model for other agencies.

Why this state chosen as a best practice and how was it successful:

Florida has been very active in bringing about change in policy and services for both the aging (a very large percentage per capita) and the I/DD populations. Florida was chosen because of its willingness to make changes and because one of the key players, The Upper Pinellas County ARC, made contact with grant project staff to express interest in conducting several workshops throughout the state as part of efforts to effect change through collaboration. UPARC was also currently working with the State DD agency and Florida Developmental Disabilities Council to bring needed changes to policy mandates and funding. Three workshops were held, one each in Tallahassee, the Tampa area, and the Fort Lauderdale area. Grant staff have attended several follow-up meetings with UPARC and state representatives. These meetings have resulted in successful collaboration efforts including discussion and actions toward needed policy changes to enable better services and efficient funding.

Expected Impact

- Setting up long-term situational response.
- Collaboration between I/DD and aging agencies to minimize expenditures.
- Increase the number of older families being served earlier and responsiveness to needs.
- Better match between adults with I/DD (living at home) and their day service needs.
- Fewer higher cost emergency requests for services by older carers.

Maine

Prevailing Issues

- Large rural geographic area to be covered.
- Difficulty in reaching out to caregivers.
- Agency structure present, but The Arc agencies mostly small and not a large presence.
- Budget constraints due to fiscal situation.

Maine Consultative Model

- Establish contact with The Arc affiliate.
- Provide TA and training to agency to build capacity.

- Agency reached out to state I/DD and Aging authorities and brought into planning process.
- TA team aided state with building capacity.
- Developed a committee representing all invested players - state and local.
- Committee used the workshop as conjoint state-wide conference for aging and I/DD staff, families, and other interested parties.

Why this state chosen as a best practice and how was it successful:

Being a primarily rural state, Maine expressed a genuine and enthusiastic interest in increasing collaborative efforts. Service delivery for older individuals and persons with I/DD face not only funding difficulties, but geographic barriers as well. The Arc representative invited key stakeholders from every state human service agency to form the planning committee for the workshop. These agencies spent an entire year planning the workshop and appropriating donations to cover travel costs for caregivers. The format used in Maine for technical assistance and workshop development was so successful that it became the finalized format for the consultative method discussed earlier in this manual. The workshop, which was a combined multi-agency statewide conference, brought in over 200 attendees. Workshop coordinators' strategic plan included setting up a list-serve with Yahoo groups to keep all attendees notified of current information and events, as well as an executive summary of issues discussed during the workshop. These strategies have become the foundation for future efforts. Since the workshop, the group has continued their collaborative meetings, and several agencies, including the State Unit on Aging, have acquired grants for outreach efforts.

Expected Impact

- Utilize executive summary to guide future collaborative efforts.
- Collaboration between I/DD and aging agencies to minimize expenditures.
- Establish an ongoing electronic list serve of workshop attendees for updated information sharing.
- Collaboration between agencies to promote better outreach to caregivers and care recipients.
- Long term committee maintains continuance of joint outreach, service provision, and training opportunities.

Washington

Prevailing Issues

- Large area to be covered, with a geographic division between eastern and western halves of state making state-wide collaboration difficult.
- Difficulty in reaching out to find caregivers.
- State aging and I/DD policies very different from other states and provided for lengthy discussions around the workshop development.
- Difficulty providing one training session for the entire state.
- Budget constraints due to fiscal situation.

Washington Consultative Model

- Established contact with The Arc affiliate and State Unit on Aging.
- Provided TA and training to agency to build capacity.
- Agencies mutually reached out to state I/DD and Aging authorities to promote aging and I/DD.
- TA team aided state with building capacity.
- A committee representing all invested players from the state, and regionally from the western half of state developed.
- Committee used workshop as a launching pad for future collaborative efforts.

Why this state chosen as a best practice and how was it successful:

Washington was chosen as a best practice state due to strong representation from all the major service and advocacy agencies in the state. This representation placed the state in a good position to move forward in collaborative efforts. In Washington, the State Unit on Aging took the lead in coordinating the workshops, a natural fit given the positive existing working relationship with the State I/DD agency and other key stakeholders such as the Washington Alzheimer's Association. The local Arc also played an active role in engaging the I/DD community in planning efforts. Washington also faced geographic challenges in facilitating statewide collaborations because of the mountain range that divides the state. Travel from city to city is very costly. Because of these geographic issues, the planning committee decided to conduct a workshop first on the western side of the state, and then later repeat the workshop in the eastern half. Given that Washington's aging and I/DD agencies had very different funding policies than the other states we worked with (they not only had federally funded programs for caregivers, but also state funded programs and a state trust fund for services and programs), the workshop curriculum was adapted to provide a large proportion of state led informational sessions for attendees. The planning committee held monthly meetings and resolved policy conflicts that arose between participating agencies, admirably resulting in a workshop with over 200 participants. As a result of the work done through the planning committee and workshop, momentum for future collaborative efforts in outreach and service provision was established. The State Unit on Aging went a step further and allocated \$27,000, to be parceled out as mini-grants for outreach efforts.

New Mexico

Prevailing Issues

- Large rural area to be covered.
- Large culturally diverse population.
- Many sovereign nations.
- Difficulty in reaching out to caregivers.
- Difficulty providing one training session for the entire state.
- Budget constraints due to fiscal situation.

New Mexico Consultative Model

- Established contact with The Arc affiliate.
- Consultant workshop faculty living in the state initiated contact with state aging agencies.
- Provided TA and training to agency to build capacity.
- TA team and consultant aided state with building capacity.
- A committee representing all invested players from the state established.
- Committee used workshop as a launching pad for future collaborative efforts.

Why this state chosen as a best practice and how was it successful:

New Mexico was included as a best practice state as they successfully overcame challenges including not only a large geographic coverage area, but also a unique and diverse cultural population. One of the workshop faculty lives in New Mexico, and having connections within the aging and I/DD field, agreed to work on developing some best practice collaborative efforts. As well as the expected impacts listed below, the collaboration team recently applied for a grant to look into aging issues for older Native Americans with and without a disability, one of the areas of great need addressed during the workshop.

Expected Impact

- Signed a memorandum of understanding between State Agency on Aging and Developmental Disabilities Planning Council to develop new program for inclusion.
- Develop collaborative relationships between the aging and I/DD networks to promote better outreach to caregivers and care recipients.
- Conduct cross-network training to build understanding.
- Institute a well thought-out inclusion program.
- Develop a community-based outreach program to identify adults with developmental disabilities who can benefit from programs offered by aging agencies.

Lessons Learned from working with all the states

- Consultation requires local initiators who are willing to take responsibility and follow-through.
- Time frames and deadlines have to be flexible as state conditions and local initiators constantly face competing pressures.
- Build off local talent and boost local efforts.
- Predictability works on the grand scale, but be open to day-to-day vagaries.
- Greater awareness of older family issues can help foster more outreach and aid via provider agencies.
- More interest in this issue is shown at the local level than at the national or state level.
- Local agencies recognize the growing challenge of a greater number of older families who will need services, yet are taxed by insufficient resources.



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IX. RESOURCES

WEB SITES/ADDRESSES TO NATIONAL ORGANIZATIONS FOR I/DD INFORMATION, RESOURCES, AND REFERRALS



Administration on Developmental Disabilities

HHH Building

200 Independence Avenue, N.W.

Washington, D.C. 20201

National agency coordinating state initiatives on developmental disabilities. Provides advocacy, community inclusion, training, research, and links to services for families and individuals with developmental disabilities.

<http://www.acf.dhhs.gov/programs/add>

Administration on Aging

US Department of Health and Human Services

1 Massachusetts Avenue, NW.

Washington, D.C. 20201

Agency coordinating health and well being programs for older adults. Technical assistance and information about model programs.

www.aoa.gov

Alzheimer's Association

225 North Michigan Ave.

Floor 17

Chicago, IL 60601

National association promoting research, training, education, conferences, and services/supports for family members caring for someone with Alzheimer's Disease. Provides information on local support groups and resources throughout the US. Has 24-hour hotline for support and referrals.

www.alz.org

Alzheimer's Disease Education and Referral Center

P.O. Box 8250

Silver Spring, MD 20907-8250

Provides educational resources, agency training materials, and information on current research initiatives and policies affecting persons with Alzheimer's Disease and their families. Provides an ongoing Alzheimer's Disease newsletter and a Speaker's Kit to aid in training, and links to critical resources available from the National Institutes on Aging.

<http://www.alzheimers.org>

American Association of Homes for the Aging

2519 Connecticut Avenue, NW

Washington, DC 20008-1520

A national association representing thousands of non-profit housing and community-based service agencies for older adults. Provides information on legislation, policies, research, career advancement, and educational opportunities. Numerous publications on housing initiatives for older adults.

<http://www.aahsa.org>

American Association on Mental Retardation

444 No. Capitol St. N.W.

Suite 846

Washington, D.C. 20001

A national organization providing curriculum and training materials, fact sheets, other information on mental retardation and other developmental disabilities. Information on measurement scales, local resources, legislative, policy, research, caregiving, health, mental health, and behavioral issues.

www.aamr.org

American Association of Retired Persons (AARP)

601 E Street, N.W.

Washington, D.C. 20049

National organization providing state and national resources on aging, including healthy aging, dementia, spirituality, medical and prescription needs, research, caregiving, and many others.

www.aarp.org

American Network of Community Options and Resources

1101 King Street

Suite 380

Alexandria, VA 22314

Network of providers offering supports to persons with disability, e.g. legislative/policy updates, conferences and trainings, leadership materials, and advocacy at the state and national levels.

www.ancor.org

American Society on Aging

833 Market Street

Suite 511

San Francisco, CA 94103

Supports a network of individuals and professionals who are committed to improving the quality of life of older adults and their families through networking, information sharing, workshops and conferences.

www.asaging.org

Association of University Centers on Disabilities

1010 Wayne Avenue

Suite 920

Silver Spring, MD 20910

1 301/588-8252

Provides education, trainings, conferences, regular publications, and current policy/legislative information and resources. Also has program performance evaluation, assessment, advocacy training and other materials.

www.aucd.org

DisAbility.Gov (New Freedom Initiative)

Links to information about government programs for individuals with disabilities, such as transportation, housing, health, income maintenance, assistive technology, community integration, disability rights,

employment, education, and many other important topics.

<http://www.disabilitydirect.org>

Gerontological Society of America

1030 15th Street N.W.

Suite 250

Washington, D.C. 20005-4006

202/842-1275

National organization providing information on research, education, service delivery, advocacy, community inclusion, and promotion of quality of life in older adulthood. Access to current literature, conference and training opportunities, and a large career center for aging jobs. Has a national hotline to help older adults and caregivers access local supports.

www.geron.org

HHS-Administration on Developmental Disabilities

Information on grants and technical assistance for programs for people with disabilities.

<http://www.acf.dhhs.gov/program/add/>

Home and Community Based Services Network (HCBS)

Provides research and summaries on home and community based services programs and initiatives.

Contains consumer and family-focused information.

<http://www.hcbs.org>

National Association of State Mental Health Program Directors, Inc.

66 Canal Center Plaza

Suite 302

Alexandria, VA 22314

Provides public mental health agencies with resources in prevention, cultural competency, advocacy, evaluation, and service delivery initiatives. Shares legislative, policy, research, and program development information.

www.nasmhpd.org

National Association of Protection & Advocacy Systems

900 Second Street, NE

Suite 211

Washington, D.C. 20002

A voluntary association of protection and advocacy systems and client assistance programs providing information and resources on policy, legislative affairs, disability issues including developmental disability, and public awareness training materials. Also has numerous links to useful conferences, timely reports, and cutting edge research and policy updates.

www.protectionandadvocacy.com or www.napas.org

National Association of State Directors of Developmental Disabilities Services

113 Oronoco Street

Alexandria, VA 22314

Provides referral sources for state and local services, technical and budgeting resources, and state best-practice initiatives.

www.nasdds.org

National Association of Councils on Developmental Disabilities

225 Reinekers Lane

Suite 650-B

Alexandria, VA 22314

Supports state and national developmental disabilities councils in implementing key legislation and policy to support persons with developmental disabilities and their families. Provides advocacy, legislative updates, individualized technical assistance and training, information sharing between organizations, training and educational opportunities, regular publications, and community support development toolkits.

<http://www.nacdd.org>

National Association of State Units on Aging

1201 15th Street, N.W.

Suite 350

Washington, D.C. 20005

Provides education, supports, and up-to-date information on elder abuse, healthy aging, Medicare issues, community inclusion, and elder rights. Has link to comprehensive online database Eldercare locator.

www.nasua.org

National Association of Area Agencies on Aging

1730 Rhode Island Avenue, N.W.

Suite 1200

Washington, DC 20036

Provides information on eldercare services, policies, advocacy initiatives, and numerous publications. Runs an innovative Aging in Place Initiative project.

www.n4a.org

National Conference of State Legislatures (NCSL)

7700 East First Place

Denver, CO 80230

Or

444 North Capitol Street, N.W.

Suite 515

Washington, D.C. 20001

Information for state legislators, their staff and advocates on current issues including focus on health care and disability policy and best practices.

<http://www.ncsl.org/>

National Council on the Aging

300 D Street, S.W.

Suite 801

Washington, D.C. 20004

National association of agencies and professionals dedicated to promoting the well-being, dignity, and self-determination of older adults. Has a user-friendly best practices database.

www.ncoa.org

National Council on Independent Living

1916 Wilson Blvd.

Suite 209

Arlington, VA 22201

Advocacy organization promoting independent living and community inclusion. Provides trainings through teleconferences, webcasts, and on-site locations and numerous publications on advocacy, policy, legislation, and services available to persons with disabilities in the community.

www.ncil.org

National Guardianship Association

1604 N. Country Club Road

Tucson, AZ 85716-3102

Provides resources for family and formal guardians, directory of registered formal guardians, current news and calendar of events related to continuing education on guardianship issues.

www.guardianship.org

National Institute on Aging

Building 31 - Room 5C27

31 Center Drive, MSC 2292

Bethesda, MD 20892

Federal agency providing health and research information, including gender and disability-specific information. Also provides aging agencies with resources for program setup, evaluation, and education/training on aging-related issues.

www.nia.nih.gov

Social Security Administration

Provides up-to-date information on financial and medical benefits for older adults and individuals with disabilities.

<http://www.ssa.gov>

The Arc of the US

1010 Wayne Avenue

Suite 650

Silver Spring, MD 20910

Provides information and resources for community inclusion, advocacy, training and education of individuals with developmental disabilities, their families and caregivers, and service provider agencies. Many publications on future care planning, family resources, state/local/agency based initiatives, legislative and policy issues, research and other pertinent resources geared toward families and agencies. Also, has a service provider search by state and mechanisms for family members and agencies to connect with one another.

www.thearc.org

United Cerebral Palsy Associations, Inc.

1660 L Street, N.W.

Suite 700

Washington, D.C. 20036

National organization providing information on cerebral palsy, disability policy and advocacy, community inclusion initiatives, health and wellness, family caregiving, housing, and service resources. Also has a link to available funding and local service locator.

<http://www.ucpa.org>

Reading Resources



A Family Handbook on Future Planning, S. Davis, Ed., The Arc of the United States and Rehabilitation Research and Training Center on Aging with Developmental Disabilities, Department of Disability and Human Development, University of Illinois at Chicago, (2003),
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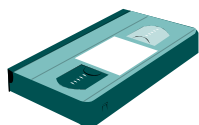
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The future is now: A future planning training curriculum for families and their adult relatives with developmental disabilities. Debrine, E., Caldwell, J., Factor, A., & Heller, T. Chicago: Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago (2003).

The Wit to Win - How to Integrate Older Adults with Developmental Disabilities into Community Aging Programs (1997 rev.). P. LePore & M.P. Janicki. Albany: New York State Office for the Aging (1997).

Videos



When People with Development Disabilities Age - For information contact, NYS Developmental Disabilities Planning Council, 155 Washington Avenue, Albany, New York 12210 (518.432.8233; FAX 518.432.8238) Or go to <http://www.ddpc.state.ny.us/>.

Dementia and Adults with Intellectual Disabilities – What Can We Do? New York Developmental Disabilities Planning Council, 155 Washington Avenue, Albany, New York 12210 (518.432.8233; FAX 518.432.8238) Or visit their Website at <http://www.ddpc.state.ny.us/>

X. HOUSING CHOICES – Non I/DD Congregate Residences

TYPE OF HOUSE	SELECTION	SIZE & COST	REPAIRS	PROXIMITY TO NEIGHBORS	RELATED INFORMATION
Single-family	* offers the greatest selection - suburban, urban or rural area	*vary in price range, size & style * <u>newer homes</u> - cost more * <u>older homes</u> - are cheaper	* <u>newer</u> - require fewer repairs * <u>older</u> - require more repairs	* offer the maximum amount of privacy	* individual/s or family purchase house; have complete say in all decisions
Multi-family	*wide range - * modern duplexes * homes with apartments * older 2-family	* vary in price range, size & style * other unit can provide income from rent	* maintenance of rental unit added expense * lease other unit to someone able to do repairs in exchange for lower rent	* neighbors are right next door	* individual/s or family purchase; rent other unit out for income *owner/s have say in all decisions
Condominiums	* found mostly in larger cities and suburban areas * located in small apartment buildings to large high-rise complexes	* vary in price range, depending on the location * can be less expensive than single or multi-family homes * monthly fee is paid by owners for upkeep of grounds & maintenance on the outside of building - fee is in addition to mortgage	* owners' responsibility for upkeep and repairs is limited to the inside of the building	* neighbors are next door, across the hall, & possibly above and below the unit	* occupant owns his or her dwelling unit with interest in grounds, hallways, and service areas

TYPE OF HOUSE	SELECTION	SIZE & COST	REPAIRS	PROXIMITY TO NEIGHBORS	RELATED INFORMATION
Co-operative Housing	<ul style="list-style-type: none"> * made up of many separate dwelling units, usually apartments * found mostly in cities 	<ul style="list-style-type: none"> * prices vary depending on location and city * all housing is jointly owned by all residents in the form of shares * deductions for mortgage and property taxes do not apply for income tax purposes 	<ul style="list-style-type: none"> * repairs outside of one's own unit, including the grounds are the responsibility of all residents * repairs to inside of unit responsibility of owner * repairs or renovations must be approved by all residents 	<ul style="list-style-type: none"> * neighbors all around, as in condominiums 	<ul style="list-style-type: none"> * this model emphasizes group participation in all decisions related to housing
Co-housing	<ul style="list-style-type: none"> * units may be apartments, town homes, or single family homes * units are individually owned or rented * residents have complete separate living spaces, but there are also separate common areas such as kitchens, dining, community rooms large enough to hold all residents 	<ul style="list-style-type: none"> * prices vary depending on location 	<ul style="list-style-type: none"> * cost and responsibility of repairs depend on how the co-housing organization is set up * repairs & cost may resemble any of the other examples cited on this chart 	<ul style="list-style-type: none"> * this model emphasizes community life and interaction with neighbors 	<ul style="list-style-type: none"> * organizing, decision making, and management of housing involves all residents * provides for a greater opportunity for natural supports and assistance

TYPE OF HOUSE	SELECTION	SIZE & COST	REPAIRS	PROXIMITY TO NEIGHBORS	RELATED INFORMATION
Apartment	<ul style="list-style-type: none"> * found mostly in larger cities, also in suburban areas * located in small apartment buildings to large high-rise complexes 	<ul style="list-style-type: none"> * vary in price range, depending on the city where they are located * can be less expensive than single or multi-family homes 	<ul style="list-style-type: none"> * owner responsible for upkeep and repairs to inside of apartment * maintenance fee required in addition to mortgage 	<ul style="list-style-type: none"> * same as in condominium 	<ul style="list-style-type: none"> * provides more freedom in making changes/modifications to owned property
Limited Equity	<ul style="list-style-type: none"> * can be any type of housing 	<ul style="list-style-type: none"> * vary in price range depending on what type of housing and location 	<ul style="list-style-type: none"> * owners share all costs of repairs in proportion to their share of equity in the house for example: if owners purchased at 50/50 then repairs would be a 50/50 split 	<ul style="list-style-type: none"> * proximity to neighbors depends on type of housing purchased * co-owner in same house 	<ul style="list-style-type: none"> * 2 or more unrelated persons purchase housing together * a contract should be established stating buy-out/selling options should one owner wish to move
Townhouse	<ul style="list-style-type: none"> * Found in cities, urban, and rural areas 	<ul style="list-style-type: none"> * vary in price range depending on location * can be less expensive than single family homes 	<ul style="list-style-type: none"> * owner responsible for repairs inside and outside home as well as any maintenance to yard, sidewalk, driveway, etc., purchased as part of house 	<ul style="list-style-type: none"> * housing units attached to each other 	<ul style="list-style-type: none"> * this model many times includes a certain amount of yard/property as part of the purchase price

XI. QUICK REFERENCE FACT SHEETS (following pages)

OVERVIEW OF AGING ISSUES AND INDIVIDUALS WITH I/DD

DEMOGRAPHICS OF AGING POPULATION

1. There are 78 million “baby boomers”
2. The number of persons age 65 to 74 will grow by 107% by 2030 – **65+ will be the fastest-growing age group**
3. By 2020, 7 million persons will be 85+ and this number will double by 2040
4. Boomers’ life expectancy has increased to over 70 – that’s 6 years more than their parent’s generation
5. “Rule of thumb” estimates are that for every 1000 older adults – age 60+ there are 4 to 5 adults with an intellectual or developmental disability.
6. Estimates are that there are some 9,000 adults with ID/DD affected by dementia in the United States

SURVIVING TO OLD AGE

1. Survival to very old age – living to 100 – depends a great deal on family genetics
2. Other factors include sex, income, physical activity, race and lifestyle (diet etc.) *but up to a point.*
3. If a sibling survives to old age, you will most likely also
4. Longevity is linked to absence of genes creating vulnerability for aging-related diseases (e.g., Alzheimer’s and cardiovascular disease) and genes that slow the aging process at a basic level
5. The distribution of where older people are will vary greatly geographically
6. The same applies to older families or carers.
7. To find out about the numbers of older people in your area, contact **the state unit on aging or the area agency on aging**
8. Data is also available on the web
<http://www.aoa.gov/aoa/STATS/2000pop/default.htm>

DEVELOPMENTAL DISABILITIES A BRIEF DEFINITION

1. Conditions originating at birth, infancy, early childhood, or during developmental period
2. Posing hindrance to typical growth and development – impairing social, vocational & economic functioning
3. Lifelong nature – expected to last through to old age
4. Categorical vs. functional perspective

1. People w/DD and where they live
 - 61% live with their families
 - 15% live with spouse
 - 14% live on their own
 - 10% live in some type of supervised setting
2. Some 1.9 million persons with DD are estimated to live at home or with a family caregiver
3. Some 25% of these caregivers are age 60 or older
4. A significant portion of in-home supports are being provided by family caregivers who will be aging beyond their capacity to provide care over the next 10 to 20 years.

OVERVIEW OF AGING ISSUES AND INDIVIDUALS WITH I/DD

INTELLECTUAL DISABILITIES A BRIEF DEFINITION

1. Below normative intellectual functioning, due to cognitive impairment (organic or functional) present since birth or infancy.
2. Vary in degree and co-impairment.
3. Compensation by training, education, remediation, habilitation, supports for life activities.
4. Currently about 75% of all older adults with intellectual disabilities are in the 40-to-60 age group.
5. Expectations are that the 60+ age group will increase threefold over the next 20 years.

Dementia vs. Intellectual Disabilities

1. Intellectual disabilities involve undeveloped or underdeveloped mental or intellectual skills and abilities
2. Dementia is a widespread loss of mental or intellectual skills and abilities from previous level of ability.
3. Key – behavioral presentation may be similar, but it is the loss from previous level of function that differentiates the two.

CAREGIVERS OF PERSONS WITH I/DD VS CAREGIVERS OF AGING PARENTS

1. Families may be two-generation elderly families
2. Role of adult with ID/DD as carer for parents
3. Parental retirement, illness, death
4. Role of siblings or “key person” for succession planning
5. Self-determination (who’s in charge?)
6. Complexity of the problems that such families often face
7. Vagaries of financial resources- that is, the unreliability or unpredictability of public funds underpinning any support effort
8. Household composition and carer relationships
9. The kind of help these families need to face the inevitable end of their caregiving role.

Source: Janicki et al. (1998).

COMMUNITY SUPPORTS - WHAT CAN AGENCIES PROVIDE?

1. Services that meet immediate needs (respite, housekeeping assistance, transportation, and emotional supports)
2. Help with getting financial supports or determinations of eligibility
3. Help with obtaining financial planning information (such as information on entitlements, guardianship and trusts)
4. Help with negotiating various services systems and advocacy for obtaining services for which they are eligible – include senior services
5. Assistance with obtaining Medicaid and resolving problems with social services agencies
6. Help with making decisions about their lives or the lives of the person for whom they are caring.
7. Physical barrier removal
8. Counseling/support groups

Janicki, M; McCallion, P; Force, LT; Bishop, K; LePore, P. (1998). Area agency on aging outreach and assistance for households with older carers of an adult with a developmental disability. *Journal of Aging and Social Policy*, 10(1), 13-36.

STRATEGIES FOR FINDING AND WORKING WITH OLDER CAREGIVERS

PLANNING AN OUTREACH STRATEGY

1. Inform families about your services

- ⇒ Prepare easy to understand written materials such as handouts and announcements which describe program
 - * convey key information in clear & concise manner
 - * reproduce in all languages spoken in the community
 - * set up displays with reordering forms, include contact phone number
- ⇒ Create public service announcements, newspaper articles, television interview
- ⇒ Plan, advertise, and hold educational workshops on specific topics of interest to caregivers
- ⇒ Visit public places where families are likely to be—shopping malls, banks, community expos
- ⇒ Attend public hearings on concerns related to disability

2. Look for families within your own system and service network

- ⇒ Use intake and information and referral personnel
- ⇒ Talk with senior centers, nutrition programs, energy assistance & weatherization programs

3. Contact other human service and health providers

4. Reach out through the business and public service community

- ⇒ Routine businesses are often point of 1st contact for older caregivers
 - * beauticians, pharmacists, police, Realtors, religious organizations, social & cultural clubs, Alzheimer's Association, VA groups, etc.

5. Work through organized groups

- ⇒ Lends credibility to effort in the community
- ⇒ Opens avenues for oral presentations at regular meetings of the organization
- ⇒ Provides access to membership lists for individual contacts or mailings

6. Tips for insuring successful outreach

- ⇒ Follow-up on referrals quickly and show your appreciation
- ⇒ Listen to the advice given to you by people in the community
- ⇒ Once personal contact is made with groups or individuals within the community, contact monthly to find out if they have identified any families in need of assistance

NOTE: Outreach takes time - don't get discouraged!

WORKING WITH OLDER CARERS

1. Work with families not just individuals - Make initial contact understanding that some families:

- ⇒ Do not have current need, but want information
 - * this is a good way to establish contact provide information
- ⇒ Are in crisis and need immediate help
 - * Emergency referrals require a rapid response
 - * Interagency collaboration most effective means to assist; develop an interagency agreement for crises' between area agency on aging, local developmental disabilities services agency and adult protective services
- ⇒ Will ask for help for a specific concern they identify, such as, housekeeping, transportation, meal preparation, home health aide, personal care attendant services, day programs, assistance with medical needs and billing
- ⇒ Provide
 - * Information
 - * Brokering - helping families contact agencies, filling out forms, making appointments
 - * Advocacy - help families communicate needs
 - * Support - a understanding/listening ear, support groups

2. Guidelines for working with families

- ⇒ Build trust - the key ingredient
- ⇒ Listen to the family
- ⇒ Acknowledge a job well done
- ⇒ Skip the jargon
- ⇒ Help and support, Don't control!
- ⇒ Begin with pressing concerns but recognize deeper concerns
- ⇒ Respect cultural values and traditions
- ⇒ Work with the whole family
- ⇒ Ask how families make decisions
- ⇒ Values, yours and theirs and how the interplay
- ⇒ **Don't Give Up!!!**

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STRATEGIES FOR FINDING AND WORKING CAREGIVERS - con't

CULTURAL ASPECTS NEEDING TO BE CONSIDERED WHEN WORKING WITH OLDER CAREGIVERS

1. The family

- ⇒ Define family; family may go beyond immediate/extended family and include friends, in-laws
- ⇒ Define who the actual care provider is; i.e., is sibling providing care but elderly mother being recognized as caregiver
- ⇒ Define the expectations *all* family members have for each other
- ⇒ Define what supports the family receives from friends and community
- ⇒ Define how the family makes decision - be careful not to impose your cultural beliefs on the family
- ⇒ Discern why the family came to this country - it may clarify the family's willingness to accept services
- ⇒ Understand the importance and effect of cultural values to family members - this applies to emigrants from other countries, as well as, African Americans, Hispanic Americans, and Native Americans who emigrate across the United States
 - * reaching out without understanding may offend families, result in missing important resources, lead to inaccuracies about the need for help and information being provided

2. The family's contact outside the cultural community

- ⇒ Willingness to accept services outside their own cultural community - families with strong cultural ties preferred to receive services within own community because of
 - * fewer problems with language and access
 - * less fear of formal service providers
 - * more familiarity with services
 - * more respect for their traditions
- ⇒ The family's native language
 - * may prevent family from learning about services - look to use existing translation services
 - * may prevent family from accessing services and medical care
 - * may impute additional expenses on families
- ⇒ The family's concern about service providers
 - * will agencies provide needed services?
 - * what will the quality of those services be?
 - * if they ask for one service, will they be required to accept other services not wanted?
 - * will a request for services be considered as justification for removing the person with a disability from the home?

3. Building Trust and communication with the family - How to Proceed?

- ⇒ Take time to understand unique meaning of the issues raised for that family
- ⇒ Network with agencies run by specific cultural groups in your catchment area; direct resources to those agencies
- ⇒ Look for successful initiatives or develop one, such as;
 - * development and dissemination of own-language materials on family caring issues and concerns
 - * recruitment and training of a group of peer outreach volunteers from an existing grandparent support program
 - * channel resources to agencies representing the cultural group and encourage strategies they know will work
 - * provide cultural sensitivity training and experiences for outreach, information and referral staff
 - * work with community leaders to reexamine agency policies and practices that may pose barriers

ISSUES AROUND TRANSITION PLANNING



ISSUE: PROVING ELIGIBILITY FOR DISABILITY SERVICES

1. Based upon federal or state statute, rules and regulations, or policy. Most state agencies use a definition such as the DD Bill of Rights and Assistance Act (PL 100-142), which generally states:

- ⇒ 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
2. Examples of difficulty in documenting that an older person has a developmental disability
- ⇒ person may never have been enrolled in a school, participated in a service or program
 - ⇒ formal documentation, (medical, school, etc.) is lost or inaccessible
 - ⇒ no family members to provide thorough history

Solution: Establish "presumptive eligibility"

GUIDELINES FOR DETERMINING PRESUMPTIVE ELIGIBILITY

1. Obtain any information about the person which is relevant and readily available.
 - ⇒ **personal sources**, such as the individual, family members, legal guardian, caregivers, neighbors & friends
 - ⇒ **formal sources**, such as social workers, physicians, dentists, psychiatrists, psychologists, podiatrists, pharmacists, home health providers, legal aid, attorneys
 - ⇒ **informal sources**, such as grocery store operators, beauticians, apartment superintendents, spiritual leaders, local community leaders
2. **Develop 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, deficits in basic educational skills
 - ⇒ Attendance at special schools or programs

Note: Don't expect people to use terms such as "developmentally delayed".
3. **Justify why you think the person is eligible for services.**
 - ⇒ summarize justification for eligibility
 - ⇒ indicate that conditions other than IDD were ruled out
 - ⇒ make sure conclusions address eligibility criteria for your state or other governmental jurisdiction

ISSUE: APPROPRIATE AND VIABLE HOUSING OPTIONS

1. Aging caregivers & their families may find current living situation is no longer viable, or may need options for the future.
2. Families may be unaware of options or uncertain about best plan

Solution: Keep certain principles in mind while working with families

- ⇒ involve the person with a disability in the decision-making
- ⇒ consider alternatives that maintain family unit, such as supportive in-home assistance, merging households with other family members
- ⇒ present as many housing alternatives as possible to the family – research your community's options

HOUSING ALTERNATIVES

1. **Home Ownership** – gives the individual most control over living arrangement
 - ⇒ can be financed with family savings, investments, first time home ownership programs or special needs trusts (see handout on legal terms)
 - ⇒ in-home services provided through health care agency, I/DD provider agency, roommate or community and family supports
2. **Renting or Leasing** – most communities have market rent or subsidized apartments available. Information can be obtained from state housing agency, public housing authorities, local affordable housing agencies, municipal & county government, housing advocacy organizations, human service agencies friends, relatives, landlords & Realtors.
3. **Home Sharing** – 2 or more unrelated persons sharing housing and expenses.
4. **Supervised Apartments** – I/DD agencies support individuals in their own individual or shared apartments. Apartment mate may or may not be an individual with I/DD.
5. **Family Care or Foster Care** – individual lives with another unrelated family. Family receive monetary support from state DD agency.
6. **Group Homes** – generally certified by government agency and operated by state or private provider agency.

ISSUES AROUND TRANSITION PLANNING

ISSUE: GUARDIANSHIP

Legal definition: One or more persons or an agency is given the right & duty to make personal and/or financial decisions for another person who has been shown to be lacking capacity in these areas.

- ⇒ “Guardian” - person or agency given right
- ⇒ “ward” - person being looked after
- ⇒ Properly exercised, it can be an important support toward maximum independence and decision making for the person
- ⇒ Families may be unaware of frequent changes in laws, also may assume that they automatically remain guardian of child with a IDD after the age of 18— *an incorrect assumption*
- ⇒ Challenge is to find a balance between maintaining autonomy and providing needed surrogate decision making

Solution: Consider *all* forms of decision making

GUARDIANSHIP continued

1. **Who can serve as guardian?**

- ⇒ Someone who has the individual’s best interest at heart
- ⇒ Someone who understands the nature and degree of the person’s disability and special needs
- ⇒ Someone whose geographical location would keep them from making frequent visits and immediate decisions

2. **How to Obtain Guardianship**

Issues

- ⇒ Procedures for becoming, standards of governing appointment of, and authority given the guardian differ from state to state
- ⇒ Many states have more than one statute governing guardianship
- ⇒ It is important to become familiar with your state’s procedures
- ⇒ Obtain information from your state’s Arc chapter, local family services agencies, the National Guardianship Association (www.guardianship.org) or the state’s protection and advocacy agency
- ⇒ Contact the National Association for Protection and Advocacy System (NAPAS—900 2nd Street, N.E., Washington, D.C. 20002; ☎ (202)408-9514

OTHER FORMS OF SURROGATE DECISION MAKING

1. **Representative Payee**

- ⇒ A person appointed who 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 for appointing representative payees
- ⇒ Appointment only applies to specific benefit program

2. **Health Care Proxy**

- ⇒ Proxy or agent who makes health care decisions for a person lacking capacity to make such decisions for self
- ⇒ Person with a I/DD can often understand their delegation of a health care proxy
- ⇒ Most states have statutes governing medical care authority

3. **Living Will**

- ⇒ Often used in conjunction with health care proxy
- ⇒ Used to express withholding or withdrawing of life-sustaining treatment wherein the person lacks capacity to make decision

4. **Power of Attorney**

- ⇒ A contract between two individuals where one party (the principal) gives to the other (the agent) authority to make any number of decisions
- ⇒ A person may lack capacity for health care decisions yet be competent to make an advance directive for power of attorney or other legal document

ISSUE: FINANCIAL PLANNING

1. **Medicaid transfer penalties**

- ⇒ Individuals over age 65 can not transfer assets to *non-disabled* children without invoking a disqualification period for Medicaid
- ⇒ Transferring assets to disabled children may disqualify disabled child for benefits

SOLUTION: - Use Special or Supplemental Needs Trusts (SNT’s)

- ⇒ A trust is a legal relationship created by a person (the settlor), in which another individual (the trustee) manages assets for the benefit of a third party (the beneficiary)
- ⇒ Provides for higher quality of life for the person with a disability
- ⇒ Special Needs Trust protect the beneficiary’s gov’t benefits as they state specifically that the individual has no legal authority to control spending of money
- ⇒ Must state that assets are to *supplement not supplant* gov’t benefits

- ⇒ Consult an attorney well versed in SNT’s

2. **Obtaining Federal Benefits - *be an educated advocate***

- ⇒ Ensure caregivers and adults with a disability are enrolled in federal benefit programs.
- ⇒ Programs include: Supplemental Security Income, Medicaid, Social Security, Medicare, Veterans Benefits, and Social Security Disability Income
- ⇒ Parents must view their adult child with a disability as financially separate from themselves.
- ⇒ It is child’s income, not parent’s income, that is reflected on a Medicaid application

KEY ISSUES IN WORKING WITH GRANDPARENT CAREGIVERS



DEMOGRAPHICS

ISSUE:

- 1. 2.4 MILLION GRANDPARENTS HAVE PRIMARY RESPONSIBILITY FOR THEIR GRANDCHILDREN**
- 2. 60% MORE LIKELY TO LIVE IN POVERTY THAN OTHER GRANDPARENTS**
- 3. HALF OF THESE CHILDREN ARE UNDER AGE 6**
- 4. 115,300 CHILDREN WITH A DEVELOPMENTAL DISABILITIES UNDER 18 LIVE IN GRANDPARENT OR OTHER RELATIVE HEADED HOMES**
- 5. REASONS FOR LACK OF PARENTAL OVERSIGHT:**
substance abuse, HIV/AIDS, teen pregnancy, death, child abuse and neglect, unemployment, divorce, family violence, poverty, incarceration, mental health

WHAT GRANDPARENTS WANT

- 1. TO MAINTAIN INDEPENDENCE**
- 2. HELP DEFINED ON THEIR OWN TERMS**
- 3. TO ASK FOR HELP WHEN THEY FEEL IT IS NEEDED**
- 4. HELP FOR SELF AND THEN FOR GRANDCHILD**
- 5. INFORMAL AND FORMAL SUPPORTS**

ISSUES AND NEEDS OF GRANDPARENTS

1. FINANCIAL

- ⇒ Milk and tennis shoes
- ⇒ Retirement savings & financial security
- ⇒ Legal barriers around obtaining assistance
- ⇒ Middle income - slip through the cracks as they earn too much for public assistance, but not enough to cover all their expenses
- ⇒ TANF, Food stamps, SSI, WIC, Foster Care, Adoption Assistance, Guardianship subsidies

2. HOUSING

- ⇒ Space inadequate
- ⇒ Senior housing that doesn't allow children
- ⇒ Lease agreements may not allow additional occupants
- ⇒ Legal barriers
- ⇒ Environmental modifications
- ⇒ Difficulty accessing safe, affordable housing

3. EDUCATION & CHILDCARE

- ⇒ Legal barriers to enrolling children in school; grandparents are not always the legal guardian
- ⇒ Participation in Individual Education Plan (IEP) for children with special needs
- ⇒ Lack of sensitivity of school personnel
- ⇒ Learning/behavior problems
- ⇒ Need respite and affordable childcare

4. LEGAL

- ⇒ Informal vs. formal legal arrangement (guardianship)
- ⇒ May need legal status to access educational, medical, mental health, financial and other services and benefits
- ⇒ Legal services expensive & long wait
- ⇒ Need access to mediation services

5. SOCIAL

- ⇒ Isolation
- ⇒ Inability to pursue personal interests due to lack of childcare
- ⇒ Being shunned by peers
- ⇒ Deferral of career goals

6. HEALTH OF GRANDPARENTS

- ⇒ Emotional strains
- ⇒ Feelings of being overwhelmed by care of child with special needs - partly due to the lack of experience in caring for a child with special needs
- ⇒ Depression/loneliness
- ⇒ Insomnia
- ⇒ Hypertension
- ⇒ Health may improve, i.e. grandparents stopped smoking because of child now in the home
- ⇒ Grandparents often over-report their own health out of fear of child being placed in foster care

KEY ISSUES IN WORKING WITH GRANDPARENT CAREGIVERS

What Agencies Can Do

HOW AGENCIES CAN HELP

1. SUPPORTING AT-HOME CARE

- ⇒ Respite
- ⇒ Housekeeping assistance
- ⇒ Emotional supports

2. PHYSICAL BARRIER REMOVAL

- ⇒ Ramps
- ⇒ Modifying doorways, bathrooms, kitchens
- ⇒ Help find affordable, safe, accessible housing

3. HELP WITH TRANSPORTATION

- ⇒ Connect grandparents with public/non-profit senior and/or accessible vans or buses

4. HELP WITH ACCESS TO SENIOR SERVICES AND SOCIAL EVENTS

- ⇒ Supply a list of local senior services
- ⇒ Hold support groups for grandparents raising grandchildren
- ⇒ Work with local theaters, performing arts centers, etc. to provide free or reduced entrance fees for performances for grandparents
- ⇒ Ageing and I/DD agencies work together to provide social events where both grandparents and grandchildren can attend together, but provide staffing to give grandparents a break

5. COUNSEL/ADVOCATE ON FINANCIAL AID & BENEFITS

- ⇒ Help with negotiating various service systems and advocacy for obtaining services for which they and/or their grandchildren are eligible
- ⇒ Assist in obtaining Medicaid and resolving problems with social services agencies
- ⇒ Provide materials or workshops on financial planning (such as entitlements, guardianship, and trusts)
- ⇒ Help with transition planning: stand-by guardian; health-care proxy; wills and living wills

6. MEDICAL/HEALTH SERVICES INTERMEDIATION

- ⇒ Help negotiate appropriate medical services for both grandparent and grandchild; provide list of specialists for children with disabilities
- ⇒ Aid with transition planning: Future grandparent health needs, i.e. dementia care and frailty
- ⇒ Support groups/counseling for emotional needs