Bridging the Aging and Developmental Disabilities Service Networks: Challenges and Best Practices

Alan Factor, Tamar Heller, and Matthew Janicki

Institute on Disability and Human Development
University of Illinois at Chicago

March 15, 2012

Funded by the Administration on Developmental Disabilities through the Association of University Centers on Disabilities

UIC UNIVERSITY OF ILLINOIS AT CHICAGO Department of Disability and Human Development
COLLEGE OF APPLIED HEALTH SCIENCES

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ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
RESEARCH, EDUCATION, SERVICE

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TABLE OF CONTENTS

EXECUTIVE SUMMARY 7

INTRODUCTION 11

NEEDS OF ADULTS WITH DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES 14

DESCRIPTION OF SERVICE NETWORKS 18

HISTORY OF BRIDGING AGING AND DEVELOPMENTAL DISABILITIES 24

FEDERAL HEALTH AND LONG-TERM SUPPORTS AND SERVICES REFORM 29

THE BRIDGING ROLE OF AGING AND DISABILITY RESOURCE CENTERS 36

SUMMARY OF KEY ISSUES 47

RECOMMENDATIONS FOR BRIDGING THE AGING AND DD NETWORKS 51

REFERENCES 55

APPENDIX 1: ACRONYM DEFINITIONS 59

APPENDIX 2: SUMMARY OF TESTIMONIES ON AGING ISSUES PRESENTED AT THE ADD ENVISIONING THE FUTURE SUMMIT SERIES 63

APPENDIX 3: MEMORANDUM OF UNDERSTANDING BETWEEN AOA AND ADD 71

APPENDIX 4: ADMINISTRATION ON DEVELOPMENTAL DISABILITIES AGING TRAINING INITIATIVE PROJECTS (TIPS) 78

APPENDIX 5: AOA AGING AND DEVELOPMENTAL DISABILITIES DISCRETIONARY GRANTS 81

APPENDIX 6: EXECUTIVE SUMMARY OF "MY THINKER'S NOT WORKING" – A NATIONAL STRATEGY FOR ENABLING ADULTS WITH ID AFFECTED BY DEMENTIA TO REMAIN IN THEIR COMMUNITY AND RECEIVE QUALITY SUPPORTS 97

APPENDIX 7: STATE PROFILES OF ADRCS SERVING PEOPLE WITH DEVELOPMENTAL DISABILITIES 103

APPENDIX 8: EXAMPLES OF UCEDD COLLABORATIONS WITH ADRCS 108

APPENDIX 9: INFORMATION SOURCES 110

EXECUTIVE SUMMARY

Background

People with developmental disabilities are aging at unprecedented rates and have unique health and service needs. Adults with developmental disabilities have a higher risk of developing chronic health conditions at younger ages than other adults, due to the confluence of biological factors related to syndromes and associated disabilities. They also may face poor access to adequate health care, as well as lifestyle and environmental issues.

These unique service needs of this population pose new challenges for existing service networks. Traditionally the aging and developmental disabilities services systems have run on parallel tracks. Large-scale legislative changes that target long-term care services and supports will require greater communication and coordination between the two systems. In this time of great transformation, it is critical for the two systems to work together as their populations face similar needs including managed long-term, integrated care for people who are dually eligible for Medicaid and Medicare, and rebalancing initiatives that promote community living.

Purpose and Objectives

By assessing key issues this population faces, and the extent to which they are being addressed, this project identifies policy and service delivery issues pertaining to adults aging with developmental disabilities and their families. This initiative includes discussion of the differential and shared philosophies and values underpinning the aging and developmental disability networks. It also provides information for the Administration on Developmental Disabilities (ADD) and other federal agencies on being catalysts for promoting progressive policies across aging and disability populations. And finally this report recommends opportunities to enhance collaboration among the aging, disability, and long-term care networks.

Policy Initiatives

This report discusses recent major policy developments that pertain to the service needs of people with developmental disabilities and their families. Widespread efforts to bridge the aging and developmental disabilities (DD) service systems began in the 1980s in response to the large numbers of adults with developmental disabilities who were surviving into old age, including many who were still living with their parents. States also began to establish managed care plans for health care and long term supports for people with developmental disabilities and other Medicaid beneficiaries to contain escalating program costs.

More recently, passage of the Lifespan Respite Care Act (P.L. 109-442) and National Alzheimer's Project Act (NAPA, P.L. 111-375) have provided the opportunity for grantees to further involve and incorporate people with developmental disabilities into their services and supports. Additionally, several provisions of the Patient Protection and Affordable Care Act (ACA, P.L. 111-148) will have a positive impact on health care for people with developmental disabilities.

Launched in 2003, the Aging and Disability Resource Center (ADRC) initiative is a joint effort of the Administration on Aging (AoA) and the Centers for Medicare and Medicaid Services

(CMS). Aging and Disability Resource Centers bridge the aging and disabilities service networks by establishing local "one-stop shops" that streamline access to long-term services and supports for older persons and younger people with disabilities. Although the ADRC program has been operating for eight years, only a handful of states targeted people with developmental disabilities as the primary disability group their ADRCs serve. Most states chose to serve people with physical disabilities through their ADRCs. AoA is positioning ADRCs to play a key role in linking people to the expanded long-term supports and services that will be provided under the Affordable Care Act. This report examines the facilitators and barriers to bridging the aging and developmental disabilities service networks and provides recommendations for improving access to long-terms services and supports for people with developmental disabilities and their families.

Recommendations

This time of dramatic policy change provides an opening for agencies to improve efficiency and coordination to better serve people with developmental disabilities and their families. The present project recommends four overarching goals: 1) raise the visibility of developmental disabilities concerns in policy reforms, 2) improve program implementation of health and long-term support initiatives to better address needs of persons with developmental disabilities, 3) develop a workforce with knowledge and skills to address disability and aging issues, and 4) better understand the age-related needs and best practices in meeting those needs through research and evaluation.

Goal A: Raise the visibility of developmental disabilities concerns in policy reforms.
ADD and developmental disabilities stakeholders need to work with CMS to develop a joint understanding of values and unifying principles regarding such concepts as "person-centered planning" and " transition planning"**.**
ADD must have a direct role in providing feedback on national rebalancing and healthcare reforms that affect people with developmental disabilities.
State DD Councils should recruit and support the participation of people with developmental disabilities on mandatory advisory committees for implementation and evaluation of state ACA initiatives.
ADD should ensure that DD self advocacy organizations are included in national advocacy efforts to implement the ACA.
ADD should partner with AoA and CMS to reconceptualize the ADRC concept as a process for linking people with long-term supports and services and mandate that local ADRCs include people with developmental disabilities**.**

ADD should support AoA's proposed amendment to the reauthorization of the Older American's Act of 2006 that expands the National Family Caregiver Support Program to target older parents caring for their adult children with disabilities.
Ensure that NAPA addresses adults with dementia and intellectual disabilities in implementing its national plan to combat Alzheimer's disease.
ADD can be a federal presence to ensure that state plans for implementing the Lifespan Respite Act adequately address the needs of families of people with developmental disabilities**.**

Goal B: Improve program implementation of health and long-term support initiatives to better address needs of persons with developmental disabilities.
Ensure that when states implement ACA programs (e.g., dual eligible integrated care programs) that the programs work with the ADD agencies (DD Councils, University Centers of Excellence in DD, and Disability Rights Centers).
Improve the responsiveness of ADRCs to people with developmental disabilities.
Include future planning for older family caregivers and adults with developmental disabilities as a function of the ADRCs.
In states that have a single waiver serving both older parents and their adult child with developmental disabilities, the ADRCs can help coordinate linkages across networks.
Establish ADRCs as focal points for coordination between state Disability Rights Centers and state programs for Prevention of Elder Abuse, Neglect, and Exploitation.
Incorporate supports for dementia care in state DD agencies.

Goal C: Develop a workforce with knowledge and skills to address disability and aging issues.
ADD, AoA and CMS should partner to develop guidelines for ADRC staff cross-training in aging and developmental disabilities that addresses misconceptions of the two networks.
ADD should work with federal partners (e.g., Health Resources and Services Administration, AoA) to include cross-training in aging and developmental disabilities for health and direct support professionals.
State Disability Rights Centers need to ensure the rights of people with developmental disabilities are protected as states implement integrated care programs for dual eligibles.
ADD, AoA, and CMS can support the development and dissemination of the assessment tools and caregiving materials the National Task Group on Intellectual Disability and Dementia Practices is developing.

Goal D: Better understand the age-related needs of people with developmental disabilities and the best practices in meeting those needs through research and evaluation.
Support the evaluation of ACA healthcare and long-term care reform outcomes for people with developmental disabilities.
The federal agencies should provide supports for further research to assess and understand the nature of the needs of older adults with developmental disabilities and their families.
Use the findings of the National Institute on Disability and Rehabilitation Research, National Institute on Aging, and AoA funded supplements on aging and disability to help inform future research in aging with developmental disabilities.

INTRODUCTION

Given the demographic imperatives of the longer life expectancy of adults with developmental disabilities and the aging of the baby boomers, a growing challenge exists to address this population's later life needs. Traditionally the aging and developmental disabilities (DD) services systems have run on parallel tracks. More recently, initiatives in health and long term services and supports reform target both networks, requiring greater communication and coordination between the two systems. It is important for the two systems to work together as their populations are facing similar transformations in services including managed long-term, integrated care for people who are dually eligible for Medicaid and Medicare, and rebalancing initiatives that promote community living.

In order to develop best practices for bridging the aging and DD networks, we need to identify the issues people aging with developmental disabilities and their families face both through research findings and stakeholder input. Also, we need to understand the structure and values of the two networks, and examine both historical and current practices.

Purpose and Objectives

The purpose of the "Bridging the Aging and Developmental Disabilities Service Networks" initiative is to identify policy and service delivery issues pertaining to older adults with developmental disabilities and their families and to recommend opportunities to enhance collaboration among the aging, disability, and long-term care networks. This report assesses key issues faced by this population and the extent to which they are being addressed. It includes discussion of both differential and shared philosophies and values underpinning the aging and DD networks. It provides information for use by the Administration on Developmental Disabilities (ADD) and other federal agencies which could help them to be catalysts for promoting progressive policies across aging and disability populations.

Project objectives are to:

1. Synthesize testimonies regarding concerns about growing older expressed by people with disabilities and other stakeholders at the Envisioning Sessions the Administration on Developmental Disabilities (ADD) convened to inform its strategic plan.

2. Identify differences and commonalities in values, philosophies, and practices in the aging and developmental disabilities services networks that shape policies and service delivery.

3. Identify, to the degree possible, the long-term impact of previous efforts to bridge the aging and developmental disabilities services networks, including the ADD's Aging Training Initiative Projects (TIPS) and the Administration on Aging's (AoA) discretionary grants.

4. Examine current federal initiatives at the Centers for Medicare and Medicaid Services (CMS) and the AoA that relate to community-based long-term care and supports of adults of all ages with disabilities, (e.g., Aging and Disability Resource Centers, Lifespan

Respite Care Act, re-authorization of the Older Americans Act, Money Follows the Person, National Alzheimer's Project Act), and the extent to which they address the needs of people with developmental disabilities and their families. Develop recommendations incorporating suggestions by the project's work group representatives from ADD, AoA, the National Association of State Directors of Developmental Disabilities Services (NASDDDS), CMS, Health and Human Services Office on Disability, and the Association of University Centers on Disabilities (AUCD) to better address the later life needs of adults with developmental disabilities and their families.

Project Activities

The methodology for gathering data for this report included the following activities:

Summarized the research on later life health and support needs of older adults with developmental disabilities and their families.

Summarized and synthesized testimonies and day two discussions related to aging and developmental disabilities from the ADD Envisioning Sessions.

Reviewed outcomes and results of ADD funded Aging Training Initiative Projects (TIPS) and AoA grants to address the needs of older adults with developmental disabilities and their families.

Identified and interviewed ADRC staff at the state and local levels to identify promising best practices and challenges to serving adults with developmental disabilities and their families.

Held three meetings with key stakeholders and policy makers to review material, discuss issues, and develop preliminary recommendations.

Our in-depth analysis of the ADRC network's role in addressing the long-term care needs of people with developmental disabilities and their families was based on:

Reviews of ADRC performance reports to determine the number of people with developmental disabilities served nationally and to identify states serving the largest numbers of people with developmental disabilities.

Telephone interviews and email correspondence with key informants in the states with the greatest outreach to people with developmental disabilities to identify the best practices and obstacles affecting their success. Participants included the state ADRC coordinator, staff from the state developmental disabilities council and state I/DD service system, and UCEDD staff that provided training and technical assistance to ADRCs.

Email surveys to the national UCEDD network to determine their role in providing training, technical assistance, and evaluations of ADRCs.

Reviews of ADRC technical assistance materials prepared by the Lewin Group, AoA and CMS reports and grant announcements, the 2006 Older Americans Act, the 2000 Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402), and the Affordable Care Act, to understand the ADRC network's role in health reform, long-term care rebalancing, and Medicaid integrated health and long-term care.

NEEDS OF ADULTS WITH DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES

Background

Demographic Trends. Over the next 20 years the number of older adults with developmental disabilities and older family caregivers will increase considerably. Based on the 2010 Census, we estimate there are 850,600 people with developmental disabilities age 60 and older living in the community.[1,2] By 2030 their numbers will swell to 1.4 million due to increasing life expectancy and the aging baby boom generation.[3] Families remain the primary providers of care for people with developmental disabilities. In addition to the general "graying of America," the last fifty years have seen trends in the US toward more dual income households and families living in poverty.[4] Each of these trends results in increased demands on families, especially parents of adults with developmental disabilities who provide periods of caregiving often extending into their own old age. Other important trends include the increasing number of ethnic minority families. The percentage of non-Hispanic Caucasians is estimated to drop from 75.6% in 2004 to 54% of the population in 2050.[5] Cultural caregiving norms and language barriers often conceal the need for services that only becomes apparent when families are in a crisis situation.

Health and Function. Adults with developmental disabilities have a higher risk of developing chronic health conditions at younger ages than other adults, due to the confluence of biological factors related to syndromes and associated disabilities, lack of access to adequate health care, and lifestyle and environmental issues. The mean age of death for persons with developmental disabilities was 66 years in 1993, compared to 59 years in the 1970s and 33 years in the 1930s. The average longevity of people with Down syndrome increased from nine years in the 1920s to 31 years in the 1960s to 56 years in 1993.[6] An Australian study reports the average age of death for people with mild and moderate intellectual impairment who do not have any chronic health conditions is 71 years.[7] Information is beginning to emerge on select genetic and nonspecific neurodevelopmental conditions, linked to intellectual disabilities, which are affected differently by maturation and aging. For example, Down syndrome has been linked to premature aging, Alzheimer's disease, and certain organ dysfunctions.[8-10] In addition to genetic disorders, specific health problems related to the older age trajectories of several common neurodevelopmental conditions such as cerebral palsy (e.g., osteoporosis and degenerative joint disease), autism (e.g., digestive system disorders and neuropsychiatric factors) and spina bifida (e.g., neuromotor and other organ system consequences) are of concern.[11] There is a greater prevalence of obesity and a sedentary lifestyle among adults with developmental disabilities than in the general population. Their health concerns and lifestyle differences point to the need for health promotion interventions, exercise and nutrition programs, health behavior education, and health screenings. Also a need exists for education of health professionals, direct support professionals, and families and other caregivers in addressing the health issues of adults aging with developmental disabilities.

Community Participation. People of all ages with disabilities want to be part of their community, and such opportunities are especially important for older adults with developmental disabilities who may want to "age in place", i.e., remain in their homes or in their jobs with adaptations for age-related changes. Some adults may want to retire from their job or vocational training. The aging network can be a resource for linking older people with disabilities to

"Two weeks ago we received a letter from the state of New Jersey stating that (our son) is now number 776 on the waiting list. (He) has seven more years to wait for residential services. He will be 43. We will be 71. This alone is unacceptable." (family member)

community activities, including volunteer work that provides opportunities to explore new interests, develop new skills, and form new friendships.

Family Support. The majority of adults with developmental disabilities live with immediate family members or kin. One quarter live in their own household or with a spouse, and sixty percent, or nearly 2.9 million people, live with their family. Twenty five percent of family caregivers are age 60 and older, and another 35% are in the 41-59 age range.[12] Only 12% of the 4.8 million Americans with developmental disabilities live in any type of formal supervised residential setting. Nationally, nearly 123,000 persons were estimated to be on waiting lists for residential services in 2009.[11] Life expectancy gains indicate there will be growing numbers of two-generation elderly households of people with disabilities living with their parents. These families remain intact out of choice or due to the shortage of alternative residential options. Both generations will require supports to age in place. Often when parents can no longer provide care, siblings may be called upon to take over that role with little formal support provided to them.

Although all states now fund family support in the form of cash subsidies and/or direct services, in 2009, national family support expenditures of $3.8 billion accounted for only 7% of total national developmental disabilities expenditures. Only 17% of families caring for a relative with a disability at home received family support.[12] The gap between need and available public resources is expected to increase with the looming demographic challenges.

"Oftentimes we find that the family needs multiple supports in order for the individual with a developmental disability to remain in the home living with their family. If they choose to do so, this requires coordination of care between long-term care agencies, education, training, and a single point of entry." (DD human service administrator)

These families often first come to the attention of the aging network through referrals from hospital discharge planners, friends, and neighbors, especially when the older parents need support due to age-related changes in health and function. In some households, the person with a disability may care for an aging parent. These families need to make informed decisions about their own support needs, as well as help the person with a disability plan for his or her future.

Future Planning. Many older parents and their adult offspring with a disability lack plans regarding what may in store in the future for the adult with a disability. Without adequate plans in place these adults could lose eligibility for benefits, lose protections and supports, and face inappropriate admission to emergency residential settings. Evidence-based interventions exist to assist these families in planning for the future that are based on peer support, person-centered planning, and inclusion of siblings, and the individuals with developmental disabilities and other families members.[13] However, currently there is no national infrastructure available to assist

these families with future planning. Future planning must include such issues as:

a. Financial planning to ensure individuals protect or maintain their eligibility for government benefits and services.
b. Legal and advocacy planning, when appropriate, to ensure continuation of guardianship or other decision-making supports for individuals with cognitive disabilities.
c. Residential planning concerning where the individuals will live when older caregivers move away, die or otherwise cannot continue to provide care or supports.
d. Vocational preferences, supports, and planning.
e. The individual's preferences for community participation.

ADD Envisioning Session Testimony on Aging Needs and Concerns

The acknowledgement of the limited knowledge of age-related health changes and the gaps in support for community participation and for families was reinforced by testimonies of people with disabilities and families at ADD's Envisioning Sessions. ADD held five regional listening summits in the last quarter of 2010 to obtain stakeholder input for preparing its five-year plan. People with disabilities, families, and community allies testified on major issues affecting childhood, adulthood, old age (i.e., age 60 until the end of life), and formal and informal supports that need to be addressed to ensure individuals with disabilities will have expanded opportunities to live richer and more satisfying lives in the future. The question related to aging was:

> *What can we do to empower older individuals with developmental disabilities to remain in their own homes with a high quality of life, to maintain independence and good health for as long as possible, and to enjoy community and family relationships through the end of life?*

We expanded our analysis to include testimony on mid-life adulthood and support issues because of the potential overlap with aging concerns. Appendix 2 contains the full report. Following are stakeholders' key concerns about old age:

> People with disabilities want to remain in their own home and stay active in their community by having access to the supports and services necessary to offset age-related declines in health and function.
>
> Families want to reduce state waiting lists for developmental disabilities services to decrease their stress about planning for the future – because supports and services will be more readily available to meet their relative's needs and preferences.
>
> Siblings want support to engage their family in making future plans. As their parents grow older, siblings increasingly worry about their brother/sister's future well-being after parents become infirm or die.

Families and professionals emphasize the importance of providing health promotion for people with developmental disabilities and educating health professionals to diagnose and treat age-related health changes that older adults experience.

Families and professionals advocate for collaboration between the aging and developmental disabilities service networks to ensure that people with developmental disabilities and their families have access to appropriate supports and services to meet their later life needs.

DESCRIPTION OF SERVICE NETWORKS

Developmental Disabilities Service System

Although the Individuals with Disabilities Education Act (IDEA, PL 101-476) requires states to provide special education and services to all children with disabilities through age of 21, there are no targeted federal entitlements for most community services for people with developmental disabilities when they exit the public education system. No single federal agency is responsible for planning and funding community services and supports that address the lifespan needs of adults with developmental disabilities. The Administration on Developmental Disabilities (ADD), within the Agency for Children and Families, is responsible for implementing the Developmental Disabilities Assistance and Bill of Rights Act (DD Act, P.L.106-402), which was reauthorized in 2000 and was scheduled to be reauthorized in 2011. The goal of the DD Act is to establish statewide systems of community services and supports that enhance the self-determination and independence of people with developmental disabilities so they can be productive and valued members of the community. ADD funds and administers three programs in each state to foster the development of progressive policies and services and engage people with developmental disabilities and their families in this process, build and strengthen service system capacity, and protect the rights of people with developmental disabilities:

1. *State Councils on Developmental Disabilities* undertake advocacy, systems change, capacity building activities, and develop a multi-year state plan in conjunction with a variety of state agencies, including the state developmental disabilities authority. Council members are appointed by the Governor. Under the federal law, at least 60% of the members must be people with developmental disabilities, parents of children, and family members or guardians of individuals who cannot advocate for themselves. Councils also are required to include the State Unit on Aging as a member. Councils examine deficiencies in state services, advocate for people with developmental disabilities, train and support people with disabilities and their families to advocate for progressive policies and services, and provide “seed” grants to implement “best practice” projects.

2. *Protection and Advocacy Agencies* (now known as Disability Rights Centers) are responsible for upholding the civil and legal rights of people with developmental disabilities through advocacy, investigating complaints of rights violations, and resolving complaints through mediation, alternative dispute regulation, and litigation. Disability Rights Centers coordinate their activities with the state unit on aging long-term care ombudsman and elder abuse programs.

3. *University Centers for Excellence in Developmental Disabilities* (UCEDDs), part of a national network funded by the ADD, provide interdisciplinary training to students and professionals, engage in research, provide technical assistance to stakeholders, and establish clinical and community service programs for people with developmental disabilities and their families.

The DD Act also funds projects of national significance that enable individuals with developmental disabilities to participate in and make contributions to all facets of community life and to develop progressive state and federal policies that support the self determination and community participation of individuals with developmental disabilities.

The DD Act's principles and programs have spurred state DD authorities to implement progressive policies and services that support and enhance the lives of people with developmental disabilities and their families. However, ADD does not have a role in establishing federal policy or funding services. De facto federal policies result from the Centers for Medicare and Medicaid Services (CMS) regulations states must comply with in establishing their Medicaid state plans and meeting Medicaid waiver requirements to fund home and community-base services.

States vary widely in the nature and availability of services and supports they provide for adults with developmental disabilities and their families. Factors contributing to this trend include:

> Whether states use the functional or categorical definition of developmental disabilities or some combination of the two to determine eligibility for services (under which not all conditions included under federal law are required for services under state law).[14, 15, 16, 17]
>
> State funding authorized by the state legislature plus the availability of local funding resources.
>
> The optional services states include in their Medicaid state plan.
>
> States' use of the 1915 (c) Medicaid waiver to fund home and community-based services.
>
> Whether states use a fee-for-service or a managed care model of service delivery.

The Aging Service System

The Older Americans Act (OAA) of 1965 (P.L. 89-73) was legislated to maximize the independence of older people and help vulnerable older adults remain in their home and community by providing a limited array of services to support these outcomes. The OAA and its amendments established a national infrastructure consisting of the Administration on Aging (AoA) and the national network of state units on aging, area agencies on aging, tribal and Native American organizations, and community agencies to plan and deliver its services, and to advocate progressive public policies and programs. The AoA within the Department of Health and Human Services administers OAA programs and services and is the federal focal point for addressing issues affecting older persons. OAA services are targeted to older adults with the greatest social and economic need and who are at risk of institutionalization. States and Area Agencies on Aging (AAAs) use OAA funds to leverage other funding sources.

Key components of the OAA include:

> Title III provides nutrition programs, supportive services (e.g., information and access, home care, adult day services, case management, and senior center activities), the National Family Caregiver Support Program, and disease prevention and health promotion programs. Title III services are entitlements that are available to all people age 60 and older (with some exceptions) at no cost, although participants are encouraged to make voluntary contributions to specific programs (such as congregate meals). Nearly two-thirds of the OAA budget is allocated to Title III services.
>
> Title IV funds research, training, demonstration and technical assistance projects to improve aging services.
>
> Title V funds the Community Service Employment Program which provides job training and employment for low income older people.
>
> Title VII funds the Long-Term Care Ombudsman and Elder Abuse programs.

The OAA was last reauthorized in 2006 and the scheduled reauthorization in 2011 did not occur. The various amendments since 1986 have contained provisions for support services to older families caring for adult children with disabilities and for state plans to coordinate services for older adults with severe disabilities which include developmental disabilities. [18, 19, 20]

Similarities between Objectives of the Aging and DD Networks

Many commonalities exist between the needs of people aging with lifelong developmental disabilities and people aging with late-life disabilities. Both groups often require health and long-term supports and services which are designed to support the same three outcomes: 1) maintaining optimal health and function, 2) participating in purposeful community activities, and 3) engaging in meaningful relationships. Table 1 demonstrates the similarities between the objectives of the Older American Act and the priorities voiced by stakeholders in the ADD Envisioning Sessions.

Table 1. Similarities of Older Americans Act and ADD Envisioning Session Objectives

Older Americans Act Objectives[17]	ADD Envisioning Session Priorities
Access to the best possible health care regardless of economic status.	Improved access to quality health care.
Opportunities to pursue a wide range of meaningful community activities.	Participation in welcoming, inclusive community.
Independently selected affordable housing that is designed and located with reference to special needs.	Promotion of incentives for affordable accessible housing.
Adequate income in retirement.	Improved economic self-sufficiency.
Efficient community support services that are coordinated in a meaningful manner and available when needed.	Access to quality home and community services and supports.
Freedom, independence, and the free exercise of individual initiative in planning and managing one's life.	Promotion and support self determination.
Avoidance of institutional care.	Elimination of congregate care.
Use of proven research knowledge to sustain and improve health and happiness.	Dissemination and sharing of information, data, strategies, and best practices.
Opportunities for employment without age discrimination.	Increased access to employment.

Philosophical Differences in Service Delivery

Despite the commonalities that exist between the needs of people aging with life-long developmental disabilities and people aging with late life disabilities, the service networks are part of two distinct systems that are underpinned by differing ideologies, conceptualizations, structures, language, and practices that can hinder opportunities for collaborative efforts between the aging and disability policy sectors. The term disability implies impairment, while aging is defined by chronological age.

Key barriers to integration between the aging and disability systems occur in a number of areas:

Deeply entrenched cultural differences with different conceptualizations–, with the disability community historically being resistant to medicalization, given a strong activist movement geared towards empowerment and independence and adherence to the social model emphasizing societal barriers as major causes of disability.

Reluctance of older people who experience the onset of impairments (or disability) in late life to be labeled as having a disability and to be included in programs for people with lifelong disabilities.

Differences in principles and values underlying such concepts as "person-centered planning" and their implementation (e.g., engaging individuals in looking for creative ways to meet their needs versus presenting them with current service options).

Reluctance of one sector to share resources and funds with the other, given perceptions of more resource availability in the DD network and of increasing budgetary constraints in both sectors.

Different organization and delivery of funding (e.g., pathway to services, waiting lists, entitlements).

Fear that the needs of one group might be short changed to the policy agenda of the other.

Lack of knowledge of aging in the disability sector and lack of knowledge of disability in the aging sector.

"We have a silo for older adults and we have silos for people with developmental disabilities. Although there are similarities and differences, these silos are not communicating or sharing or working together to really understand the supports that are needed. I don't think we have developed, in most states, a sufficient infrastructure to address the needs of aging individuals with developmental disabilities." (UCEDD administrator)

The aging service system has adopted the disability community's ingrained philosophies of self-direction, person-centered planning, and participant- directed services. Yet, disparities in their implementation coupled with differences in the structure of the aging and DD service systems and the services they provide are often barriers to collaboration (there are exceptions – particularly in situations where key staff have experienced employment in both sectors). Older Americans Act programs serve a large number of people at a relatively low cost per person.[21] In contrast people with developmental disabilities often require intensive staff support to provide varying degrees of skills training, personal assistance services, and supervision. People with developmental disabilities consumed 72% of 2006 Medicaid waiver expenditures although they accounted for only 40% of waiver enrollees.[22] The 2008 average per

capita expenditure for home and community based services under the 1915 (c) Medicaid waiver was $42,896 for people with developmental disabilities, $9,510 for the aged and $18,043 for people with physical disabilities.[23]

People with developmental disabilities also experience long waiting lists for services in most states. In 2010, 268,220 people were on state wait lists for Medicaid 1915 (c) HCBS DD waivers which was double the combined wait list size for the elderly and people with physical disabilities, and their average waiting period for a waiver slot to open was three times as long (36 months compared to 9-13 months for the 'aged and disabled' waivers).[23]

Service system structural differences and staff attitudes also pose barriers to collaboration between the aging and DD networks. In comparison, it is easier to forge collaborations between the aging and independent living networks. Older people and younger people with physical disabilities primarily need support with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). Area Agencies on Aging and Centers for Independent Living both have locations across the state.

To some extent partnerships between networks serving people primarily with physical disabilities, such as the centers for independent living (CIL) have faced fewer barriers in establishing partnerships with the aging network than have DD agencies. AAAs and CILs both have regional offices and primarily provide advocacy and Information and Referral.

History of Bridging Aging and Developmental Disabilities

Widespread efforts to bridge the aging and developmental disabilities (DD) service systems began in the 1980s when community agencies realized growing numbers of people receiving services were surviving into old age. It became apparent that vocational, habilitation, and residential programs were not designed and staffed to address age-related changes including reduced stamina, skill loss, and the onset of chronic health conditions that many participants experienced. Older families caring for a relative with developmental disabilities at home also would need support. Extended caregiving responsibilities would conflict with parents own age-related vulnerabilities. Older parents also needed to make future plans with their adult child who was increasingly likely to outlive them. Heller and Factor's study of older Illinois families (1987) found that less than half made future residential plans concerning the adult with a disability.[24]

By the mid-1980s, thirty seven state DD agencies were conducting needs assessments and developing policies to serve the growing number of adults that were surviving into old age.[25] A national survey identified 192 residential programs and 135 day services programs that were newly opened or had been adapted to specifically meet the needs of older adults with developmental disabilities.[26] These activities created the momentum for a groundswell of national research, training, and policy initiatives through the mid-1990s to bridge the aging and DD service systems.

Formal national organizations including the American Association on Intellectual and Developmental Disabilities, the Gerontological Society of America, the Association of University Centers on Disabilities (AUCD), the International Association for the Scientific Study of Intellectual Disabilities, and the American Society on Aging established formal interest groups in aging and developmental disabilities.

The 1986 Wingspread Conference on Aging and Developmental Disabilities brought together directors of state DD agencies and state units on aging to explore opportunities for bridging the service systems. However, the conference did not produce any long-term results due to the (politically linked) high turnover of directors in both agencies. [27]

The 1987 reauthorization of the Developmental Disabilities Act (P.L. 100-146) included two provisions that recognized the aging of adults with developmental disabilities as a priority. UCEDDs were able to apply for grant supplements to their core funding to train personnel in the age-related needs of adults with developmental disabilities as one of three areas of emerging national significance. State developmental disability council membership was expanded to include the State Unit on Aging.

Several provisions were incorporated in the 1987 reauthorization of the Older Americans Act (P.L. 100-175) to foster collaboration between the aging and developmental disabilities service systems. Older persons with a severe disability were designated as a service priority, and the definition of "severe disability" was identical to the functional definition of developmental disability in the 1978 amendments of the Developmental Disabilities Act (P.L. 95-602). The AoA also was authorized to establish a

multidisciplinary gerontology center with special emphasis on disability including people with severe disabilities. The Commissioner of AoA was authorized to consult with the Commissioner of ADD on the administration of the DD Act and the Older Americans Act with an emphasis on community-based alternatives to long-term care. State and area agency on aging plans were to include older people with severe disabilities as a service priority. The state unit on aging long-term care ombudsman program was required to coordinate ombudsman services with the Protection and Advocacy agency for people with developmental disabilities. Disabled dependent adults under the age of 60 were allowed to be served at nutrition site programs when accompanied by an eligible older caregiver.

In 1988 the Health Care Financing Administration (HCFA) (now CMS) included an Active Treatment objective to minimize skill regression due to aging.

The 1992 Amendments to the Older Americans Act targeted outreach to older parents caring for an adult son or daughter with developmental disabilities at home and authorized Title IV funding for training and demonstration projects to address the needs of older adults with developmental disabilities and older family caregivers.

In 1989 ADD and AoA executed a Memorandum of Agreement[28] (Appendix 3) to discuss and develop joint initiatives to improve the coordination of their programs and activities which support the independence and well-being of older adults with developmental disabilities. The three goals were to:

1) Promote a better understanding of each agency's programs by increasing information sharing stimulating linkages across network programs and resource centers.

2) Demonstrate a national commitment between AoA and ADD for serving older persons with developmental disabilities by providing policy guidance, promoting staff training, encouraging linkages between national organizations and federal, state, and local agencies serving older adults with developmental disabilities, and jointly developing discretionary funds announcements.

3) Improve services to older adults with developmental disabilities by identifying their unmet service needs, facilitating the development of quality services, promoting training of health care professionals, and mainstreaming older adults with developmental disabilities in aging network programs.

The purpose of the 1990 Memorandum of Understanding between AoA and the National Institute on Disability and Rehabilitation Research (NIDRR) [29] was to promote cooperative efforts to expand research on the health and function of older persons with disabilities, apply the research findings to their health care and long-term supports and services, and increase the number of researchers and professionals working with older adults with disabilities.

Administration on Developmental Disabilities

The 1987 amendments to the DD Act authorized ADD to fund a network of Training Initiative Programs (TIPs) in aging, early intervention, and direct care training. The Aging TIPs were funded twenty years ago, and neither ADD nor AUCD had information of the projects or their outcomes. We were able to identify nine UCEDDs that were awarded Aging TIPs based upon the Rehabilitation Research and Training Center on Aging and Developmental Disabilities (RRTCADD) Clearinghouse materials, information provided by long-time staff at UCEDDs, and an abstract of ADD TIP projects archived at the National Rehabilitation Information Clearinghouse (NARIC).[30] The UCEDDs conducting training initiatives in aging and developmental disabilities included the Shriver Center, University of Illinois at Chicago, Indiana University, University of Montana, University of Miami, University of Georgia, University of Rochester, University of Missouri-Kansas City, and University of Wisconsin. The TIPs focused on three age-related concerns: 1) age related changes in health and function, 2) caregiving and future planning for older adults with developmental disabilities and their families, and 3) person-centered planning for free-time activities in the community. These UCEDDs became centers to which researchers and agency staff with an interest in aging could gravitate. Appendix 4 contains descriptions of these projects.

Many Aging TIPs had a shelf-life of several years, and their leaders formed a national network that still exists within the AUCD's aging and developmental disabilities workgroup. The eventual demise of some TIPs was the result of the aging-out of its leaders, changing research interests, and the withdrawal of funding by ADD for aging-related initiatives. The latter resulted in the closure or transfer of some aging clinics to generic or specialized health facilities. For example, the Illinois UCEDD's Cerebral Palsy Clinic moved to the Rehabilitation Institute of Chicago.

However, several UCEDDs funded as Aging TIPs continue research and training in aging and developmental disabilities and have branched out in new directions. The Indiana University UCEDD has ongoing projects in building community supports for older adults with developmental disabilities through the work of gerontologist Phil Stafford. Some Aging TIPS that included a research component have built upon this to develop a larger research portfolio. The University of Wisconsin's Waisman Center has expanded its research on older family caregivers through other funding sources. The University of Rochester's Strong Center is developing a dataset on adult lifespan health issues and continues to conduct staff training on aging with developmental disabilities. The Illinois UCEDD has been funded as the RRTC on Aging with Developmental Disabilities since 1993 by the National Institute on Disability and Rehabilitation Research (NIDRR) and has subcontracted with the UCEDDs in Indiana Wisconsin, Rochester, Kentucky, Cincinnati, Hawaii, Florida, and Minnesota to conduct specific research projects.

Administration on Aging and Developmental Disabilities Discretionary Grants

A search of the AoA bibliographic data base to date identified 11 grants that were awarded to seven states (NY, HI, MO, IL, WI, PA, VA) from 1986 to 1994.[31] The majority of projects

established collaborations between aging and DD agencies to integrate older people with developmental disabilities into community programs, conduct outreach and provide supports for older family caregivers, and support older families and their relative with disabilities to make future plans. The AoA also awarded discretionary grants to two national organizations during this time period. A grant to The Arc funded coalitions between local Arc agencies and other community agencies to build community capacity for outreach and support to at-risk older parents caring for adults with developmental disabilities. National Easter Seals was funded to heighten the disability community's awareness of the growing need for services and supports among older persons with disabilities and functional limitations and developed three models for assisting at-risk older persons with disabilities. In 2001, AoA funded five demonstration projects for outreach and support to older family caregivers of adults with developmental disabilities in conjunction with the National Family Caregiver Support Program that was established with the 2000 amendments to the Older Americans Act. In 2002, AoA awarded a three-year Alzheimer's Disease Demonstration Grant to States to the New York State Office on Aging to increase the ability of persons with developmental disabilities to age in place while their Alzheimer's disease progressed. Descriptions of these grants are in Appendix 5.

AoA recently has partnered with the National Institute on Aging (NIA) to fund supplements that will expand the focus of four studies of people with long term disabilities who are aging. These studies will also address health disparities, economic and social costs of disability, and interventions and services for older persons aging with disabilities.

National Institute on Disability and Rehabilitation Research

In 1988, the National Institute on Disability Rehabilitation and Research (NIDRR) in the U.S. Department of Education initially funded the Rehabilitation Research and Training Center on Aging with Mental Retardation (RRTCAMR). The grant was awarded to the University of Cincinnati UCEDD which submitted the proposal in collaboration with the five UCEDDs in Indiana, Illinois, Kentucky, Wisconsin, and Minnesota, plus the University of Akron. Research projects addressed analyses of fiscal policies supporting community services for older adults, age-related changes in health and function, impact of transitions from nursing homes to community residences, factors associated with residential transitions and their outcomes for adults moving from the natural home to community residences, and interagency funding models of small scale community residences for older adults. In 1993, the successor grant was awarded to the Illinois UCEDD where it is now the Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function (RRTCADD). Current research priorities are to: 1) improve the health and function of adults with developmental disabilities across the lifespan; 2) enhance consumer-directed home and community-based services; 3) reduce environmental barriers to healthy homes and community participation; and 4) improve instruments and measures to assess intervention outcomes. Over the years, there was turnover in participating UCEDDs due to changing RRTCADD research priorities and new research interests among UCEDD principal investigators. NIDRR recently awarded funding supplements to the RRTCADD and the Rehabilitation Research and Training Center on Aging with Physical Disabilities at the University of Washington to conduct environmental scans of the epidemiological data and best practice interventions for people with disabilities who are aging.

Long-Term Impact of Previous Efforts to Bridge the Gap

Several factors undermined the long-term effectiveness of these efforts to foster collaboration between the aging and DD service networks at the state and local levels. The goals that were specified in the MoUs between AoA and ADD and AoA and NIDRR were never achieved due to turnover of agency personnel and changing federal and congressional priorities. The three agencies had no records of assigning specific staff or implementing projects to carry out their MoU objectives. Another factor undermining ongoing collaboration is the lack of support at the state level due to the frequent turnover of directors of state aging and DD agencies (usually coinciding with changes in the political party of the governors) and political factors affecting human services priorities. By 1988, several states had executed MoUs or similar cooperative agreements between the state unit on aging and the state DD agency. We contacted both agencies in each of these states two years later while gathering data on fiscal policies for services to older adults with developmental disabilities. Staff at both agencies in these states was not aware of these cooperative agreements.

Federal Health And Long-Term Supports And Services Reform

The introduction of the Medicaid Home and Community-Based Services (HCBS) waiver in 1981 enabled states to target community services and supports to specific Medicaid populations as an option for individuals requiring institutional care and to limit the number of people to be served. These restrictions were not allowed for services provided under state Medicaid plans. Since the 1980s, CMS (formerly the Health Care Financing Administration) has funded several national initiatives (e.g., Channeling Demonstration, Choices for Independence, Real Choice Systems Change, Deficit Reduction Act (DRA of 2005, P.L. 106– 224) to encourage states to rebalance their long-term care systems by reallocating funds from institutional care to community services and supports. The more recent initiatives have incorporated person-centered planning, participant-directed services, and paying family caregivers to give consumers greater input in determining the services and supports they needed and how they would be provided. Nationally, although funding allocated to HCBS has increased as a percent of total long-term care expenditures, states vary widely in their rebalancing efforts despite the Supreme Court Olmstead decision (Olmstead vs. L.C., 527 U.S., 1999) which requires public entities to provide community-based services to people with disabilities in the most integrated setting so they can interact with nondisabled people to the fullest extent possible.

Barriers to rebalancing long term care include:

> The administrative costs and inefficiencies states experience because they are required to develop separate home and community-based service waivers for each target population they serve. These waivers also require periodic reauthorization because they are time-limited.
>
> Structural flaws such as lack of integration between acute care and long-term supports frequently result in service fragmentation and increased care costs.
>
> Stakeholder groups that support institutional care such as nursing home operators, employee unions, and families who believe their relative with a developmental disability will be better served in an institutional setting.
>
> State specific factors such as population density, economic conditions, and political issues affecting human services funding levels and agency allocations.

The DRA of 2005 established the State Plan Home and Community-Based Services (HCBS) benefit 1915 (i) option to overcomes the administrative problems state experience with the Medicaid HCBS 1915 (c) waiver. The 1915 (i) option allows states to include services in their state Medicaid plan that were previously available only under a Home and Community Based Service waiver. This new provision has several advantages. First, states can offer HCBS services to all Medicaid-eligible individuals rather than comply with the waiver limitation of targeting only those people who require nursing home or institutional care. Second, unlike waivers which are time-limited and have to be reauthorized by the federal government, these services can be permanently included in the state Medicaid plan if they do not target a specific population.

The Patient Protection and Affordable Care Act (ACA) (P.L. 111-148)

The Patient Protection and Affordable Care Act (ACA, P.L. 111-148) was legislated to expand access to health care, improve the quality of care, and contain health care costs. Several provisions of the Affordable Care Act (ACA) will have a positive impact on health care for people with developmental disabilities. These include:

> Raising the income limits for Medicaid eligibility to expand coverage to the "working poor."
>
> Eliminating pre-existing conditions as a reason to deny coverage, and assisting income-eligible subscribers with premiums and cost sharing.
>
> Requiring habilitative as well as rehabilitative services in plan coverage.
>
> Increasing Medicaid reimbursement for primary care physicians and Community Health Centers.
>
> Reducing health disparities by mandating accessible health care facilities and diagnostic equipment, prioritizing training in developmental disabilities for certain specialties, and expanding the definition of culturally competent health care curricula to include people with disabilities.

The ACA also features several provisions that encourage states to rebalance their long-term care systems by reallocating funds from institutional care to community services and to integrate acute care with long-term services and supports.

State Balancing Incentive Payment Program.[33] The Balancing Incentive Program is targeted to states that allocated less than 25% or less than 50% of their 2009 Medicaid long-term care expenditures for community-based services. CMS will increase the Federal Medical Assistance Percentage (FMAP) states receive as an incentive to reallocate funds to provide more community services. States that are selected will receive a 5% increase in their FMAP to achieve a 25% rebalancing benchmark by October 1, 2015, and a 2% increase in their FMAP to achieve a 50% community services benchmark by October 1, 2015. States also must implement structural reforms to increase access to non-institutional long term services and supports that include:

> A No Wrong Door/Single Entry Point System (NWD/SEP) where consumers can receive information about services and complete initial and comprehensive eligibility determinations for services.
>
> Using standardized assessment instruments to determine eligibility for services.
>
> Conflict-free case management services in which there is no relationship between the entities responsible for the assessment, evaluation, and plan of care.

Community First Choice Option. An important provision of the ACA is the Medicaid Community First Choice Option, also known as the HCBS Attendant Service Option. Effective October 1, 2011 states were able to provide person-centered attendant services and supports under their state Medicaid plan to assist individuals with their activities of daily living, instrumental activities of daily living, and health-related tasks. States can also cover costs of moving individuals from institutions to the community. States that participate in this program receive a 6% increase in their federal match rate for these services.[34]

Money Follows the Person. The Money Follows the Person demonstration program created by the Federal Deficit Reduction Act of 2005 gives people residing in state institutions and nursing homes the option to live in the community. States that participate in the program must use the increased FMAP they receive to expand long-term community services and supports. The 29 states and the District of Columbia that were funded in 2007 transitioned 11,924 people to the community by December 31, 2010, including 3,100 individuals with intellectual and developmental disabilities.[35] The ACA extends Money Follows the Person through 2016 and reduces the minimum institutional length of stay to participate from six months to 90 days. In 2011, an additional 13 states received grants to initiate Money Follows the Person demonstration projects. As of August, 2011, nearly 17,000 persons had transitioned back to the community and another 5,700 transitions were in progress.[36]

Health Home Model for Medicaid Beneficiaries with Multiple Chronic Conditions. The ACA permits states to amend their state Medicaid plan to fund medical home services to people with multiple chronic conditions including mental illness, substance use disorder, asthma, diabetes, heart disease, and being overweight per a body mass index of over 25. Participant eligibility is based on having at least two of these conditions, one chronic condition and being at risk for another, or having one serious and persistent mental health condition. States have flexibility in which conditions they want to target, but include all categorically needy individuals and individuals who are dually eligible for Medicare and Medicaid. Health homes provide the medical, behavior health, and social services and supports the individual needs based on their chronic conditions. This provision went into effect in January 2011 and raises the federal matching rate to 90% for two years for states choosing the health home option.[36]

Medicaid Managed (Integrated) Care

States began to establish managed care plans for health care and long term supports for targeted groups of Medicaid beneficiaries, including developmental disabilities, in the 1980s to contain escalating program costs. Managed care plans can be implemented by amending the state Medicaid plan or under a Medicaid waiver. Waiver plans allow states to enroll people who are dually eligible for Medicare and Medicaid. In 2010, 47 states and the District of Columbia had established Medicaid managed care plans that in aggregate served 71% of the total Medicaid population.[37] States use two basic models including various hybrids to finance and administer their managed care programs. [38]

> Risk-based managed care organizations receive a fixed (capitated) monthly rate per enrollee and assume the full financial risk for delivering a set of services. Organizations that provide a limited scope of services on a prepaid basis assume partial risk.

> Primary Care Case Management plans blend of traditional fee-for-service and managed care. States contract with a provider, usually the beneficiary's primary care physician, to provide basic care, coordinate care and make referrals for specialty care. The physician is reimbursed for medical care on a fee-for-service basis and also receives a small monthly fee for each person to cover their care coordination.

Gettings[39] noted the anticipated expansion of Medicaid managed care to cover long-term services and supports for people with developmental disabilities did not occur as expected because of:

> Strong opposition from stakeholders including disability advocates, professionals, and service providers including nursing home operators who associate managed care with reduced quality of care or perceived it as an economic threat.
>
> The lack of available and willing suppliers, especially in rural areas.
>
> Hesitation from many traditional managed care organizations to entering the DD sector (doubt as to whether typical managed care strategies would yield significant cost savings).

However, states are renewing their interest in managed care for both acute health care and long-term services and supports for adults with developmental disabilities due to the weak economy, integrated care for people who are dually eligible for Medicare and Medicaid (dual eligibles), and enhanced Primary Care Case Management models which pay primary care physicians a higher monthly case management fee for high-risk patients.[40]

Despite the slower than expected pace of moving Medicaid long-term services into managed care programs, as of 2010 at least 15 states had moved part of their long term services into a managed care program.[41] However, most of these state initiatives typically restricted their managed care program to only a portion of the long term service sector. For example, five states (AZ, NY, VT, NM, and TN) targeted only those consumers eligible for nursing facility placement. Three states (MN, FL, and MA) focused on aged consumers while three other states (MI, NC, and HI) targeted people with developmental disabilities. Three states (WI, TX, and RI) included any populations requiring long term care, and Washington restricted managed care to long-term services in one county. To date, there is little information on cost savings and improved consumer outcomes associated with Medicaid managed care models for long-term services and supports.

Partnering with States to Coordinate Integrated Care for 'Dual Eligibles'

Approximately 9.4 million people are eligible for both Medicare and Medicaid, including 3.4 million individuals with disabilities under the age of 65. Estimates of the proportion of dual eligibles that have developmental disabilities range from 5% to 18% of total enrollees.[42] Under the *State Demonstrations to Integrate Care for Dual Eligible Individuals* CMS awarded contracts to fifteen states to design service delivery models that integrate health care and long term services and supports and to improve the coordination of Medicare and Medicaid benefits to cover their costs. Thirteen states specified they will include dual eligible individuals with

developmental disabilities in their demonstrations. These fifteen states plus 22 other states and the District of Columbia have submitted letters of intent to test two financial alignment models CMS proposed to determine their impact on improving beneficiary experiences and quality outcomes while reducing health and long-term care costs. Both models will include all primary, acute, behavioral health, and long-term services and supports covered by Medicare and Medicaid.

1. The Capitated Model provides the managed care organization with a blended rate in which CMS covers the Medicare portion of the payment and states fund the Medicaid share. CMS and the state will share any savings resulting from the capitated rate compared to fee for service costs.

2. The Managed Fee-for-Service Model makes the state responsible for coordinating the care of dual beneficiaries and delivering fully integrated Medicare and Medicaid benefits. Under the current system, CMS administers Medicare benefits. Both managed care options permit states to incorporate coordinated service delivery modes included in the ACA such as Medicaid Health Homes and primary care case management. States will be eligible for a retrospective performance payment if the targeted level of Medicare savings exceeds any Medicaid cost increases and specific quality levels are met. Medicaid and Medicare providers are reimbursed on a fee-for-service basis by the state and CMS respectively.[43]

> *"As you look at your five-year strategic plan, recognize the need for improved dementia care for individuals with intellectual and developmental disabilities in conjunction with increased support for family members as caregivers and advocates." (sibling)*

Both models must incorporate specific safeguards for consumers including person-centered assessment and service planning, the right to choose care providers and self-direct services, voluntary plan enrollment, continuity of care when they transition to the integrated model, accessible services, and due process for grievances and appeals. Dual eligible beneficiaries will have meaningful input on implementing these models by serving on advisory boards and plan governing boards. [44]

Lifespan Respite Care Act (P.L. 109-442)

The Lifespan Respite Care Act authorizes funding for state grants to develop coordinated systems of respite care across the lifespan for all disability groups. It was enacted in 2006 and is up for reauthorization in 2011. Since 2009, Congress appropriated approximately $2.5 million annually for the Lifespan Respite Care Act and designated AoA responsible for its implementation and administration. Over the past three years, 30 states have been awarded grants to implement respite programs, including four states that are serving large numbers of individuals with developmental disabilities: Arizona, Texas, Massachusetts, and Wisconsin. State grantees must involve the ADRCs. The AUCD is on the steering committee for the respite technical assistance grant AoA awarded to the ARCH National Respite Network.[45]

National Alzheimer's Project Act (P.L. 111-375)

In January, 2011, President Obama signed into law the National Alzheimer's Project Act (NAPA). This legislation will lead to the development of a coherent and coordinated national strategy on dealing with Alzheimer's disease in the United States, which the Alzheimer's Association predicts will increase three-fold by 2050. Health professionals and researchers knowledgeable about aging and developmental disabilities have long recognized that a disproportionate number of adults with Down syndrome develop Alzheimer's disease if they live past fifty years of age. It is possible that more adults with other at-risk developmental conditions will also be prone to Alzheimer's due to increasing life expectancy.

To complement this federal initiative and to address the myriad requests for more specific information and practice models for providing quality care for people with developmental disabilities affected by dementia, the American Association on Intellectual and Developmental Disabilities, the American Academy on Developmental Medicine and Dentistry, along with the Rehabilitation Research and Training Center on Aging and Developmental Disabilities-Lifespan Health and Function with support from AUCD organized the National Task Group (NTG) on Intellectual Disabilities and Dementia Practices. The NTG has been structured into three working groups (dementia screening, health care supports, and community supports) which were charged to review and update the technological and clinical practices used by agencies in delivering supports and services to adults with intellectual disabilities affected the various dementias. It is the intent that the National Task Group' s work will he fed into the NAPA effort so as to ensure that the concerns and needs of people with intellectual disabilities and their families, when affected by dementia, are considered as part of this national strategy.

The National Task Group and the NAPA federal council both released their work plans this month. The NAPA Draft Framework for the National Plan to Address Alzheimer's Disease has five goals: 1) prevent and effectively treat Alzheier's disease by 2025; 2) enhance care quality and efficiency; 3) expand patient and family support; 4) enhance public awareness and engagement; and 5) improve data to track progress. Most importantly, NAPA identifies "people with certain intellectual disabilities" as one of the populations disproportionately affected by Alzheimer's disease that requires improvements in care to achieve goal 2. The National Task Group report *"My Thinker's Not Working"*document contains five goals that will support NAPA's efforts to improve the quality of care for adults with intellectual disabilities.[46] The NTG goals are to:

> Better understand dementia and how it affects adults with intellectual disabilities and their caregivers.
>
> Institute effective screening and assessment of adults with an intellectual disability at-risk for showing the early effects of dementia.
>
> Promote the health and function of adults with intellectual disability affected by dementia.
>
> Produce appropriate community and social supports and care for adults with an intellectual disability affected by dementia.

Produce a capable work force and produce education and training materials.

The Executive Summary of the NTG report is in Appendix 6. The entire report can be downloaded at http://www.rrtcadd.org.

The Affordable Care Act, the Lifespan Respite Care Act, and the National Alzheimer's Project Act have potential to dramatically improve the coordination, quality and cost-effectiveness of health care and long-term services and supports for an aging population that includes people with long-term physical, developmental, and psychiatric disabilities. The AoA and CMS jointly established Aging and Disability Resource Centers (ADRCs) as a national effort to streamline access to government-funded and private pay long-term services and supports. The next section of this report examines the ADRC program's role in serving people with developmental disabilities. It discusses the barriers and best practices in using the ADRC model to link people with developmental disabilities to long term supports and services. The report also includes recommendations for strengthening the DD service network's role in formulating federal policies for long-term services and supports, including using the ADRC initiative to improve aging and DD service network collaboration at the state and local levels and to improve outreach and services to older adults with developmental disabilities and their families.

THE BRIDGING ROLE OF AGING AND DISABILITY RESOURCE CENTERS

The Aging and Disability Resource Center (ADRC) initiative is a joint effort of AoA and the Centers for Medicare and Medicaid Services (CMS). The goal is to establish a national network of ADRCs that serve as local "one-stop shops" by streamlining access to long-term services and supports for older persons and younger people with disabilities. ADRCs are patterned after Wisconsin's successful county-based model that provides access to long-term supports and services for older adults and younger individuals with physical and developmental disabilities. AoA and CMS envision the ADRCs as a key element of health and long-term care reform that will:

Rebalance states' long-term care systems from institutional care to home and community-based services and supports to facilitate compliance with the Olmstead decision.

Improve state and local governments' ability to manage resources and monitor program quality.

Encourage middle-aged people to plan for their future long-term care needs by providing information and options counseling about publicly funded and private pay services and

Encourage middle-aged people to plan for their future long-term care needs by providing information and options counseling about publicly funded and private pay services and supports.

Use a person-centered approach to plan and deliver long-term services and supports according to the needs and preferences of the individual and his/her family caregivers including paying family caregivers and participant-directed services.

ADRCs have five core functions to facilitate these outcomes: [47]

1. Information and access/referral which includes promoting awareness of options for under-served, hard to reach, and private pay populations as well as resources individuals can use to plan ahead for future long-term care needs.

2. Options Counseling and Assistance which helps individuals assess and understand their needs, assists them in making informed choices about appropriate long-term service and support options, and supports them in making service plans and arranging for services.

3. Streamlined eligibility determination for all publically funded services and supports by serving as a single entry point or no wrong door model that appears as a seamless entity to consumers.

4. Person-Centered Care Transitions along the continuum of care occur to reduce hospital readmissions and to ensure that people end up in the settings that provide the health and social services that best meet their needs and preferences.

5. Quality Assurance and Continuous Improvement by implementing management information systems that may include linkages to electronic health records and Medicare

and Medicaid information systems to track consumers, services, performance, and costs for ongoing evaluation and improvement of ADRC services and outcomes for consumers and their families.

ADRCs are required to serve adults 60 years of age and older and at least one other target population of younger individuals with disabilities.[47] The intent is to have an ADRC in all states and these eventually will also serve younger people with physical disabilities, developmental disabilities, and persistent and severe mental illness. States were required to designate at least one disability population the ADRC would initially serve in addition to older people. Eventually all states are to have ADRCs that serve people with physical and developmental disabilities, and individuals with severe and persistent mental illness under age sixty.

The ADRC local site model consists of the Area Agency on Aging (AAA) and the partnering agencies that service its targeted disability populations. AAAs are the lead agencies at the vast majority of ADRCs and Centers for Independent Living are the second most reported lead agencies. Although AoA and CMS originally conceptualized ADRCs as a single entry point for older and younger people with disabilities seeking long-term services and supports, most ADRCs operate as a “No Wrong Door” model because of logistical and financial barriers to co-locating staff at one agency and each agency’s desire to maintain its identity in the community. Partnering agencies are linking their management information systems and incorporating telecommunications systems that transfer calls between agencies to present the image of a seamless point of entry.

The first round of ADRC grants was awarded to twelve states in 2003. The 2006 amendments to the Older Americans Act (P.L. 109-365) required the Assistant Secretary for Aging to establish ADRCs in all states (Title II Section 202 (b) (8)). By June 2011 there were 365 ADRC program sites in 54 states and territories.

The OAA authorizes the Assistant Secretary for Aging to take the lead in galvanizing federal efforts to develop and implement comprehensive and coordinated systems of long-term care at the federal, state, and local levels, and AoA is positioning ADRCs as a key component of the long-term service and support system. AoA awarded grants to 28 states to access and coordinate Community Living Program (formerly the Nursing Home Diversion initiative) services and supports through their ADRCs for people with limited financial resources who are not Medicaid eligible but who are at risk of nursing home placement. In 2008, eight states received CMS Person-Centered Hospital Discharge Planning Model grants to include ADRC options counseling and person-centered planning in hospital discharge planning for people with multiple chronic health problems to reduce the likelihood of re-hospitalization. ADRCs were involved in Money Follows the Person programs in 37 of the 44 states that received grant awards in 2007 and 2011.[31]

Challenges of ADRCs in Bridging Aging and Disabilities

Given the well-established community identity of the aging and disability lead and partner agencies in their community, there is confusion among providers, families, and persons with disabilities regarding the role and function of the ADRCs. When the ADRCs were first implemented under the previous administration the model was not conceptually well thought out. ADRCs were initially conceptualized as single points of entry for long term supports and services for people with disabilities who are aging and people aging into disability. ADRCs were then reconceptualized as the "No Wrong Door" approach because each population has unique needs and their service networks are based on different philosophies. Consequently, each ADRC partner agency is autonomous and operates mostly with "business as usual"; their service network has not integrated these parallel service systems.

> *"There is the concern that ADRC may seem like a good idea at the 30-thousand foot level, but cannot provide the individualized responsiveness that people need on the ground. Not funneled enough to be operational, not able to embrace all disability populations." (UCEDD administrator)*

ADRC Outreach to People with Developmental Disabilities

Table 2 indicates that people with developmental disabilities are considerably underserved by the national ADRC network. ADRCs served only 2.3 % of the estimated 4.9 million individuals with developmental disabilities compared to 9.4% of the estimated 36.2 million people with any disability.[48] The latter is based on the 3.6 million people with disabilities served less the number served with developmental disabilities. The data are based on the number of people ADRCs served since April 2006 because that is when reports first enumerated people by type of disability.

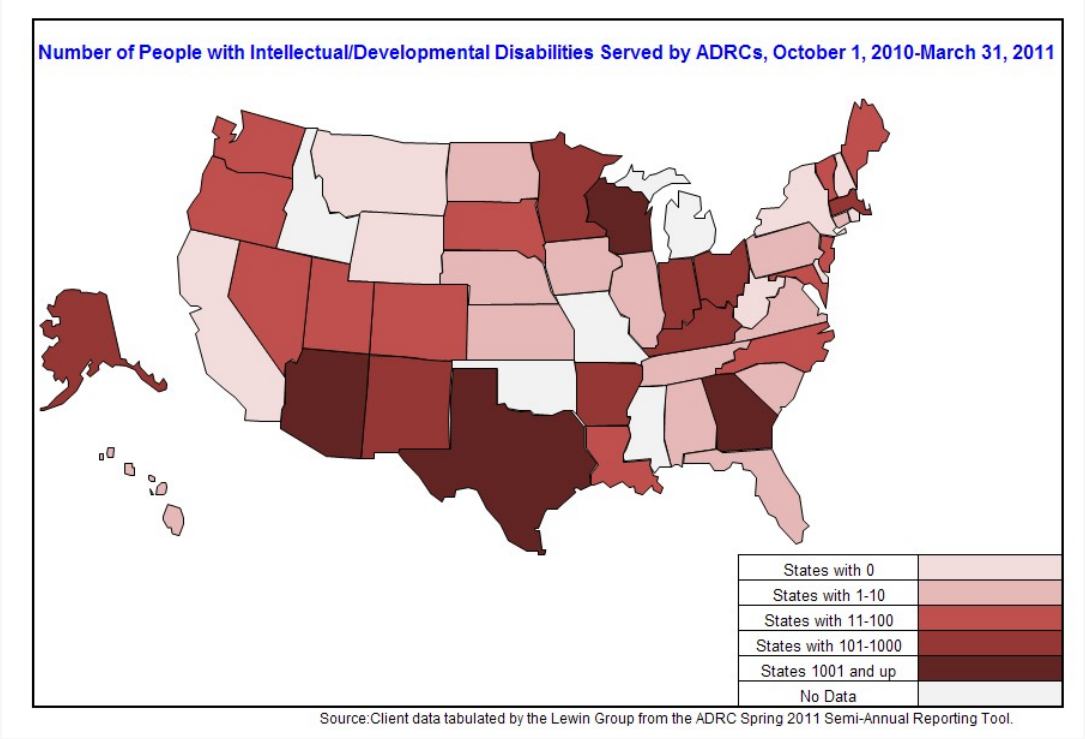
Table 2. Number of Persons Served by the ADRC National Program April 1, 2006 – March 31, 2011	
Disability*	**Number of Persons Served**
Physical Disability	448,553
Developmental Disability	113,812
Mental Illness	124,198
Traumatic Brain Injury**	10,473
Dementia**	40,055
Multiple Disabilities	96,025
Disability Unspecified/Unknown	2,677,018
Total People with Disabilities	3,510,134
Age Group	
Age 60+	2,047,510
Under Age 60	694,428
Age Unknown	949,409

* The numbers served by disability type include people age 60+.
**Data collection began in April 2007
Source: The Lewin Group. Special data tabulation received by email on 9/28/11.

Most states selected people with physical disabilities as the first younger population to be served by their ADRCs. There is a natural inclination for the aging network to partner with the CILs in establishing ADRCs. Younger and older people with physical or sensory disabilities both require varying degrees of support to perform activities of daily living and instrumental activities daily living. Smaller percentages of both groups also may require assistance with frequent health maintenance routines. States are encouraged to use the same functional assessment tools for both populations, and many serve both populations in the same human services agency. Forty states provide long-term home and community-based services for older persons and younger people with physical disabilities under the same 1915 (c) Medicaid waiver.[23] In contrast, people with developmental disabilities require a much broader array of services and supports, and neither the aging network nor most CILs have experience in serving this population.

We reviewed data from the Spring 2011 Semi-Annual Reporting Tool (SART), which covers October 1, 2010 through March 31, 2011, to determine the number of people with developmental disabilities each state served. We did not adjust client data to reflect variations in state population because not all states had statewide ADRC coverage. Our goal was to identify states serving

large numbers of people with developmental disabilities so we could identify the factors contributing to their successful outreach. The following map depicts the number of people with developmental disabilities served by state ADRCs. SARTs for eight states did not contain any data on people with developmental disabilities: DE, RI, NY, ID, OK, MO, MI, MS.



The 2011 Spring SART indicated that 155 local ADRCs in 36 states and the District of Columbia served individuals with developmental disabilities during the six-month reporting period. Two criteria were used to include states in the sample:

1. The total number of people with developmental disabilities states served through their ADRCs.

2. The proportion of people with developmental disabilities served by at least one local ADRC had to account at least 10% of all people with disabilities it served to indicate at least one location with successful outreach to this population.

We did not adjust the data to account for population density because individual ADRC start-ups occurred at different times and community visibility also would affect their market draw. The sample consisted of six states: Georgia, Alaska, Massachusetts, Texas, Arizona, and Wisconsin.

Table 3 compares the number of people with developmental disabilities these states served compared to the other target populations. All the states except Texas and Wisconsin have statewide ADRC coverage. The large number of people with developmental disabilities served in Georgia reflects 15,060 people reported and verified by the Atlanta ADRC staff. The aggregate number of people with developmental disabilities served by these six states (29,338) represents 88% of the 33,453 people with developmental disabilities served by all ADRCs during this six month period.

Table 3. States with ADRCs Serving Large Numbers of People with Developmental Disabilities October 1, 2010 to March 31, 2011

State	No. of ADRCs	Years Operating	I/DD	% of All Disabilities	Physical Disability	Psychiatric Disability	TBI	Age 60+
GA	12	1 – 6	17,633	63	8,147	1,788	247	58,795
WI	35	1 – 6	8,232	17	29,109	11,009	0	93,657
AZ	5	1 – 4	1,269	36	1,766	360	172	5,832
TX	11	<1 – 4	1,404	26	3,789	245	12	12,393
MA	11	3 – 7	423	7	4,873	868	79	41,628
AK	4	1 – 7	377	24	946	195	32	2,048

TBI: Traumatic Brain Injury
Source: The Lewin Group. Special tabulation of ADRC clients by age and disability

ADRC Best Practices in Partnering with Developmental Disabilities Agencies

"I was looking for services for my brother. My brother is 'mentally retarded' and has been since birth. He lived with my mother all of her life… she got to a point where she couldn't take care of my brother and herself, so we found them an assisted living home which was a really nice place. They both liked it very much. And mother passed away. They allowed Jeff to stay there… but even at a reduced rate we couldn't afford it for very long... I got this book from Social Security, it was overwhelming. I started crying. I looked at the back of the book and there was a [ADRC] phone number. And I thought "well, maybe somebody will me…" luckily I got Norma on the phone and I told her my situation on the phone and she helped me, first of all recover my composure because I was so upset… she explained what I needed to do in small bites so I could get started. I just couldn't have done this without Norma. It's hard enough living my own life without having to figure out how to take care of my brother that I love dearly and have a life for him that he would be happy with…. My mother had done no planning whatsoever-- she didn't want to think about it, my father died 20 years previous to that and he didn't want to think about it-- and so it fell to me… it [my mother's death] was overwhelming… and at the same time ensure that Jeff had a place to stay even beyond me if he survives me. And there's nobody else to look into it but me. I just felt overwhelmed and burdened and close to tears most of that time. When I would talk to Norma she'd always talk to me… she would tell me that we can do it, and this is what you need to do next so I didn't have like a million things on my plate… "you need to call so and so then call me back and we'll discuss where to go from there." And without that, I couldn't have done it." Nora, Georgia ADRC Client

State profiles that identify the factors contributing to their successful ADRC outreach to people with developmental disabilities are in Appendix 7. Of the six states, Georgia and Wisconsin have several best practices that reinforce their ADRC network's commitment to serving people with disabilities and their families:

Georgia's ADRC website has video clips of families of people with developmental disabilities explaining how they benefitted from ADRC options counseling and assistance in accessing services. Its ADRC brochure prominently displays their ADRC network as a resource for people with disabilities and their families as shown in Figure A.

Both states have dedicated staff that support local ADRC operations. The Wisconsin Division of Long Term Care Office for Resource Center Development has 17 staff that support local ADRCs with training and technical assistance on doing community outreach, preparing contracts, improving administrative procedures, customer service, and working with their local consumer boards. Six field staff constitute an ADRC Quality Team that works closely with the ADRCs in their region.

Figure A.

Georgia's ADRC Brochure

Each ADRC site in Wisconsin has a Board whose members represent the service area's targeted disability groups and ethnic and cultural diversity. Similarly, Georgia has a statewide ADRC Advisory Council as well as local ADRC advisory groups that include people with disabilities and their families.

Georgia's ADRC program funds three developmental disability staff specialists and has been approved to hire a fourth. Each is assigned to a regional DD office to provide training and technical assistance to four of Georgia's twelve ADRCs.

Georgia's ADRCs are a "No Wrong Door" model because none house regional staff from the state Department of Behavioral Health and Developmental Disabilities. However, from the consumer's perspective the ADRC offers one-stop shopping because the DD regional offices are linked to the ADRCs by "warm" phone transfers and have access to the Enhanced Service Performance directory which is the aging network database of services and resources.

Georgia and Wisconsin ADRCs enroll people with developmental disabilities in aging waiver programs if they have an urgent need for service and meet program eligibility requirements because the waiting lists are shorter. Wisconsin makes the PACE program an option for people with developmental disabilities who meet program requirements because it has better dental coverage.

UCEDD Collaboration with ADRCs

The national network of University Centers for Excellence in Developmental Disabilities (UCEDDs) can be a valuable resource for supporting ADRC outreach and services to people with developmental disabilities. We sent email surveys to the 65 UCEDDs in the fifty states and the District of Columbia to identify those serving as resources to the ADRCs in their state and the nature of their collaboration. Twenty directors completed the surveys (a 43% response rate), and UCEDDs in 11 states indicated they were a resource to ADRCs. Table 4 on the next page summarizes their activities. Eight UCEDDs were members of their state or local ADRC advisory committee. The majority provided staff training and technical assistance to the ADRC network and five were evaluating ADRC performance. The Wyoming Institute on Disabilities was awarded the first grant to establish an ADRC, and the Utah UCEDD was a collaborator in establishing that state's ADRC. Appendix 8 contains brief profiles of UCEDD collaborations. The high non-response rate to the survey may suggest that most UCEDDs are underutilized as a resource to their state ADRCs.

Table 4. UCEDD and ADRC Collaboration				
UCEDD	**Advisory Committee Member**	**Train ADRC Staff**	**Provide Technical Assistance**	**Program Evaluation**
University of Kentucky Human Development Institute				X
Virginia University Center for Excellence Virginia Commonwealth University		X	X	X
University of Oklahoma Health Sciences Center	X	X	X	
Iowa UCEDD	X	X	X	
Center for Persons with Disabilities Utah State University	X	X	X	
Institute for Disability Studies The University of Southern Mississippi	X	X	X	X
Wyoming Institute for Disabilities University of Wyoming	X			
Center for Human Development University of Alaska Anchorage	X	X		X
Institute on Disability University of New Hampshire	X	X	X	
Institute on Disability and Human Development The University of Illinois at Chicago	X	X	X	X
Rural Institute UCEDD, University of Montana		X	X	

ADRC Role in the ACA

CMS and AoA envision that ADRCs will play a key role in implementing health and long-term care reform by improving the ability of state and local governments to manage the system, monitor program quality, and assess the robustness of state and local systems of care. The Patient Protection and Affordable Care Act (ACA, P.L. 111-148) specifically includes ADRCs in several of its initiatives and has appropriated $10,000,000 per year for five years (FY 2010 through 2014) to provide ongoing support for ADRC activities. FY 2010 funds supported three grant competitions and provided formula grants to states to expand and strengthen their ADRC networks by participating in health and long-term care reform initiatives.

Twenty states received two-year grants to strengthen Options Counseling and Assistance Programs. Local ADRCs and their stakeholders developed, implemented, and evaluated statewide standards for options counseling and are collaborating with grantees and stakeholders in other states to develop national standards.

Twenty-four states that were Money Follows the Person grantees received supplemental administrative funds from AoA and CMS to strengthen ADRC capacity to participate in nursing home diversions and transitions programs.

Sixteen states received two-year grants under a competitive application process to reduce hospital readmissions among older adults and younger people with disabilities by implementing one of five evidence-based discharge planning models that provide integrated follow-up social supports and medical care to reduce the likelihood of re-hospitalization. States can use the funds to strengthen ADRC capacity by adding additional staff, expanding the intervention to new populations or to additional sites, and by increasing their role in streamlining access to public benefits, accessing community services and supports, and providing options counseling. The goal is to make ADRCs a key component of person-centered hospital discharge planning by either directing care transitions or by supporting other organizations to do so.

States received formula grants for 24 months to support ADRC outreach to low income individuals who are Medicare beneficiaries and advise them about specific programs and benefits that will reduce their out-of-pocket health care and medication costs. are to coordinate their outreach efforts similar activities provided by State Health Insurance Programs (SHIPs), Area Agencies on Aging (AAAs), and organizations providing benefits counseling.

The ADRC's Role in Providing Medicaid Integrated (Managed) Care

ADRCs can serve as the gatekeeper to Medicaid Integrated (Managed) health care and home and community-based services. Since the 1980s states have been enrolling segment of their Medicaid beneficiaries in managed health care plans in an effort to control spiraling costs. Their success in controlling health care costs led states such as Minnesota, Wisconsin, and Colorado to begin including long-term services and supports in their managed care programs. States have

included segments of the Medicaid beneficiaries in managed health care to care for older persons and people with developmental disabilities. In contrast, fewer states have been moving people with developmental disabilities into Medicaid long-term care programs due to strong opposition from disability advocates, DD professionals, and some providers, especially nursing homes, who view managed care as an economic threat.

SUMMARY OF KEY ISSUES

The major reforms in health and long term supports nationally highlight the gaps and challenges in addressing both the populations who age into disability and those who age with disabilities. Both of these populations have similar needs for supports that are community based, person-centered, and coordinated with their health care needs. Yet, unique needs exist for individuals with developmental disabilities who require life-long supports. Also there are differences in the structure and philosophies of the aging and DD networks. Previous efforts to bridge the two systems have had mixed results and provide insights into fostering future collaborations. The recent ADRC initiative offers us as example of the challenges in working across systems.

The following are key findings of this project:

People aging with developmental disabilities and their families have unmet needs for health and long-term supports that will continue to grow as the population ages.

People with developmental disabilities consumed 72% of 2006 Medicaid waiver expenditures although they accounted for only 40% of Waiver enrollees. They need lifelong services and many individuals have extensive support needs. The 2008 average expenditure per person was $42,896 for developmental disabilities, $9,510 for aged and $18,043 for physically disabled Medicaid 1915(c) Waiver funded HCBS.[36]

People with developmental disabilities experience long waiting lists for services. In 2010, 268,220 people were on state wait lists for Medicaid 1915 (c) HCBS DD waivers which is double the combined wait list size for elderly adults and people with physical disabilities, and their average waiting period for a waiver slot to open was three times as long. The average waiting time to receive DD waiver serves is 36 months compared to 9-13 months for the aged and disabled waivers.[36]

Approximately 1.36 million adults with developmental disabilities live independently or with a spouse. Most probably do not receive DD services and after age 60, are likely to be referred to the aging network for any needed supports and services. Emerging concerns include protection from abuse and financial exploitation and support with taking multiple medications due to the onset of age-related of chronic health conditions because many individuals may no longer have family to provide this support.

Adults with developmental disabilities have a higher risk of developing chronic health conditions at younger ages than other adults, due to the confluence of biological factors related to syndromes and associated disabilities, access to adequate health care, and lifestyle and environmental issues.

Although all states now fund family support in the form of cash subsidies and/or direct services, 2009 national family support expenditures accounted for only 7% of total

national DD expenditures. Only 17% of families caring for a relative with a disability at home received family support.[11]

There has been limited and short-term success in bridging the aging and DD service networks, despite many attempts to do so at the federal, state, and local levels.

Provisions supporting collaboration in both the OAA and the DD Act as well as their 1989 MoU were not implemented; nor were there mechanisms for monitoring these activities and reporting their outcomes.

The Aging TIP projects and the AoA discretionary grants fostering collaboration between networks were time limited. State level efforts were often undermined by turnover in agency and UCEDD directors and other competing policy priorities. Momentum at the local level was lost when staff leading the projects left the agency.

The concerns and issues of adults with developmental disabilities are often unrepresented in planning and implementation of health and long-term care reform initiatives.

Developmental disabilities stakeholders (people with developmental disabilities, their families, and providers) are often under-represented in state and national stakeholder advisory groups regarding implementation of health and long-term supports reforms.

The DD network is underutilized in the planning of major national long-term care initiatives, such as the ADRC program. ADD and its national network (including the UCEDDs, the DD Councils and the Disability Rights Centers) bring expertise in person-centered planning and participant-directed services for people with developmental disabilities to the table.

When the ADRC was implemented under the previous administration it was not conceptually well thought out.

ADRCs are a process not a center. ADRCs were initially conceptualized as single points of entry for long term supports and services for people with disabilities who are aging and people aging into disability. ADRCs were reconceptualized as the “No Wrong Door” approach because each population has unique needs and is oriented towards different philosophies of service. Consequently, each ADRC partner agency is autonomous and operates largely as “business as usual”.

Branding for ADRCs has never been uniformly established or implemented, which results in confusion for staff and consumers.

The ADRC program has been operating for eight years with limited collaboration between the aging and DD networks.

AoA envisioned the national ADRC network eventually would serve all people with disabilities. However, AoA has not supported partnering with the DD network as the ADRCs expanded nationally. Less than half (42%) of the 365 local ADRCs served people with developmental disabilities during the six month period ending March 31, 2011. By comparison, 213 ADRCs partner with Centers for Independent Living (CILs), and CILs are the lead agencies at 93 of these locations (NCIL, 2011). Nine out of ten people with developmental disabilities that the ADRCs served were concentrated in just six states.

Funding announcements for grant applications to expand and enhance ADRCs do not require, or even suggest, that awards be used to include individuals with developmental disabilities as a target population, even though RFPs specify that "Grantees are required to serve adults 60 years of age and older and at least one other target population of younger individuals with disabilities in at least one community at all income levels."[47]

AoA does not include the imagery of people with developmental disabilities on ADRC brochures and websites to demonstrate that ADRCs serve this population. Figure A, from Georgia's ADRC brochure, is an example of how imagery can be used to convey that ADRCs serve people with developmental disabilities.

There is a predisposition for AAAs to collaborate with CILs because both primarily serve people with physical and sensory disabilities. CMS is encouraging states to use the same functional assessment tool across populations and some states serve both older adults and younger adults with physical disabilities under the same 1915 "c" Medicaid waiver.

AoA and CMS envision that ADRCs will play key roles in implementing state health and long-term services and supports reforms.

ADRCs are involved in implementing Money Follows the Person in states.

Several initiatives in the Affordable Care Act for rebalancing state service systems require ADRCs to play a role in case finding, options counseling, and service coordination so they will become a permanent component of these systems.

The Older Americans Act and the CMS waiver modifications create opportunities for collaboration between the aging and DD networks.

Title III Part B Section 321(a) of the 2006 amendments to the Older Americans Act authorizes grants to states to support older parents providing uncompensated care to their adult children with disabilities through permanency planning, counseling, and provision of services and assistive devices.

AoA plans to add “parent caregiver” to the National Family Caregiver Support Program (subject to the 10% cap) to provide much needed services to older individuals providing care to their adult children (ages 19 to 59) for the reauthorization of the 2006 Older Americans Act in response to stakeholders’ input.

CMS has modified the 1915 “c” waiver regulations to serve more than one population in the same waiver, specifically referencing older parent caregivers and their adult children with developmental disabilities.

Professional and direct support staff in health care settings and in the aging and DD service networks are often ill-equipped to address the age-related issues of adults with developmental disabilities and their families.

UCEDDs in several states provide training, technical assistance, and conduct ADRC evaluations as well as serve on the advisory council. However, they are underutilized by the national ADRC network.

Primarily health care professionals need training in adults and aging health care issues for people with developmental disabilities.

Comprehensive data on the health care needs and the impact of health and long-term support and services reforms on people with developmental disabilities is lacking.

Surveillance instruments documenting health disparities often lack reliable information on people with developmental disabilities. While the CDC is working toward establishing a national health surveillance system for people with developmental disabilities, it is not yet in place.

Past evaluations of the ADRCs have reported little data on the program’s outcomes for people with developmental disabilities and their families.

RECOMMENDATIONS FOR BRIDGING THE AGING AND DD NETWORKS

With the "sea of change" in federal health and long-term supports and service reforms targeting aging and disability populations, it is important ADD, AoA , CMS and other federal agencies are actively engaged to effectively collaborate on ways to improve outreach and support to people with developmental disabilities and their families: Key goals and recommendations arising from this project are to: a) raise the visibility of developmental disabilities concerns in policy reforms, b) improve program implementation of health and long-term support initiatives to better address needs of persons with developmental disabilities; c) develop a workforce with knowledge and skills to address disability and aging issues; and d) better understand the age-related needs and best practices in meeting those needs through research and evaluation.

Goal A. Raise the visibility of developmental disabilities concerns in policy reforms

1. **ADD and developmental disabilities stakeholders need to work with CMS to develop a joint understanding of underlying values and unifying principles regarding such concepts as "person-centered planning" and " transition planning"**. Clear guidelines and tools are necessary for incorporating these concepts in applications to adults with developmental disabilities with respect to health and long term support and services initiatives. To accomplish this we recommend a national task force consisting of enlightened state Medicaid agency and state DD and Aging directors that would tackle these policy and implementation issues with input from advocacy organizations.

2. **ADD must have a direct and influential role in providing feedback on national rebalancing and healthcare reforms that affect people with developmental disabilities** which include: Money Follows the Person, the role and efficacy of ADRCs , managed and integrated care innovations, integrated care for people whole are dually eligible for Medicare and Medicaid; and possible consolidation of state Medicaid waivers. ADD can increase its voice on current and future national policy issues by including and involving national and regional DD organizations in implementation of federal health and long term supports and services reforms.

3. **State DD councils should recruit and support the participation of people with developmental disabilities and family members or advocates on mandatory advisory committees for implementation and evaluation of state ACA initiatives.** This provision would be particularly applicable to middle-age and older adults with developmental disabilities who are caregivers themselves and family members or other supporters who are well versed with the issues and challenges of older age and caregiving.

4. **ADD should ensure that DD self advocacy organizations are included in national advocacy efforts to implement the ACA.** For example Self-Advocates Becoming Empowered should be included in the Disability Rights and Education and Defense Fund initiative to protect the rights of people who are dually eligible for Medicare and Medicaid.

5. **DHHS should enable a partnership among ADD, AoA, and CMS to reconceptualize the ADRC concept as a process for linking people with long-term supports and services and mandate that local ADRCs include people with developmental disabilities as an integral part of their clientele.**. Federal agencies need to clarify the explicit obligations and roles of aging and disability organizations in order to successfully implement an ADRC network.

6. **ADD should actively support AoA's proposed amendment to the reauthorization of the Older American's Act of 2006 that expands the National Family Caregiver Support Program to also include older parents caring for their adult children (ages 19 to 59**, not just those 60+) with developmental disabilities to ensure that the Act addresses the needs of older families of adults with developmental disabilities.

7. **ADD should take an active role in the federal NAPA process to ensure that the National Alzheimer's Plan being submitted to Congress addresses the needs of adults with dementia and intellectual disabilities in all facets of the implementation of the national plan to support persons affected by Alzheimer's disease.** The early drafts recognize the inclusion of adults with intellectual disabilities but are in jeopardy of being neglected during the final plan development process.

8. **ADD can be a federal presence to ensure that state plans for implementing the Lifespan Respite Act adequately address the needs of families of people with disabilities**. One approach would be to require state DD councils to participate in their state respite coalitions.

Goal B: Improve program implementation of health and long-term support initiatives to better address needs of persons with developmental disabilities

1. **Ensure that when states implement ACA programs (e.g. dual eligible integrated care programs) that the programs work with the ADD agencies (DD Councils, UCEDDs, and Disability Rights Centers).**

2. **Improve the responsiveness of ADRCs to people with developmental disabilities** by a) requiring the involvement and review of the state DD agency in any plans, projects, and programs established by the ADRC; b) increasing the visibility of developmental disabilities in any marketing and publicity efforts by the ADRCs (including their websites and brochures); and c) exposing the ADRC network to the best practices used in Georgia and Wisconsin.

3. **Include future planning for older family caregivers and adults with developmental disabilities as a function of the ADRCs**.

4. **In states that have a single waiver serving both older parents and their adult offspring with a developmental disability, the ADRCs should be asked to help coordinate linkages across networks.**

5. **Establish ADRCs as focal points for coordination between state Disability Rights Centers and state programs for Prevention of Elder Abuse, Neglect, and Exploitation.** Collaboration between the aging and DD service network to address this future need complements the coordination that already has been established between state protection and advocacy long-term care ombudsman program.

6. **Incorporate in state DD agencies supports for dementia care**. Encourage ADRCs to work with state and private entities engaged in planning and implementing state efforts to better provide assistance to families affected by dementia, in particular those with an adult with a developmental disability at home. These plans should draw upon support models and caregiving resources in the aging network.

Goal C: Develop a workforce with knowledge and skills to address disability and aging issues

1. **ADD, AoA and CMS should partner to develop guidelines for ADRC staff cross-training in aging and developmental disabilities that mitigates misconceptions and builds a better understanding of the two networks.**

2. **ADD should work with federal partners (e.g., HRSA, AoA) to encourage cross-training in aging and developmental disabilities for health and direct support professionals.** The resources of the UCEDDs, Geriatric Education Centers (GECs) and the American Academy of Developmental Medicine and Dentistry should be used to identify and develop training materials.

3. **State Disability Rights Centers need to ensure that the rights of people with developmental disabilities are protected as states implement integrated care programs for 'dual eligibles'.** The Centers should be asked to prepare fact sheets adapted from resources developed by the National Senior Citizens Law Center.

4. **ADD, AoA, and CMS should support the development and dissemination of the screening tools and informational materials developed by the National Task Group on Intellectual Disability and Dementia Practices.** They can use their websites, Internet media, and other mechanisms to alert their networks of these materials and see collaborations from the network members in the work of the National Task Group.

Goal D: Better understand the age-related needs and best practices in meeting those needs through research and evaluation

1. **Support the evaluation of ACA healthcare and long-term care reform outcomes for people with developmental disabilities.** This can include joint grant announcements across such federal agencies as AoA, CMS, NIDRR, Agency for Health Care Research and Quality (AHRQ), NIA, and ADD.

2. **The federal agencies should provide supports for further research to assess and understand the nature of the needs of older adults with developmental disabilities and their families** with respect to using federally supported program and conduct outcome studies with respect to quality, satisfaction, and impact.

3. **Use the findings of the NIDRR, NIA and AoA funded supplements on aging and disability to help inform future research in aging with developmental disabilities.**

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APPENDIX 1
ACRONYM DEFINITIONS

AAA	Area Agency on Aging
AADMD	American Academy of Developmental Medicine and Dentistry
ACA	Affordable Care Act
ADD	Administration on Developmental Disabilities
ADLs	Activities of Daily Living
ADRC	Aging and Disability Resource Center
AHRQ	Agency for Health Care Research and Quality
AMA	American Medical Association
ANA	American Nurses Association
AoA	Administration on Aging
ARCH	Access to Respite Care and Help
AUCD	Association of University Centers on Disabilities
AZ	Arizona
CDC	Centers for Disease Control and Prevention
CIL	Center for Independent Living
CMS	Centers for Medicare and Medicaid Services
COMPASS	Common Point of Access to Social Services (Georgia)
DBHDD	Department of Behavioral Health and Developmental Disabilities (Georgia)
DD	Developmental Disability (ies)
DD Act	Developmental Disabilities Act
DE	Delaware
DHHS	Department of Health and Human Services
FL	Florida
FMAP	Federal Medical Assistance Percentages
HCBS	Home and Community Based Services
HCFA	Health Care Financing Administration
HDM	Hospital Discharge Model

HI	Hawaii
HRSA	Health Resources and Services Administration
I/DD	Intellectual and Developmental Disabilities
IADLs	Instrumental Activities of Daily Living
ID	Intellectual Disability
IDEA	Individuals with Disabilities Education Act
IDHD	Institute on Disability and Human Development
IHP	Individual Habilitation Plan
IL	Illinois
MA	Massachusetts
MI	Michigan
MN	Minnesota
MO	Missouri
MoU	Memorandum of Understanding
MR/DD	Mental Retardation and Developmental Disabilities
MS	Mississippi
NAIC	National Aging Information Center
NAPA	National Alzheimer's Project Act
NARIC	National Rehabilitation Information Center
NASDDDS	National Association of State Directors of Developmental Disabilities Services
NC	North Carolina
NIA	National Institute on Aging
NIDRR	National Institute on Disability and Rehabilitation Research
NM	New Mexico
NTG	National Task Group
NWD	No Wrong Door
NY	New York
OAA	Older Americans Act
OK	Oklahoma
PA	Pennsylvania

RCSC	Regional Community Support Center
RI	Rhode Island
RRTCADD	Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function
RRTCAMR	Rehabilitation Research and Training Center on Aging with Mental Retardation
SART	Semi-Annual Reporting Tool
SEP	Single Entry Point
SHIP	State Health Insurance Program
STAR	Short-Term Referral and Assistance
TBI	Traumatic Brain Injury
TIP	Training Initiative Project
TN	Tennessee
TX	Texas
UCEDD	University Centers for Excellence in Developmental Disabilities
VA	Virginia
VoIP	Voice-over-Internet Protocol
VT	Vermont
WA	Washington
WI	Wisconsin
WILR	Wyoming Independent Living Rehabilitation

APPENDIX 2
SUMMARY OF TESTIMONIES ON AGING ISSUES PRESENTED AT THE ADD ENVISIONING THE FUTURE SUMMIT SERIES

The RRTC on Aging with Developmental Disabilities synthesized and summarized testimony on aging issues that stakeholders presented at five regional Envisioning the Future summits the Administration on Developmental Disabilities (ADD) held in the last quarter of 2010. ADD convened these "listening" summits in Dallas, Philadelphia, Orlando, Detroit, and Denver to obtain stakeholder input for preparing its five-year plan. People with disabilities, families, and community allies were invited to present testimony on the major issues that need to be addressed and any recommendations for their resolution so individuals with disabilities will have expanded opportunities to live richer and more satisfying lives in the future. One full day of each summit was devoted to these "listening sessions" which were organized into four categories: childhood (0-21), adulthood (21-60), aging (60-end of life), and supports from families, caregivers, professionals, and other allies. Presenters were asked to respond to questions ADD prepared for each topic. The question related to aging was:

> *Aging concerns affect us all. The number of adults with developmental disabilities age 60 years and older is projected to nearly double from 642,000 in 2000 to 1.2million in 2030. What can we do to empower older individuals with developmental disabilities to remain in their own homes with a high quality of life, to maintain independence and good health for as long as possible and to enjoy community and family relationships through the end of life?*

We also reviewed testimony on adulthood and support to identify any issues that were relevant to aging. The questions in these categories were:

> Adulthood (21-59)
> *The question ADD proposed in the area of adulthood was in the future, what would be the most important contributing factors to ensuring that adults with developmental disabilities achieve equality of opportunity, independent living, economic self-sufficiency and full participation as valued members of inclusive integrated communities. Which critical issues must we attack? Access to healthcare? Employment? Supports and services? Technology? Housing? Transportation or other issues?*
>
> Supports from families and other allies
> *Over 75% of people with developmental disabilities live with families often with aging parents, direct support workers usually earn very low wages, and families and caregivers often struggle to access any level of formal support at all. How can we address the future care giving and support challenges of communities, families, and the allies who care about people with developmental disabilities?*

Our summary is based on content analysis of the listening session transcripts (rough edit) that are on the Envisioning the Future website (http://www.envision2010.net/) and a review of the issues that stakeholder work groups prioritized on Day 2.

Supports for Community Living

"I want to talk to you about when I get old. I don't want to live in a care facility. I want to live in my own house. I already do that. I want access to services and I want to let people know my needs and wants. And I want to have time and I want to have other people spend time with me. And I want to ride the buses and go to work. And have my own, do not cut my wages… be in control of my money. And learn self-determination. And I belong to OASIS self advocacy group. And I want doctors to explain my body as it gets older. And I want to exercise and eat good food. And go to school. And have a family. And be able to go to the movies and go out to eat (…). When I get older, I eventually want to have a care nurse, maybe a wheelchair. An electric wheelchair to get around my house if I need to, and then, maybe, somebody to go shopping for me if I cannot do it myself." **(DENVER. Sheree Lloyd, Phoenix, AZ, self advocate and member of the Family Council)**

Ms. Lloyd expresses what most people with and without disabilities want in their later years. Most people want to be to remain in their own home and community as long as possible (age in place) instead of moving to an assisted living facility or a nursing home. The ability to age in place is contingent on having access to needed supports, services, and technologies that compensate for age-related declines in health and function that result in the need for assistance in performing activities of daily living. She also wants health professionals who are knowledgeable about aging and how to maintain good health. People also want the option to work as long as possible the option to continue to working and to remain active in their community. In essence, older people want to remain in control of their lives despite their growing dependency, or interdependence, on others. Stakeholder testimony brings to light the key issues that are affecting these outcomes.

The most frequent concerns presenters expressed were the need to bridge the aging and developmental disabilities service systems and to address the large waiting list for adult services. These two issues profoundly affect older families' ability to access currently needed services for their relative with a disability and for themselves as caregivers.

Bridging the Aging and Developmental Disabilities Service Networks

In Utah, [developmental disability] support systems were designed, at best, to support individuals who were adults, hopefully working, hopefully living in the community, they were not really designed to address individuals in their 70s or their 80s and yet, these individuals become the most vulnerable, after years of being able to maintain community participation, being members, and doing what they want to. Not sure why we don't think about this as much, perhaps because none of us want to think about what is going to happen to us too, but as a field, I don't think that we are giving it sufficient attention.

We have a silo for older adults and we have silos for people with developmental disabilities. Although there are similarities and differences, these silos are not communicating or sharing or working together to really understand the supports that are needed. I don't think we have developed, in most states, a sufficient infrastructure to address the needs of aging individuals

with developmental disabilities. [I] Hope that ADD will take the lead in working not only to address the training needs of supports to form individuals that support for aging individuals with developmental disabilities, but also to work with the Administration on Aging to initiate new initiatives in this area. **(DENVER. Judith Holt, Center for Persons with Disabilities, Utah State University)**

Waiting Lists

Reducing state waiting lists will make it less stressful to plan for the future if families know that appropriate services and supports will be available to meet their relative's later life needs and preferences.

*My son Matthew is 36 years old as of yesterday and he has autism and intellectual disability and a seizure disorder. (…) my husband and I are 64, and Matt is waiting for housing in the community outside the family home. (…)Two weeks ago we received a letter from the state of New Jersey stating that Matthew is now number 776 on the waiting list. (…) (He) has seven more years to wait for residential services. He will be 43. We will be 71. This alone is unacceptable. However, I add to the mix the fact there is no funding available for us to bring services into our home to help support Matthew while he waits for housing. We have received respite, $178 a month since 1998. (****PHILADELPHIA. Elaine Buchsbaum, chair of the New Jersey Council on Developmental Disabilities)***

Two issues were germane to the discussion of waiting lists for services. Foremost, it is important for states to follow a standardized procedure for collecting and reporting waiting list data to ensure its accuracy and to present this information to Congress.

*The second major area I would like to address is… the extensive waiting list for services and supports. This is a challenging issue and I think it is going to be difficult to solve. One place I think we can start is to collect better data on the waiting list. This issue is invisible to policymakers. Part of the reason is that we don't have accurate data on the waiting list. Sometimes you have to identify the issue before policy even gets policymakers to address the issue. What we do know is that there are over 393,000 individuals waiting for 1915C home community-based services. The vast majorities are individuals with developmental disabilities. Some of the things I think that ADD could do is to work with CMS and try to get CMS to issue better guidance on reporting on the waiting list data from states. I think ADD could also partner with NIDRR, which is the National Institute on Disability and Rehabilitation Research to look beyond the waiting list, but to really collect better data on unmet needs of individuals and families and what are they waiting for and what do they need. The third thing that ADD could do is to leverage the resources of the DD network to work in partnership with the DD service system and collect better data on the waiting list. (****ORLANDO. Joe Caldwell, adjunct professor, University of Illinois at Chicago, National Council on Aging, and parent of teenager with disabilities)***

Second, presenters stated there may not be portability of services between states. That is, if an individual with a developmental disability receiving services in one state moves to another state due to a change in family circumstances, s/he may be placed on a waiting list rather than

immediately transition into comparable services. This affects individuals with disabilities of all ages including adults who relocate to the state where their sibling lives when their parent dies or who accompany older parents when they retire to another state.

Future Planning

Parents of adults of all ages expressed concerns about their child's future well-being after they died. However, these concerns typically become more pressing with age.

"First thing I need to point out is I think the biggest issue that faces all of us parents and families, is what happens when we die. What happens to our kids when we die? That is the overarching issue and it needs to be in the forefront of everybody's mind. Families face many different problems, but by the time they grow up, they realized that what happens to your kids when you die is probably more important than anything…." ***(ORLANDO. Phillip Pearson, father of a 36 year old man with a disability)***

Aging and Disability Resource Centers that serve people with developmental disabilities were identified as a resource to assist families in making future plans and to address older parents' own age-related support needs. ADRCs provide information on long-term care and options counseling, and can address the needs of both generations if they are jointly staffed by professionals from aging and developmental disabilities agencies.

Oftentimes we find that the family needs multiple supports in order for the individual with a developmental disability to remain in the home living with their family. If they choose to do so, this requires coordination of care between long-term care agencies, education, training, and a single point of entry. The system builds capacity and efficiency across systems so that family members can get the help they need to successfully keep the family together in their home. Advice is to consider funding the further development of aging and disability resources, centers, funding grants that promote collaboration between long-term care organizations that serve people with developmental disabilities, physical disabilities, and elderly so we can support families who have multiple needs to remain living in their homes and communities.

(DETROIT. Cathy Fikes, Community Living Services, a non-profit organization in southeast Michigan that transitions people out of nursing homes and back to their families in their homes in the community)

Family Support

The majority of people with developmental disabilities of all ages live with their families, and demographic trends indicate a growing need to support older families because people with disabilities are living longer. They are more likely to remain at home longer due to the wait list for residential services.

"More funding needs to be directed towards family support. Right less than 5% is spent towards family support, even if 75% of people with developmental disabilities live at home with their families. That really needs to change. Just because if for no other reason, the enormous fiscal

restraints that our Medicaid system is going to face in the future with the aging of the population, we have to support families. Within that population of family caregivers, there is a significant growing population of older caregivers of adults with developmental disabilities. Right now, the current estimates are that there is, 716,000 caregivers who are over the age of 60 caring for a family member with developmental disabilities. That population is going to significantly expand with the aging of the baby boom generation. Some of the things that we can do to support families is to strengthen Title two of the DD Act, is family support. I think that should also have a separate line item that would facilitate additional advocacy for family support."

"… I think we need to partner with the Administration on Aging and work to improve the national family caregiver support program. That is really one of the premier programs in the country that supports families. It is expanded over its 10 year history. The one population that is not covered right now is caregivers of adults with disabilities. As that Act is up for re-authorization this year, I think that is an opportunity for ADD and AOA to partner together." ***(ORLANDO. Joe Caldwell, adjunct professor, University of Illinois at Chicago, National Council on Aging, and parent of teenager with disabilities)***

Testimony also emphasized the role of adult siblings as the next generation of family caregivers after their parents' death and the importance of providing them with information on how to access supports and services for their brother or sister with a disability.

*"The Sibling Leadership Network is an organization of siblings, family members, professionals, educators and others dedicated to the promotion of family support and empowerment for people with developmental disabilities across the life span. Our purpose is to establish a network of the siblings to share the experience of disability and to connect them to social, emotional, governmental and provisional supports…so that we can better advocate with and for our brothers and sisters. Even though most of us know that we are the natural next step in the caretaking support chain, we don't know how to prepare for that role. The Sibling Leadership Network has developed a series of suggested …changes, research initiatives, services and supports, and strategies that ADD can adopt and/or administer…to better support siblings and subsequently their brothers and sisters with disabilities. Today I am going to highlight four of those recommendations. Number one, redefine the term family in legislative documents to explicitly include brothers and sisters to ensure their involvement in all programmatic and systemic initiatives. Number two, enhance the collection and analysis of national family support data to include issues and trends that is relevant to siblings. Number three, include all types of family members, in addition to parents, as representatives on state developmental disability councils. We would particularly suggest one seat be occupied by a sibling representative. Number four, create programs to reach out to, inform and involve siblings of people with disabilities…. Providing siblings with services is a low cost, high impact means for improving the lives of people with disabilities and their families. Because supported, informed siblings are more likely to remain lovingly involved in their siblings' lives particularly when parents are no longer able to act as caregivers.****"(DENVER., Emily Tanis, sibling and professional, University of Colorado)***

Health

Testimony on health coalesced around three issues: 1) health promotion for people with disabilities, 2) educating health professional about age related health changes experienced by older adults with developmental disabilities, and 3) dementia care.

*"The third area I would like to highlight is healthy aging and health promotion of people with disabilities. I think there are incredible opportunities in the affordable care act that ADD can play a key role in. One of those is to collect better data on health disparities for people with disabilities which is a requirement of the act. I think ADD can play a key role in there. There is also a prevention and public health trust fund that has dedicated funding. We need to make sure that some of that funding goes to promote healthy aging and health promotion of people with disabilities."**(ORLANDO. Joe Caldwell, adjunct professor, University of Illinois at Chicago, National Council on Aging, and parent of teenager with disabilities)***

*"Thirdly, primary care practitioners must be educated about the health needs of aging adults with developmental disabilities. ADD should work with HRSA the health resources service administration to ensure this topic is addressed by all of the geriatric education centers in this country and there are 50 of them. ADD should establish joint workgroup with the major healthcare professional associations, AMA, ANA, and geriatric professional associations to ensure that each group educates their members about the healthcare needs of older individuals with DD**." (ORLANDO. Jean Sherman, University of Miami's School of Medicine faculty member and has 42-year old son with intellectual disabilities)***

"*In January 2006 at the age of 45, Bill, my brother who had Down syndrome, was diagnosed with dementia Alzheimer's type. Over the course of the next four years, his journey became far more complex. He experienced a very rapid deterioration during the last 13 months of his life and died of chronic aspiration pneumonia (…) Extraordinary efforts to advocate for Bill were required during the final years of his life. Active advocacy was sometimes lonely and often a very frustrating process. Obstacles for advocacy increased very significantly after Bill's diagnosis of Alzheimer's disease."*

Individuals with Down syndrome are at increased risk for developing Alzheimer's disease, families, caregivers, and medical providers and researchers as well must work together to maintain their quality of life.

I hope that:

> *Efforts will be made to update best practices for support and services for aging individuals with intellectual disabilities, developmental disabilities, and Alzheimer's disease and related dementias.*
>
> *Regional model communities, which will be funded by federal or state agencies to demonstrate the ability to implement best practices quickly and with cost effectiveness. Specialized dementia care group homes serving four to six residents will be established to provide continuity of care in a homelike setting while maintaining quality of life and*

utilizing well-trained staff. In personal journey as an advocate for brother, resources were very limited.

A consortium of providers developing a much-needed brochure, a written document, on Down syndrome and Alzheimer's disease enabling families to access information both about disease process and advocacy. Suggests a review of what has been produced in Australia as a sample of what might be accomplished here and of what's been made available in Scotland with review in hopes that we could duplicate something the same.

Medical and nursing school curriculums will require competence in the provision of care to intellectually and developmentally disabled populations including those with dementia. This population will no longer be marginalized and Health Care disparities will be eliminated 10 years after the Surgeon General's 2002 initiative to close the gap and improve the health of individuals with intellectual disabilities.

As you look at your five-year strategic plan, recognize the need for improved dementia care for individuals with intellectual and developmental disabilities in conjunction with increased support for family members as caregivers and advocates

I think what I was looking for when I was advocating for my brother was very specific ideas about in what domain can I advocate. I cannot change the disease process, but I certainly could figure out areas in which I could help. I used, for instance, brother's response to people helping him dress. The conclusion was that he was acting out because he was -- he had dementia. When, in fact, he was acting out because he had broken ribs. It leads me to say that once a diagnosis of dementia is made, I think there are a lot of conclusions that are made that are inaccurate. I sought help for the opportunity to improve the quality of his life, so I couldn't do anything about the disease process. I felt that the resources that I looked to often wanted to avoid the topic of Alzheimer's in this particular population. It's a very difficult part of life to have to cope with. Therefore, I looked around the world - and Matt Janicki actually referred me to the documents in Scotland - and then he in turn used what I had produced and gave me a contact in Australia. The people in Australia have developed a fabulous document on Down syndrome and Alzheimer's disease. It's very user-friendly. It gives families pointers and describes the disease process in a useful way. It also makes some suggestions about advocacy."
(DETROIT. Mary Hogan, sister of brother with Down syndrome)

"*I propose that the Administration on Developmental Disabilities take the lead and help convene another meeting amongst organizations for persons with disabilities (Alzheimer's Association, Administration on Aging, American Association on Intellectual and Developmental Disabilities, AUCD, University Center, etc.) to help develop a consensus document and contemporary plan on best practices for support and services for people with I/DD affected by Alzheimer's and related dementias. Time to create the policy and practice framework that would help families and providers have the hope that what they are doing in providing community care and avoiding institutionalization is within the realm of best practice and is contributing to the best quality of life for older adults with I/DD"* ***(ORLANDO. Matthew Janicki, associate research professor, University of Illinois at Chicago****)*

Adults with intellectual disabilities have a higher prevalence of obesity that the general population and are more sedentary. Because they are living longer they are at greater risk for such age-related health problems as hypertension, diabetes. Their greater vulnerability makes it important to educate health professionals about adult health issues for people with developmental disabilities, including their greater risk for specific age-related health problems The high rate of Alzheimer's disease among adults with Down syndrome creates an opportunity for ADD to collaborate with the Alzheimer's Association and the Administration on Aging to ensure that service agencies and families are adhering to best practices in providing dementia care and can access the caregiving supports they need.

Summary

The Envisioning Session testimony on Aging has identified several issues that ADD can address in developing its five-year strategic plan. A key issue is bridging the aging and DD service systems to improve services and supports for older adults with developmental disabilities and older family caregivers. Collaboration between networks will result in a holistic approach for addressing later life needs, especially for the two-generation elderly families. Also, it is important for addressing future planning, waiting lists for services, family support, and health disparities. Although these are adult lifespan issues, the Administration on Aging is taking the lead on several national initiatives that are addressing these concerns for older adults and people with acquired disabilities.

APPENDIX 3
MEMORANDUM OF UNDERSTANDING BETWEEN AOA AND ADD

hds human development services

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Administration on Developmental Disabilities

1. Log No. ADD-IM-89-2	2. Issuance Date: 8/7/89
3. Originating Office: Administration on Developmental Disabilities	
4. Key Word: Memorandum of Understanding	5. ADD/AoA
6.	7.

RECEIVED
AUG 21 1989
TPCGD

INFORMATION MEMORANDUM

TO : Directors, State Administering Agencies
Chairpersons, State Planning Councils
Executive Directors, State Planning Councils
Directors, State Protection and Advocacy Agencies
Directors, University Affiliated Programs and Satellite Centers

SUBJECT : Memorandum of Understanding between the Administration on Aging and the Administration on Developmental Disabilities

LEGAL AND RELATED REFERENCE : Public Law 100-175, The Older Americans Act Amendments of 1987. Public Law 100-146, The Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987.

INFORMATION : This memorandum transmits a Memorandum of Understanding (MOU) between the Administration on Aging (AoA) and the Administration on Developmental Disabilities (ADD) of the Office of Human Development Services, Department of Health and Human Services. The purpose of the MOU is to improve the coordination of the programs related to older persons who have a developmental disability.

Under the agreement, AoA and ADD will jointly develop and implement activities to:

- Promote better understanding between the National Network on Aging and the Developmental Disabilities Network of programs serving older persons with disabilities.

- Improve services to older persons with developmental disabilities.

- Demonstrate, at the national level, a commitment between AoA and ADD to improve services to older persons with developmental disabilities.

The new agreement provides a framework for AoA and ADD to work together to promote the independence, productivity and integration of older persons with developmental disabilities into the mainstream of society.

INQUIRIES TO : Raymond Sanchez, Director
Program Development Division
Administration on Developmental Disabilities
Telephone: (202) 245-1961

Will Wolfstein
Acting Commissioner
Administration on Developmental Disabilities

Memorandum of Understanding
Between
The Administration on Aging
and
The Administration on Developmental Disabilities

INTRODUCTION

The Administration on Aging (AoA) was created under the Older Americans Act of 1965 and is the only Federal agency devoted exclusively to the concerns and potential of America's older population. AoA serves as the visible advocate on behalf of the elderly within the Department of Health and Human Services and with other Federal agencies and national organizations administering programs affecting older people. The major goal of the Administration on Aging is to help older people live more meaningful, independent, and dignified lives in their own homes and communities for as long as possible.

The Administration on Developmental Disabilities (ADD) is the lead agency within the Department of Health and Human Services responsible for planning and carrying out programs which promote the self-sufficiency and protect the rights of the nearly four million Americans with developmental disabilities. The major goal of ADD is to work in partnership with State governments, local communities and the private sector to increase the social and economic integration of individuals with developmental disabilities into the fabric of society.

The purpose of this agreement is to improve the coordination of programs administered by AoA and ADD which relate to the welfare of older persons with developmental disabilities.

BACKGROUND

It is estimated that 2 out of every 1,000 older adults have a developmental disability. The total number of elderly persons in the United States who are developmentally disabled is estimated to be as high as one-half million persons. These older persons are in double jeopardy. Their problems are complicated by long-standing physical or mental impairments and they frequently need individualized housing, day-care, and other supportive services. Assistance, through the provision of appropriate services, to this priority older population can be made available and accessible within the community through a comprehensive, coordinated, community-based service system. This system of services should be designed to enable older persons with developmental disabilities to attain and maintain emotional well being and independent living.

The Older Americans Act now contains many requirements for services to elderly disabled people and cooperation with agencies and organizations regarding the developmentally disabled. For example, the Act requires the State Agency on Aging to establish and operate an Office of the State Long Term Ombudsman. This Office is required to coordinate ombudsman services with the protection and advocacy systems for individuals with developmental disabilities and mental illness established under Part A of the Developmentally Disabilities Assistance and Bill of Rights Act and under the Protection and Advocacy for Mentally Ill Individuals Act of 1986.

With respect to the needs of elderly persons with severe disabilities, the Act requires State plan assurances for the coordination of planning, identification, assessment of needs, and services with State agencies primarily responsible for disabled, including severely disabled, persons. The State plan must also contain an assurance that the State will work with these agencies to develop collaborative programs to meet the needs of older individuals with disabilities.

There is a need for the AoA and ADD to undertake the development of collaborative activities to improve the coordination of programs administered by AoA and ADD which promote the independence and well-being of older persons with developmental disabilities.

SCOPE OF THE AGREEMENT

The immediate objective of this agreement is for AoA and ADD to discuss, and develop action plans for, joint initiatives which improve the coordination of AoA and ADD programs and activities in order to improve services to older persons with developmental disabilities, promote the integration of these individuals into the mainstream of society, and promote a better understanding of programs serving elderly and disabled persons between the National Network on Aging and the Developmental Disabilities Network.

Under this agreement, AoA and ADD agree to jointly develop and implement initiatives in support of the goals and objectives outlined below and to undertake the development of other collaborative activities which promote the independence and well-being of older persons with developmental disabilities.

GOAL I

Promote a better understanding of programs serving elderly and disabled persons between the National Network on Aging and the Developmental Disabilities Network.

OBJECTIVES

1. To increase best practice and other information sharing/exchange between the Network on Aging and Developmental Disabilities Network.

2. To stimulate linkages between the Ombudsman and Protection and Advocacy Programs.

3. To explore potential linkages between the Aging Resource Centers and University Affiliated Programs.

4. To encourage the development of memoranda of understanding between the State Developmental Disabilities Councils and State Agencies on Aging.

GOAL II

To demonstrate a commitment at the national level between the Administration on Aging and the Administration for Developmental Disabilities regarding serving older persons with developmental disabilities.

OBJECTIVES

1. To provide policy guidance to National Network on Aging and the Developmental Disabilities Network on serving older persons with developmental disabilities.

2. To promote training of Network on Aging and Developmental Disabilities Network staff and others regarding the abilities and unmet needs of older persons who are developmentally disabled.

3. To increase collaboration and linkages between national organizations and Federal, State, and local agencies serving the older persons who are developmentally disabled.

4. To jointly develop a priority area on elderly persons with developmental disabilities for the discretionary funds announcements.

GOAL III

Improve services to older persons with developmental disabilities.

OBJECTIVES

1. To identify the unmet needs of older persons with developmental disabilities.

2. To facilitate the provision of quality services in intermediate care facilities which meet the needs of older persons who are mentally retarded.

3. To promote training of health care professionals to provide services to older persons with developmental disabilities.

4. To promote training of family caregivers on how to care for older persons with developmental disabilities.

5. To promote the successful integration of older persons with developmental disabilities in aging network programs (mainstreaming those elderly persons who are developmentally disabled as participants and volunteers at senior centers and nutrition sites).

ADMINISTRATION OF MEMORANDUM OF UNDERSTANDING

The Administration on Aging and Administration on Developmental Disabilities jointly agree to:

1. Designate staff to be responsible for administering all aspects of this agreement; and

2. Designate staff of AoA and ADD to meet regularly to review the progress of the joint agreement and to identify new joint initiatives.

PERIOD OF AGREEMENT

This agreement is effective upon signature and shall continue in effect until terminated by either party.

AUTHORITY

The Economy Act of 1932, as amended (31 U.S.C. 1535)

MODIFICATION OR CANCELLATION PROVISION

This agreement may be modified or amended by written agreement of both parties. Requests for modification and amendments to the agreement may be initiated by either party through written notification to either party.

COSTS

To be determined upon the completion of specific action plans for dissemination activities and/or research and demonstration projects.

ACCEPTANCE AND SIGNATURE OF EACH APPROVING PARTY

Joyce T. Berry

Joyce T. Berry, Ph.D.
Acting Commissioner on Aging
Administration on Aging
U. S. Department of Health
and Human Services

6/27/89
Date

Will Wolstein

Will Wolstein
Acting Commissioner
Administration on Developmental
Disabilities
U. S. Department of Health
and Human Services

6/22/89
Date

APPENDIX 4
ADMINISTRATION ON DEVELOPMENTAL DISABILITIES AGING TRAINING INITIATIVE PROJECTS (TIPS)

The 1987 amendments to the DD Act authorized ADD to fund a network of Aging Training Initiative Programs in aging and developmental disabilities. New and creative training and education programs were set up at University Centers of Excellence in Developmental Disabilities (UCEDDs) in several states including the Shriver Center in Massachusetts, the University of Illinois at Chicago, Indiana University, the University of Montana, the University of Miami, the University of Wisconsin, the University of Georgia, and the University of Missouri among others. They became centers within their state around which workers with an interest in aging could coalesce. Each had their own character and specialization as noted in the following programs:

The University of Georgia UCEDD developed and evaluated drama, art, dance, and fitness programs to demonstrate that old age for persons with developmental disabilities can be a time of fulfilling activity and creativity.

Strong Center for Developmental Disabilities**,** Program in Aging and Developmental Disabilities at the University of Rochester developed a training curriculum on aging and DD, conducted staff training, established a geriatric health clinic, and organized work groups on aging with cerebral palsy that resulted in a consensus conference on age-related health concerns of older people with cerebral palsy.

The Institute for the Study of Developmental Disabilities at Indiana University developed a curriculum for training staff to become "Community Builders." Community Builders establish community partnerships with individuals and organizations to enable older adults with developmental disabilities to participate in local activities based on their individual interests.

The University of Missouri-Kansas City Institute for Human Development developed cross-network staff training on bridging the aging and developmental disabilities that included content for meeting the needs of older adults and their families living in rural areas. The UCEDD also produced a series of fact sheets on age-related health and psychosocial changes that were disseminated nationally.

The Center on Aging and Developmental Disabilities at the Mailman Center for Child Development, University of Miami School of Medicine focused on the needs of aging parents of older adults with developmental disabilities, particularly as they looked to the future care of their dependent adult children with severe disabilities.

The Waisman Center, University of Wisconsin established a clinic for older adults with cerebral palsy and shared assessment tools and research measures with the University of Illinois UCEDD.

The Shriver Center implemented The Community Membership Project that engaged eight older adults to establish Circles of Support consisting of paid staff as well as unpaid family members and friends. The older adults included individuals who had severe levels of impairment and people who recently transitioned from state institutions to living in the community. The Circles of Support enabled these eight individuals to identify their goals related to community life and worked with them to establish and implement action plans to realize their aspirations. Their goals included singing in the church choir, being reunited with family, making new friends based on mutual interests, and giving a presentation at an international conference.

The University of Montana Rural Institute on Disabilities developed and implemented innovative training, transitioning and integration models to equip staff in day services and residential settings in rural areas with the knowledge and skills to accommodate age-related changes in health and function and to support older adults' participation in community activities.

The Institute on Disability and Human Development (IDHD), University of Illinois at Chicago, developed and provided three statewide training programs to support future planning by older adults with developmental disabilities and their families. The training series included: 1) attorney-led workshops on legal and financial planning for families; 2) cross-network training for staff at aging and developmental disabilities agencies to collaborate on outreach and support to older families and to integrate older adults in community activities; and 3) implemented peer training for later life (*Making Choices as We Age: A Peer Training Program*). Older adults with disabilities learned how to teach their peers to be informed consumers about later life choices such as maintaining good health and participating in community activities. The Aging TIP also established a specialized clinic for adults with cerebral palsy at the UCEDD's Family Clinic that evaluated the benefits of assistive devices on functioning and provided technical assistance to the Adult Down Syndrome Clinic in Chicago to develop its clinical information system. The grant together with support from IDHD's NIDRR funded Rehabilitation Research and Training Center on Aging with Developmental Disabilities and an Administration on Aging discretionary grant in aging and developmental disabilities supported the *8th International Roundtable on Aging and Intellectual Disabilities: Emerging National and Global Perspectives on Aging with Developmental Disabilities* that IDHD organized and hosted. The Aging TIP also contributed to the development and dissemination of the following products:

- *Opening All the Doors Under the ADA: Making Your Programs Accessible to Older Adults with Cognitive Disabilities*

- *Aging with Developmental Disabilities: An Information Packet on Understanding Age-Related Changes and Supporting Successful Aging*

- *Assistive Technology and You: A Guide for Families and Persons with Disabilities*

- *Opening All the Doors Under the ADA: Making Your Programs Accessible to Older Adults with Cognitive Disabilities*

Many Aging TIPs had a shelf-life of several years, and their leaders formed a national network that still exists within the AUCD's aging and developmental disabilities workgroup. The eventual demise of some TIPs was the result of the aging-out of its leaders and changing research interests and the withdrawal of funding by ADD for aging-related initiatives. The latter resulted in the closure or transfer of some aging clinics to generic or specialized health facilities. For example, the Illinois UCEDD CP Clinic moved to the Rehabilitation Institute of Chicago. However, several UCEDDs funded as Aging TIPs continue research and training in aging and developmental disabilities and have branched out in new directions. The Indiana University UCEDD has ongoing projects in building community supports for older adults with I/DD through the work of gerontologist Phil Stafford. Some Aging TIPS that included a research component have built upon this to develop a larger research portfolio. The Waisman Center has expanded its research on older family caregivers through other funding sources. The Strong Center is developing a dataset on adult lifespan health issues and continues to conduct staff training on aging with developmental disabilities. The Illinois UCEDD has been funded as the RRTC on Aging with Developmental Disabilities since 1993 by the National Institute on Disability and Rehabilitation Research and has subcontracted with the Indiana University UCEDD, the Waisman Center, and the Strong Center to conduct specific research projects.

APPENDIX 5
AOA AGING AND DEVELOPMENTAL DISABILITIES DISCRETIONARY GRANTS

AoA Bibliographic Database Search

WISCONSIN

Grant Number: 90-AJ-2014 (AoA)
Grant/Project Title: Life Long Planning: Developing State and Local Planning Linkages to Improve Opportunities for Older Persons with Developmental Disabilities
Grant Year Initiated: 1990
Grantee Name: Wisconsin Department of Health and Social Services
Grant Performed By: Wisconsin Council on Developmental Disabilities - Division of Community Services, Wisconsin Department of Health and Social Services, Waisman Center, Program on Aging and Developmental Disabilities. University of Wisconsin-Madison

Products:

NAIC accession number: 00305
Title: Lessons Learned from Listening to Our Elders: The Wisconsin Life Long Planning Initiative. Developing State and Local Planning Linkages to Improve Opportunities for Older Persons with Developmental Disabilities. Final Report
Author(s) of document: Wilson, Marilyn
Publication Date: January 1993
Abstract: An easy, informal, and thoughtful discussion of Wisconsin's Life Long Planning Initiative. The project's stated goals: (1) to expand formal services and other opportunities for integration for older persons with developmental disabilities; (2) to expand and improve informal supports for older persons with developmental disabilities and their lifelong caregivers; and (3) to develop and disseminate policy and programming models which impact on the resources and services available to older persons with developmental disabilities. Through the activities of this grant, a variety of person-centered, coordinated, and flexible models were explored that are more responsive to the needs and aspirations of older persons with developmental disabilities and their families. This project also addressed ways to better meet the needs of the state's American Indian elders with developmental disabilities. According to the author, recommendations from this project are now beginning to be implemented under the direction of a newly established Wisconsin Life Long Planning Task Force with staff assistance provided by the Developmental Disabilities Office. While the activities of the grant were Wisconsin-based, in the author's view, the findings appear to be applicable to any community interested in addressing the needs of older persons with developmental disabilities and their families. Bibliography included.

NAIC accession number: 00307
Title: Memorandum of Agreement -- Wisconsin Council on Developmental Disabilities, Wisconsin Developmental Disabilities Office, Wisconsin Bureau on Aging, Wisconsin Coalition for Advocacy, and the University of Wisconsin, Waisman Center, Program on Aging and Developmental Disabilities
Institutional Author: Waisman Center, Program on Aging and Developmental Disabilities. University of Wisconsin-Madison
Publication Date: January 1993
Abstract: A short, written statement outlining the terms of an agreement to promote the continuation and expansion of Wisconsin's Life Long Planning Initiative through strengthening of linkages between the aging network and the developmental disabilities system at the state, regional, county and service provider level.

NAIC accession number: 00308
Title: Planning Strategies for Meeting the Needs of Older Individuals with Developmental Disabilities: An Agenda and Action Plan for the 1990's
Corporate Author: Wisconsin Life Long Planning Initiative
Publication Date: September 1992
Abstract: A gallery of charts, graphs, and outlines. Illustration titles: What Are We Learning from People? What Did We Learn from Listening to People with Disabilities Who Are Older? State and Local System Change Issues. State and Local System Issues - Jackson County. Ideas and Platforms for Organization Change: What Can We Do with What We've Learned? Developing an Action Plan. Areas for Development. An Agenda for Development in the 1990's. Action Plans. This is a road map for state and local service system design. It contains no explanatory narrative.

NAIC accession number: 00309
Title: Respecting the Past, Enjoying Life Now, and Embracing the Future: Lessons Learned from Listening to Parents
Author(s) of document: McManus, Mark, Will, Dorothy, Laubenstein, Alice, Endres, Mary and Orville
Publication Date: September 1992
Abstract: This monograph is a working document, developed from focus group discussions with aging parents of older individuals with developmental disabilities. The first section of the monograph shares the stories of two families and provides an overview of the parent focus groups. Section two includes a summary discussion of the parents' hopes and concerns for the future. Invitation, agenda, and resource list included in an appendix.

NAIC accession number: 00304
Title: Creative Retirement Strategies: A Positive Response from the Dane County Department of Human Services and Elder Care of Dane County
Corporate/Institutional Author: Dane County Department of Human Services. Division of Adult Community Services & Elder Care of Dane County
Publication Date: January 1993
Abstract: This document contains both a request for proposals (RFP) and a local community agency's proposed program design to provide retirement services for persons with developmental disabilities in Dane County, Wisconsin.

Grant Number: 90-AM-0874
Grantee Name: Coalition of Wisconsin Aging Groups (CWAG)
Grant Performed By: Coalition of Wisconsin Aging Groups (CWAG)

Product:

NAIC accession number: 03466
Title: Citizen Action for Community-Based Care: 'The Wisconsin Model.' Final Report
Author(s) of document: Coalition of Wisconsin Aging Groups (CWAG)
Publication Date: 1996
Abstract:
The primary goal of this project was to join the forces of Wisconsin's state aging network and disability advocacy community to work together on long term care issues. For those interested in starting grassroots advocacy organizations, this final project report appends an advocates' handbook that was produced for Wisconsin advocacy and long term care coalition members, titled 'Change Through Action: A Model Training Package for Empowering Consumers in the Aging and Disability Communities.'

ILLINOIS

Grant Number: 90-AM-0681
Grant/Project Title: Innovative Internetwork Service Models Serving Older Adults with DD and Their Families
Grant Year Initiated: 1993
Grantee Name: Illinois Department on Aging
Grant Performed By: The University of Illinois at Chicago, Institute on Disability and Human Development

Product

NAIC Accession Number: 03377
Title: Final Report: Innovative Internetwork Service Models Serving Older Adults with Developmental Disabilities and Older Family Caregivers
Author(s) of document: Factor, Alan R., Ph.D.
Publication Date: July 9, 1996
Abstract:
'Internetwork' planning groups (IPG) were established in three Area Agency on Aging (AAA) planning and service areas (PSAs) to demonstrate collaborative approaches to serving older adults with developmental disabilities and older family caregivers. Each site reported unique needs. Among the specific needs, a public education campaign to increase community inclusion and employment opportunities, getting information out to older caregivers on government benefits, more bilingual staff in training programs and supports to help families deal with their relative's challenging behaviors. Training was provided to 549 aging network staff and 495 developmental disabilities staff to promote collaboration between the service systems.
Abstract:
A notebook of materials used at a training session for family caregivers. The focus of the workshop is to aid families in making future living arrangements for relatives with a disability. The objectives of the session were: (1) identify and limit barriers to planning for family caregiving, (2) identify ways to support individuals with disabilities with housing, work, leisure & retirement, and strengthen relationships issues. The training's primary objective is to have families prepare a "Letter of Intent" that describes their relative's desired future living arrangements, community role and lifestyle preferences and specifies the available resources and needed support to achieve these outcomes.

Other Products

The grant also produced other products with additional support from the Department on Disability and Human Development's NIDRR funded Rehabilitation Research and Training Center on Aging with Developmental Disabilities and the Administration on Developmental Disabilities Aging Training Initiative Project:

Opening All the Doors Under the ADA: Making Your Programs Accessible to Older Adults with Cognitive Disabilities
Aging with Developmental Disabilities: An Information Packet on Understanding Age-Related Changes and Supporting Successful Aging
Assistive Technology and You: A Guide for Families and Persons with Disabilities
Opening All the Doors Under the ADA: Making Your Programs Accessible to Older Adults with Cognitive Disabilities

NEW YORK

Grant Number: 90-AJ-2012 (AoA)
Grant/Project Title: Technical Assistance and Training in Aging and Developmental Disabilities: Network Planning, Services and Program Linking
Grant Year Initiated: 1990
Grant Performed By: New York State Office of Mental Retardation and Developmental Disabilities
Grantee Name: New York State Developmental Disabilities Planning Council

Products

NAIC accession number: 00301
Title of item: Community Integration Project in Aging and Developmental Disabilities. Final Report
Author(s) of document: Janicki, Matthew P.
Publication Date: May 1993
Abstract:
Final report on New York State's aging and developmental disabilities initiative, jointly funded by the Administration on Aging (AoA) and the Administration on Developmental Disabilities (ADD). The project's stated purpose: 'to disseminate products from New York's experiences to other states and to assist other states implement the technologies that foster nationwide development of a network of local services for aging persons with developmental disabilities.' Major products that were disseminated nationally include: (1) a 66-page working manual, revised and updated, titled 'The Wit to Win: How to Integrate Older Persons With Developmental Disabilities Into Community Aging Programs, (2) a 149-page handbook titled 'Building the Future: Planning and Community Development in Aging and Developmental Disabilities,' and (3) a 182-page casebook titled 'Integration Experiences Casebook: Program Ideas in Aging and Developmental Disabilities. This readable report recounts the history of aging and developmental disabilities initiatives within New York State, with a summary and interpretation of key lessons learned. Recommended.

NAIC accession number: 00302
Title of item: Integration Experiences Casebook: Program Ideas in Aging and Developmental Disabilities
Author(s) of document: Janicki, Matthew P., Keefe, Robert M.
Grant Year Initiated: 1990
Abstract:
This Casebook is a collection of 38 case studies written by practitioners, administrators and other program personnel from around the country and abroad who have worked at integrating elderly individuals with developmental disabilities into generic aging services. Models and practice experiences are grouped within eight clusters: Bridging Networks; Top Down Efforts; Retirement Assistance Ventures; Pull-Out Programs; Senior Companion Programs; Senior Center Ventures; Social Model Site Programs; and Adult Day Health Model Programs. Illustrating different integration approaches, each study provides a background and description of the project, lessons learned, as well as some final thoughts. A valuable reference for researchers, MR/DD specialists and everyone who is concerned with older persons with mental retardation and other developmental disabilities. Other Community Integration Project publications: The Will to Win: How to Integrate Older Persons with Developmental Disabilities into Community Aging Programs; Serving Seniors with Severe Disabilities; and Building the Future: Planning and Community Development in Aging and Developmental Disabilities.

Grant/Project Title: **New York State Alzheimer's Disease Demonstration Grant: Coordinated Care for Adults with Developmental Disabilities Who Have Alzheimer's Disease**

Principal investigator: Philip McCallion, Ph.D., Center for Excellence in Aging Services, University of Albany
Grant Year Initiated: 2002
Abstract:
The grant trained developmental disabilities providers and family members to recognize the symptoms of dementia, secure a diagnosis of dementia, identify levels of need for dementia-appropriate services and supports and environmental modifications, and create dementia-specific care plans; surpassed the stated goal of allowing 150 individuals with developmental disabilities and Alzheimer's disease to age in place in community residences with direct services, supports, and environmental modifications. The grant also created a network of local providers offering dementia-appropriate direct services (e.g., staff time to help get ready for attending a day program) and supports (e.g., support groups); changed physical surroundings at day programs and community residences that provided a more appropriate space (e.g., simpler environment) and augmented the value of the more traditional direct services administered through the grant.

VIRGINIA

Grant Number: 90-AM-0484 (AoA)
Grant/Project Title: Improving Services to Older Persons with Developmental Disabilities: Policy, Training, Services
Grant Year Initiated: 1990
Grantee Name: Virginia Department for the Aging
Grant Performed By: Virginia Department for the Aging

Products:

NAIC accession number: 01330
Title: Improving Services to Older Persons with Developmental Disabilities: Policy, Training, Services. Final Report
Corporate/Institutional Author: Virginia Department for the Aging
Publication Date: November 1992
Abstract:
Final report to Virginia Commonwealth's cross-state communication, planning, and training initiative addressing the needs of the elderly developmentally disabled. The project's stated goal: to develop state and local linkages between the aging and developmental disabilities service networks with the aim being to maintain, as appropriate, older adults with developmental disabilities in community settings. The project's objectives: (1) to identify current regulations and procedures in Virginia that impede or facilitate the provision of services to older adults with developmental disabilities, (2) to improve the knowledge and skills of community-based personnel in the aging network and in the developmental disability service systems, and (3) to assist older persons with developmental disabilities and their family caregivers to identify and use locally-based community resources. This was a partnership of the Virginia Department for the Aging, Virginia Board for Persons with Disabilities, Virginia Department of Mental Health, Virginia Commonwealth University Center on Aging, Virginia Institute for Developmental Disabilities at Virginia Commonwealth University, and three locally-based, community service agencies. [*] Cited in 'Putting Knowledge to Work,' December 1993.

NAIC accession number: 01332
Title of item: Older Persons with Developmental Disabilities: Planning for Independence. Report of a Project to Enhance the Community-Based Long-Term Care System for Older Persons with Developmental Disabilities

Corporate/Institutional Author: Virginia Department for the Aging
Publication Date: August 1992
Abstract:
Project briefing paper distributed to state human service administrators and members of the Virginia General Assembly. Through this project, the Virginia Department for the Aging sought to enhance the capacity for community living of older persons with developmental disabilities.

NAIC accession number: 01326
Title of item: Aging with Lifelong Disabilities: Virginia's Response to an Emerging Population Group
Author(s) of document: Cotter, J. James, Wood, Joan B., Ansello, Edward F.
Publication Date: March 1992
Abstract:
This paper highlights the main areas of activity undertaken by Virginia's aging and developmental disabilities Partners Project. Paper presented at the annual meeting of the Southern Gerontological Society, Nashville, Tennessee, March 18-21, 1992.

NAIC accession number: 01335
Title of item: Rappahannock-Rapidan Community Services Center Demonstration Site. Project Summary
Corporate/Institutional Author: Rappahannock-Rapidan Community Services Board
Publication Date: November 1992
Abstract:
An overview of a field demonstration called 'Support for Aging Caregivers of Developmentally Disabled Individuals.' The overall design of the project was to pair the resources of the services network and the developmental disability system to identify aging developmentally disabled and their families. Once the individuals and their families were identified, aging advocates and case managers in the developmental disability system worked together to assess their needs and to assist in providing needed community supports. Rappahannock-Rapidan Community Services Board is the only locally-based organization in the Virginia Commonwealth which is both an area agency on aging and community services board.

NAIC accession number: 01334
Title of item: Partners II: Successes and Limitations in Interagency Collaborations
Author(s) of document: Wood, Joan B. , Ansello, Edward F., J. James Cotter, Coogle, Constance L.
Publication Date: May 1992
Abstract:
Virginia's aging and developmental disabilities Partners Project is briefly described in this paper. Paper presented at the annual meeting of the American Association on Mental Retardation, New Orleans, May 26-30, 1992.

NAIC accession number: 01333
Title: Partners II: Enhancing Interagency Cooperation
Author(s) of document: Wood, Joan B., Ansello, Edward F.
Publication Date: March 1992
Abstract:
This paper provides a very brief overview of Virginia's aging and developmental disabilities partnership initiative. Paper presented at the annual meeting of the American Society on Aging, San Diego, March 14-19, 1992.

NAIC accession number: 01329
Title: Improving Services to Older Persons with Developmental Disabilities: Policy, Training, Services. Project Briefs
Corporate/Institutional Author: Virginia Department for the Aging
Publication Date: November 1992
Abstract: Project abstract, executive summary, and major products.

NAIC accession number: 01328
Title: Cross-Training of Personnel in the Aging and DD Networks: Responses from the General Evaluation Questionnaire. A Partners II Project Evaluation Report
Corporate/Institutional Author: Virginia Department for the Aging, Virginia Center on Aging, Virginia Institute for Developmental Disabilities in cooperation with Virginia Geriatric Education Center
Publication Date: August 1992
Abstract: A statistical analysis of pre- and post-test data. Extremely technical. Tables are presented separately at the back of the report.

NAIC accession number: 01331
Title: Norfolk Senior Center Demonstration Site. Project Summary
Corporate/Institutional Author: Norfolk Senior Center
Publication Date: November 1992
Abstract: An overview of a field demonstration to alert older developmentally disabled adults and their family caregivers to available resources.

Grant Number: 90-AM-0680 (AoA)

Products:

NAIC accession number: 03456
Title of item: Partners: Building Inter-System Cooperation in Aging with Developmental Disabilities
Author(s) of document: Ansello, Edward F., Coogle, Constance L., and Wood, Joan B.
Publication Date: 1997
Abstract:
'The Integrated Model of Service for Older Persons with Disabilities' is a strategy or process for improving community services for persons who have grown old with lifelong, developmental disabilities (DD). Collaboration, Outreach, and Capacity Building are its key ingredients. Incorporating best experiences of earlier years of work, the model was tested in the real world by five community-based agencies in Maryland and Virginia. This document is an assemblage of strategies found effective by local aging network and DD system partners for integrating service delivery.
Grantee Name: Virginia Center on Aging, Virginia Commonwealth University
Grant Performed By: Virginia Center on Aging, Virginia Commonwealth University

NAIC accession number: 01328
Title of item: Cross-Training of Personnel in the Aging and DD Networks: Responses from the General Evaluation Questionnaire. A Partners II Project Evaluation Report
Corporate/Institutional Author: Virginia Department for the Aging
Corporate/Institutional Author: Virginia Center on Aging
Corporate/Institutional Author: Virginia Institute for Developmental Disabilities in cooperation with Virginia Geriatric Education Center
Publication Date: August 1992

Abstract: A statistical analysis of pre- and post-test data. Extremely technical. Tables are presented separately at the back of the report.

MISSOURI

Grant Number: 07-AT-0336 (AoA)
Grant/Project Title: Enhancing Services for Mentally Retarded/Developmentally Disabled Residents in Nursing Homes
Grant Year Initiated: 1987
Grantee Name: University of Missouri
Grant Performed By: University of Missouri-Kansas City (UMKC) Institute for Human Development. University Affiliated Program for Developmental Disabilities and University of Missouri-Columbia School of Medicine. Office of Continuing Education and Extension

Product:

NAIC accession number: 00243
Title: Enhancing Services for Mentally Retarded/Developmentally Disabled Residents in Nursing Homes
Author(s) of document: Kultgen, Phyllis, Guidry, Jacqueline, Cohen, Gerald J., Sanddal, Nels, Bourne, Bonnie
Publication Date: February 1989
Abstract:
Directed to nursing home administrators, this training guide provides practical and meaningful information on caring for mentally retarded/developmentally disabled (MR/DD) residents. The guide is divided into nine training modules: 1) Historical Background; 2) Overview of Mental Retardation and/or Developmental Disabilities; 3) The Effects of the Aging Process on Older Persons with Developmental Disabilities; 4) Social and Emotional Needs of the Older Person with Developmental Disabilities; 5) Managing Behavior; 6) Providing Leisure and Recreational Activities for the Developmentally Disabled Elderly; 7) Statutory Trends; 8) Decision Making for Persons with Developmental Disabilities; and 9) Legal Responsibilities of Nursing Homes Serving Clients Who are Developmentally Disabled. Each of the modules includes small group exercises, worksheets, case studies, definitions, and summary notes. References are provided at the end of the volume. This is a valuable text. There is good material here for nursing home administrators, practitioners, aging and MR/DD advocates, long term care ombudsmen, and others. Recommended.

Grant Number: 90-AM-0349 (AoA)
Grant/Project Title: National Resource Center for Rural Elderly
Grantee Name: University of Missouri-Kansas City
Grant Performed By: University of Missouri-Kansas City. Center on Aging Studies. National Resource Center for Rural Elderly
Grant Year Initiated: 1988

Product:

NAIC accession number: 00838
Title of item: Aging and Developmental Disabilities in Rural America
Author(s) of document: Rinck, Christine, Cohen, Gerald J., Griggs, Peter A.
Publication Date: 1990
Format of Item: Other print media format (29).
Physical Description: 114 pp.
Abstract:

The purpose of this book is to introduce the reader to issues of aging and developmental disabilities in rural settings, their significance to both the aging and disabilities networks, and strategies of benefit to consumers of both systems. Vignettes are presented to address major issues in this field. Chapters include: Definitions; Agencies and Resources to Assist Older Rural Persons with Developmental Disabilities and Their Families; Case Management for Persons with Developmental Disabilities; Issues in Residential Placement; Work and Leisure Activities; The Older Care Provider; Funding Sources for Projects in Aging and Developmental Disabilities. An excellent resource. Recommended. [*] Reviewed in 'Putting Knowledge to Work for Older Americans' (September/October 1993): 5.

Grant Number: 90-AJ-2011 (AoA)
Grantee Name: University of Missouri-Kansas City (UMKC)
Grant Performed By: University of Missouri-Kansas City, Institute for Human Development, University Affiliated Facility for Developmental Disabilities (UMK-UAF)

Products:

NAIC accession number: 04328
Title: A Composite Approach to the Service Needs of the Developmentally Disabled Elderly. Final Report
Author(s) of document: Kultgen, Phyllis, and Rinck, Christine
Publication Date: April 1988
Abstract: This project was designed to disseminate materials and information developed by an earlier training and demonstration grant (Expanding the Life Chances and Social Support Networks of Elderly Developmentally Disabled Persons). The project created a senior center volunteer model to improve the social supports available to elders with developmental disabilities.

NAIC accession number: 04503
Title: Expanding the Life Chances and Social Support Networks of Elderly Developmentally Disabled Persons
Author(s) of document: Kultgen, Phyllis, Rinck, Christine, Calkins, Carl F., and Intagliata, James
Publication Date: April 1986
Abstract:
This demonstration study aimed to improve the quality of life and enlarge the life chances and social networks of older people with developmental disabilities. The report analyzes and compares outcomes of three case management/individual habilitation planning (IHP) models: 1) age-integrated caseload; 2) age segregated caseload, and 3) consultant to case managers model. The age segregated model is the most effective case management strategy, the study concludes. IHP rating instrument, informant mood scale, client assessment instrument, and profile of client medical/physical needs and mental status are included in the report.

Grant Number: 90-AJ-1022 (AoA)
Grantee Name: University of Missouri-Kansas City (UMKC)
Grant Performed By: University of Missouri-Kansas City, Institute for Human Development, University Affiliated Facility for Developmental Disabilities (UMK-UAF)
University of Missouri-Kansas City, National Resource Center for Rural Elderly (NRCRE)

Product:

NAIC accession number: 04329
Title: Training Guide for Aging Specialists
Author(s) of document: Kultgen, Phyllis, Rinck, Christine, and Pfannenstiel, Dorothy

Publication Date: April 1986
Abstract:
This manual is intended as a self-study guide/reference manual for providers who work with older persons with mental retardation or developmental disabilities. Cover topics ranging from physical changes, emotional changes, cognitive changes, and social changes. Self-test questions at the end of each chapter provide reinforcement for each topic.

Grant Number: 90-AJ-1022
Grantee Name: University of Missouri-Kansas City (UMKC)
Grantor Organization: Administration on Aging (AoA), and Administration on Developmental Disabilities (ADD)
Grant Performed By: University of Missouri-Kansas City, The UMKC Institute for Human Development, University Affiliated Program for Developmental Disabilities

Product:

NAIC accession number: 04350
Title: Aging and Developmental Disabilities in Rural America
Author(s) of document: Rinck, Christine, Cohen, Gerald J., and Griggs, Peter A.
Publication Date: 1990
Abstract:
The purpose of this book is to introduce the reader to issues of aging and developmental disabilities in rural settings, their significance to both the aging and developmental disabilities networks, and strategies of benefit to consumers of both systems. There are chapters on agencies and resources, case management, residential placement, work and leisure activities, the older care provider, and funding sources. A glossary is included at the end of the book.

Grant Number: 90-AM-0349 (AoA)
Grantee Name: University of Missouri-Kansas City
Grant Performed by: University of Missouri-Kansas City, The UMKC Institute for Human Development, University Affiliated Program for Developmental Disabilities

Product:

NAIC accession number: 04503
Title: Expanding the Life Chances and Social Support Networks of Elderly Developmentally Disabled Persons
Author(s) of document: Kultgen, Phyllis, Rinck, Christine, Calkins, Carl F., and Intagliata, James
Publication Date: April 1986
Abstract:
This demonstration study aimed to improve the quality of life and enlarge the life chances and social networks of older people with developmental disabilities. The report analyzes and compares outcomes of three case management/individual habilitation planning (IHP) models: 1) age-integrated caseload; 2) age segregated caseload, and 3) consultant to case managers model. The age segregated model is the most effective case management strategy, the study concludes. IHP rating instrument, informant mood scale, client assessment instrument, and profile of client medical/physical needs and mental status are included in the report.

HAWAII

Grant Number: 90-AM-0677
Grantee Name: Hawaii State Planning Council on Developmental Disabilities
Grant Performed By: Hawaii State Planning Council on Developmental Disabilities, Hawaii Executive Office on Aging and Hawaii University Affiliated Programs

Products:

NAIC accession number: 03857
Title: Collaborative Teaming to Promote Inclusive and Appropriate Aging Experiences for Persons with Developmental Disabilities. Final Report of Project Activities, 1994-1995
Author(s) of document: Tizard, Diana, Stodden, Robert A. and Suttie, Janene N.
Publication Date: December 1995
Abstract:
A growing number of persons with developmental disabilities are living longer – posing a challenge to caregivers and community service providers alike. This final report is an account of the Hawaii State Planning Council on Developmental Disabilities efforts to help broaden public dialogue about ways to promote the inclusion of older persons with developmental disabilities into general aging programs in the community. Contains a diagram of Hawaii's teaming process for restructuring services and programs, plus an evaluation plan.

NAIC accession number: 03856
Title of item: Persons Aging with and without Developmental Disabilities: A Resource Reference Collection
Author(s) of document: Hawaii State Planning Council on Developmental Disabilities, Hawaii Executive Office on Aging and Hawaii University Affiliated Programs
Abstract:
An extensive scholarly bibliography, intended to inform the project, 'Collaborative Teaming to Promote Inclusive and Appropriate Aging Experiences for Persons with Developmental Disabilities.' Organized by subject area, includes annotated descriptions. Sections include: Leisure and Recreation; Caregivers; Dementia and Alzheimer's, Cognition and Memory; Residential Options; Day Care; Service Needs; Retirement; Stress; Social Relations; Mental Health and Depression; Health and Medical; Social Theories of Aging; Psychological Theories of Aging; Mental Retardation and Aging; Behavior; Biological Theories of Aging; Volunteers; Legal Issues; Deinstitutionalization; Personality; Ageism; Futures Planning; Quality of Life; Cerebral Palsy; Mobility and Transportation; Empowerment; Advocacy; Staff Training; Down Syndrome and Aging; Support Networks; Aging in General; Community Integration; Research on Aging; Death and Dying; Choice; Cultural Issues; Training; Technology; and Seniors.

PENNSYLVANIA

Grant Number: ARCPA-1001 (AoA)
Grantee Name: n.a.
Grantor Organization: Administration on Aging
Grant Performed By: The Arc of Pennsylvania, Pennsylvania Department of Aging, and Pennsylvania Department of Public Welfare, Office of Mental Retardation

Product:

NAIC accession number: 00073
Title: Working Together: Bridging Systems to Better Serve Older Adults
Corporate/Institutional Author: The Arc, Pennsylvania [formerly the Association for Retarded Citizens of Pennsylvania] in cooperation with the Pennsylvania Department of Aging
Corporate/Institutional Author: Pennsylvania Department of Public Welfare, Office of Mental Retardation
Abstract:
This manual is a guide to be used to begin or further the process of promoting collaborative efforts by those who work with the aging and mental retardation service systems on the local level. It was developed out of the recognition that the continuing increase in the number of older people with mental retardation will require agencies from both systems to work cooperatively with shared resources to provide effective services to this special population group.

NATIONAL

Grant Number: 90-AM-0698101
Grantee: National Academy for State Health Policy
Year Grant Awarded: 1994

Publication:

NAIC accession number: 04620
Title: Coordinating Services with and for Persons with Disabilities: A Challenge for State Government
Document Author(s): Scully, Diana; Snow, Kimberly Irvin; Riley, Trish
Publication Date: August, 1995
Abstract:
This paper reflects the conversations and considerations of a focus group of 18 individuals representing persons with disabilities and their advocates and state and federal officials. The paper sets forth a framework for re-thinking policy for persons with disabilities and strengthening states' capacities to work closely with consumers to forge more comprehensive and coordinated care for persons with disabilities and their families. The paper also presents the range of possibilities available if federal programs serving persons with disabilities could be better coordinated or consolidated.

Grant Number: 90-AM-0701 (AoA)
Grant/Project Title: National Resource Center on Long Term Care
Grantee Name: National Association of State Units on Aging
Grantee Project Director: Justice, D.
Grant Year Initiated: 1993

Product:

NAIC accession number: 02753
Title: Serving the Elderly and Younger Adults With Disabilities: A Summary of the Long Term Care Symposium on Aging and Disability Issues
Author(s) of document: Williams, L.M.
Audience Code: Aging network agencies (109); Mental retardation/developmental disabilities (MR/DD) professionals and advocates (147).

Abstract:
On June 16, 1994, the National Resource Center for Long Term Care held a half-day policy symposium on aging and disability issues. The purpose of the session, and this issue brief, was to compare and contrast the perspectives of younger and older adults who have disabilities and to describe the characteristics of programs that serve both population groups. This conference summary highlights experiences of Washington State, Indiana, and Delaware in designing service systems to meet the needs of all adults with disabilities. Implications of State program experience for long term care reform are identified.
Title IV Product (Yes/No): Yes

Grant Number: 90-AM-0603 (AoA)
Grant/Project Title: Operation Care for At-Risk Elderly Parents and Their Sons/Daughters With Mental Retardation
Grantee Name: The Arc
Grant Year Initiated: 1992
Grant Performed By: The Arc of the United States

Product:

NAIC accession number: 01850
Title: Meeting the Needs and Challenges of At-Risk, Two-Generation, Elderly Families
Author(s) of document: Davis, Sharon; Berkobien, Rick
Publication Date: August 1994
Format of Item: Other print media format (29).
Physical Description: 50 pp.
Abstract:
A replication handbook for use by chapters of The Arc and other agencies throughout the United States. The manual includes the following sections: Two-Generation Elderly Families: Problems and Needs; The Community Service Systems for Aging and Mental Retardation/Developmental Disabilities; Building Community Coalitions to Serve Two-Generation Elderly Families; Coalition-Building Experiences of Chapters of The Arc; Helping Families Plan for the Future; and Resources.

NAIC accession number: 01851
Title: Operation Care for At-Risk Elderly Parents and Their Sons/Daughters With Mental Retardation. Final Report
Author(s) of document: Davis, Sharon; Berkobien, Rick
Publication Date: August 1994
Abstract:
Final project report. This project sought to demonstrate how local chapters of The Arc could build the capacity of their communities to find and assist at-risk families of elderly parents who are caretakers of older adults with mental retardation.

Grant Number: 90-PD-0129 (AoA)
Grant/Project Title: Disseminate Materials on Self-Sufficiency
Grantee Name: Birch & Davis Associates, Inc.
Grant Year Initiated: 1986
Grant Performed By: Birch & Davis Associates, Inc.

Product:

NAIC accession number: 02535
Title: Disseminate Materials on Self-Sufficiency. Final Report
Author(s) of document: Karsten, Stephanie E.; Kasab, Dale S.
Publication Date: June 1990
Format of Item: Other print media format (29).
Physical Description: 75 pp.
Abstract:
This is a final report to a project, conducted by Birch & Davis Associates with assistance from the National Association of Area Agencies on Aging, to market and distribute information and materials on independent living for aging persons and adults with developmental disabilities that were produced under federal grants. Major project activity categories included: (1) market research; (2) product research; (3) professional review; (4) product packaging; and (5) product marketing. Audiences for this publication include writers, dissemination specialists, communications consultants, research utilization specialists and professionals from the fields of aging and developmental disabilities who are active in knowledge transfer.

Grant Number: 90-AM-0509 (AoA)
Grantee Name: National Easter Seal Society
Grant Performed By: National Easter Seal Society

Product:

NAIC accession number: 03943
Title: Easter Seal Eldercare Project Program Guide
Author(s) of document: Kaufman, Nancy and Rutta, Randall L.
Publication Date: 1995
Abstract:
This program guide documents a National Easter Seal Society aging America initiative and its outcomes. The goals were to (1) heighten the disability community's awareness of the growing need for services and supports among older persons with disabilities and functional limitations, and (2) demonstrate three models for assisting at risk elders. The report has five sections: Respite Care for Older Rural Residents with Disabilities: Easter Seal Society of North Carolina; Integrating Older Persons into Mainstream Senior Activities: Easter Seal Society of Utah; Senior Volunteer Supports for Rural Families with Children with Disabilities: Easter Seal Society of Utah; Improving Linkages Between the Disability and Aging Communities: National Easter Seal Society; Selected Resources. Recommendations for replicating the National Easter Seal Society’s aging and disability models are included.

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM GRANTS

Grant Number: 90-CG2648
Grant/Project Title: Applying the National Family Caregiver Support Program to Persons with Developmental Disabilities
Grant Performed By: The Arc of the United States
Grant Year: 2000
Abstract:
The Arc project will work to build service capacity to aging network constituents and disability provider organizations through cooperative planning, coordinating and supportive services to older caregivers of children and adults with intellectual and developmental disabilities. This will be accomplished through a

national technical assistance and training program provided across the United States in collaboration with receptive aging and disability-based organizations and the development and dissemination of technical resource materials. The Arc will also assess state aging agency practices as they relate to implementing these provisions by recommending efficiencies or improvements to local aging network outreach strategies to organizations and families.

NAIC accession number:
Title: Aiding Older Caregivers of Persons with Intellectual and Developmental Disabilities: A Tool Kit for State and Local Aging Agencies
Author(s) of document: Baxley, D.L., Janicki, M.P., McCallion, P., & Zendell, A.
Abstract: This technical assistance manual explains how states can develop aging and developmental disability service network partnerships to better address the needs of older adults with I/DD and the families. It is based on the outcomes of a three-year AoA National Family Caregiver Support Program demonstration the developed and conducted collaboration-building workshops in 33 states. The project was undertaken by The Arc of the United States in collaboration with the Center of Intellectual Disabilities, University at Albany and the Rehabilitation Research and Training Center of Aging with Developmental Disabilities, University of Illinois at Chicago.

Grant/Project Title: A Multi-State Family Caregiver Mediation Project
Grant Performed By: The Center for Social Gerontology, Inc., Ann Arbor, Michigan
Grant Year: 2000
Abstract:
The project is testing a highly innovative approach — mediation — to assist older persons and family caregivers in addressing problems and disputes that often arise when they face the physical emotional and financial demands of providing ongoing care to a family member. The long term goal is to make mediation a part of mainstream caregiver support services. Mediation is a means of promoting informed, person- and family-centered care decisions. It identifies the needs and issues of all parties, along with exploring options available to meet those needs, thereby enhancing the autonomy and well-being of older persons and family caregivers.

Grant/Project Title: Elder Caregivers of Adults with Disabilities
Grant Performed By: Pennsylvania Department on Aging
Grant Year: 2000
Abstract:
The project provided a support system for primary caregivers, age 60 and older, who are caregivers of relative adult children, age 19 to 59, with mental retardation and/or developmental disabilities, who live in the same household. This project looks to reach this particular target population which is not specifically addressed in many service systems. Older parents of children with disabilities have traditionally isolated themselves, providing needed care at home without accessing community services. Services provided by the project are: specialized information and referral, assessment, family consultation/care planning, care management, benefits counseling, legal consultation, access to support groups and caregiver education and training. Reimbursement based on total household income was provided for services and supplies e.g., respite, emergency response, home modifications, assistive technology and any other goods and services that can be justified as being directly related to the caregiving. It was a very flexible service package and care plans were individually tailored to meet the specific needs of each family served in the project.

Grant/Project Title: Project ACE (Aging Caregivers and Exceptional Children)
Grant Performed By: United Cerebral Palsy of Southern Arizona
Grant Year: 2000
Abstract:
Project ACE was designed to assess access to service systems for older caregivers (grandparents and older caregivers) of children with developmental disabilities (children with special needs under their primary care). Following the assessment, tools will be put in place to increase knowledge about and access to services.

Grant Number: 90CG 2535
Grant/Project Title: Serving Illinois Seniors and Their Adult Family Members with Developmental Disabilities
Grant Performed By: Illinois Department on Aging
Grant Year: 2000
Abstract:
The project trained aging and developmental disabilities service providers in rural areas of Illinois to conduct outreach to older families caring for an adult relative with a disability, jointly address their current service needs, and engage these families in making future plans. Families participated in training that used *The Future is Now: A Future Planning Training Curriculum for Families and Their Adult relative with Developmental Disabilities* developed by the Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTCADD) at the University of Illinois at Chicago. The RRTCADD's evidence-based evaluation indicated the training significantly contributed to families completing a letter of intent, taking action on residential planning, and developing a special needs trust. Families' caregiver burden decreased and daily choice making for their relative with a disability significantly increased.

Product:

AIRS Accession Number: 04593
Title: The Future is Now: A Future Planning Training Curriculum for Families and Their Adult Relatives with Developmental Disabilities
Author(s) of document: Elizabeth DeBrine, M.Ed., Joe Caldwell, M.S., Alan Factor, Ph.D., and Tamar Heller, Ph.D.
Publication Date: 2003

APPENDIX 6
EXECUTIVE SUMMARY OF "MY THINKER'S NOT WORKING" – A NATIONAL STRATEGY FOR ENABLING ADULTS WITH ID AFFECTED BY DEMENTIA TO REMAIN IN THEIR COMMUNITY AND RECEIVE QUALITY SUPPORTS

'My Thinker's Not Working'

Executive Summary

'My Thinker's Not Working': A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports, prepared by the National Task Group on Intellectual Disabilities and Dementia Practices, provides a summary of the challenges facing the nation as we observe an increasing rate of dementia found in older people with intellectual disabilities. The Report offers recommendations for the various stakeholders in the field of intellectual disabilities and anticipates that its findings and recommendations will be considered and integrated into the annual reports and plans developed by the federal Advisory Council on Alzheimer's Research, Care, and Services.

The National Task Group on Intellectual Disabilities and Dementia Practices first and foremost recognizes that the number of older adults with an intellectual disability affected by dementia is growing and this growth is posing a significant challenge to families and friends, provider agencies, and federal and state agencies concerned with supports and services to people with an intellectual disability. It also recognizes that although the research community is making significant strides in better understanding the causal and evolutionary factors leading to the onset of Alzheimer's disease and other dementing illnesses and is also making significant progress in identifying means for the early detection of the disease – all of which will benefit subsequent generations – the social care system still remains challenged with the 'here and now' of offering the best and most efficacious means of identification, daily supports, and long-term care.

The key findings of the National Task Group include:

- Most adults with an intellectual disability live in community settings, either independently or with support from families, friends and service providers; with advanced age, they may experience age-related conditions and diseases, including dementia.
- Epidemiological research has not arrived at reliable population counts of adults with an intellectual disability affected by mild cognitive impairment and dementia and more effort is needed to create a more reliable estimate of this population.
- Dementia has a devastating impact on adults with an intellectual disability as well as on their families, friends, housemates, and service provider staff who often provide key long-term support and care.
- Community services' providers are facing a 'graying' of their service population, many of whom are affected by cognitive decline and dementia, and are challenged to provide the most effective and financially viable daily supports and long-term care.

● Primary care and supports for adults with an intellectual disability affected by dementia can be primarily provided within the community and appropriate services can preclude institutionalization.
● Providers are beginning to adapt small group homes for specialized community care and supports for persons with an intellectual disability affected by dementia.
● Professional staff are often ill-equipped to help identify and support interventions that may be the most efficacious for adults with an intellectual disability affected by dementia.
● There is a lack of background knowledge and training in late life problems of adults with an intellectual disability among primary care health providers (including physicians, physician assistants, and nurses) in community practice.
● Specialized assessment and diagnostic resources are needed to help more effectively identify adults with an intellectual disability and dementia.
● A common screening instrument would be useful for the cognitive impairment review that is part of the Affordable Care Act's annual wellness visit.
● Creating a national program of trainings using workshops, webinars, and other teaching methods, would advance the knowledge and skills among workers and clinicians working with adults with an intellectual disability affected by dementia.
● Creating a national information and education program for adults with an intellectual disability and family members would improve their understanding of dementia and potentially lead to earlier identification and acquisition of timely supportive services.
● Access to appropriate professionals and supportive services outside major urban settings needs to be improved; technology may play an important role in achieving this goal.
● State and local developmental disabilities' authorities could more constructively forecast and budget for supporting in-community care of adults with an intellectual disability affected by dementia.

The Report concludes with a series of recommendations that comprise a **National Action Plan** (see page 105) for more effectively addressing needs and helping adults with an intellectual disability affected by dementia. Summarized below are some of the main areas that are covered by the recommendations.

Dementia often hits harder. Alzheimer's disease and other dementias generally affect adults with lifelong intellectual disabilities in similar ways as they do other people, but sometimes have a more profound impact due to particular risk factors – including genetics, neurological injury, and deprivation. While such illnesses generally follow a typical course in terms of impact and duration, some adults are profoundly and aggressively affected. Yet all need the typical types of supports and services usually associated with dementia-capable care. ***The National Task Group believes that adults with an intellectual disability require the same early and periodic diagnostic services, community education, and community-based supports for themselves, their caregivers, and the organizations working with them, as do other adults affected by dementia.***

Lifelong caregiving may create 'double jeopardy'. Many families are the primary lifetime caregivers for adults with an intellectual disability and when Alzheimer's disease and these dementias occur, they are particularly affected and need considerable supports. These families

not only include parents, but also siblings and other relatives. Many such families are at a loss for providing extensive care at home once dementia becomes pronounced and care demands may overwhelm them. ***Thus, the National Task Group recommends that the nation's providers and federal and state aging and developmental disabilities authorities invest in increased home-based supports for caregivers who remain the primaries for support and care for adults affected by dementia.***

Providers are being challenged. Many intellectual disabilities' provider organizations that are the primary resources for residential and day supports are vexed by the numbers of adults with an intellectual disability in their services showing signs of early decline and dementia with potentially more demanding care needs. In many cases, staff may be unfamiliar with the signs and symptoms of mild cognitive impairment (MCI) or dementia and may misrepresent or ignore these changes, when early identification and intervention could prove beneficial. ***Thus, the National Task Group recommends that the nation's providers and federal and state aging and developmental disabilities authorities invest in increased education and training of personnel with respect to Alzheimer's disease and other dementias and invest in promoting best practices in models of community care of adults with an intellectual disability affected by dementia.***

Early identification is crucial. As it is important to recognize signs of dementia-related cognitive decline early on, the National Task Group has identified a potentially adaptable instrument, applicable particularly to adults with an intellectual disability, which can be utilized as a 'first-instance screen' and recommends adoption of such an instrument by providers and regulatory authorities to identify those adults at-risk due to early signs of mild cognitive impairment (MCI) or dementia. ***Thus, the National Task Group recommends that the nation's providers and health authorities undertake a program of early identification – beginning at age 50 for adults with an intellectual disability and at age 40 for adults with Down syndrome and others at early risk – using a standard screening instrument.***

Commitment to living in the community. Research has shown that community-based models of care for adults with an intellectual disability and dementia including community-based options, such as support for living at home or in small group homes, are viable and gaining preference for all individuals affected by Alzheimer's disease and other dementias. The institutionalization of adults with an intellectual disability and dementia is anathema to the field's core beliefs and commitments to care practices; institutionalization (via use of long-term care facilities) can have an adverse effect on lifespan and quality of life. ***Thus, the National Task Group recommends that the use of such community-care options be expanded and an investment be made in developing more small community-based specialized 'dementia capable' group homes.***

Education is what's missing. Information at all levels is needed to enhance the capabilities of staff, clinicians, community providers and administrators. Training of various sorts is necessary to raise awareness of dementia and how it affects adults with an intellectual disability. The National Task Group recognizes the need for more information related to age-associated cognitive decline and neuropathologies (such as dementia), particularly how they apply to people with an intellectual disability and impact their families, friends, advocates and caregivers. ***The National Task Group recommends the institution of a national effort on***

training and education to prepare the workforce and eliminate disparities in dementia services provision for adults with an intellectual disability.

A final word. Dementia has a devastating impact on all people – including people with an intellectual disability and their friends, families and the staff who may be involved with them as advocates and caregivers. ***The National Task Group believes that the federal Advisory Council on Alzheimer's Research, Care, and Services should include concerns and considerations for people with lifelong intellectual disabilities in any and all documents, plans, and recommendations to Congress that are part of the work of the Council through to 2025***. To this end, the National Task Group stands ready to assist and contribute to such efforts.

What follows is a matrix listing the National Task Group's recommendations as to what should be undertaken and which organization or group could be involved.

National Dementia and Intellectual Disabilities Action Plan

Goal A: To better understand dementia and how it affects adults with an intellectual disability and their caregivers

#	*Recommendations*	*Who could do it?*
#1	Conduct nationwide epidemiologic studies or surveys of adults with intellectual disabilities that establish the prevalence and incidence of mild cognitive impairment and dementia.	Federal agencies and institutes (Administration on Developmental Disabilities, Administration on Aging, National Institute on Disability and Rehabilitation Research)
#2	Conduct studies to identify and scientifically establish the risk factors associated with the occurrence of dementia among adults with an intellectual disability.	Universities' academic and research centers
#9	Conduct studies on the impact of aging of family caregivers on the support and care of adults with intellectual disabilities residing in at-home settings.	Universities' academic and research centers
#11	Conduct nationwide medico-economic studies on the financial impact of dementia among people with intellectual disabilities in various service provision settings.	Universities' academic and research centers

Goal B: To institute effective screening and assessment of adults with an intellectual disability at-risk, or showing the early effects of, dementia

#	*Recommendations*	*Who could do it?*
#3	Develop guidelines and instructional packages for use by families and caregivers in periodically screening for signs and symptoms of dementia.	American Academy of Developmental Medicine and Dentistry
#4	Encourage provider agencies in the United States to implement screenings of their older-age clientele with an intellectual disability who are at-risk of or affected by dementia.	State developmental disabilities planning councils, State developmental disabilities authorities
#5	Examine the utility of adopting an instrument such as an adapted Dementia Screening Questionnaire for Individuals with Intellectual Disabilities for use annually in preparation for the annual wellness visit.	Universities, Providers, American Academy of Developmental Medicine and Dentistry
#6	Conduct an evaluation of a workable scoring scheme for the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities that would help identify individuals in decline.	Universities' academic and research centers

Goal C: To promote health and function among adults with an intellectual disability

#	*Recommendations*	*Who could do it?*
#15	Develop and disseminate a set of nutritional and dietary guidelines appropriate for persons with an intellectual disability affected by dementia.	American Academy of Developmental Medicine and Dentistry
#16	Develop and disseminate health practice guidelines to aid primary care physicians and related health practitioners address assessment and follow-up treatment of adults with an intellectual disability with symptoms of dementia.	American Academy of Developmental Medicine and Dentistry, Developmental Disabilities Nurses Association
#17	Conduct studies on the nature and extent of health compromises, conditions, and diseases found among adults with an intellectual disability and affected by dementia.	Universities' academic and research centers

Goal D: To produce appropriate community and social supports and care for adults with an intellectual disability affected by dementia

#	*Recommendations*	*Who could do it?*
#10	Enhance family support services to include efforts to help caregivers to identify and receive assistance for aiding adults with an intellectual disability affected by dementia.	State developmental disabilities authorities, State units on aging, Area agencies on aging, The Arc, National Down Syndrome Society
#12	Plan for and develop more specialized group homes for dementia care as well as develop support capacities for helping adults affected by dementia still living on their own or with their family.	State developmental disabilities authorities
#13	Plan and develop community-based dementia-capable supports to address the needs of those persons at-risk or affected by dementia.	State developmental disabilities authorities
#14	Develop and disseminate social care practice guidelines to community agencies and professionals that address assessment, service development and life planning for adults with an intellectual disability presenting with symptoms of dementia.	American Association on Intellectual and Developmental Disabilities

Goal E: To produce a capable workforce and produce education and training materials

#	*Recommendations*	*Who could do it?*
#7	Establish undergraduate, graduate, and continuing education programs, using various modalities, to enhance the diagnostic skills of community practitioners.	American Academy of Developmental Medicine and Dentistry, American Association on Intellectual and Developmental Disabilities, Council of Deans of Medical Schools and Allied Health Colleges
#18	Develop a universal curriculum, applicable nationwide, on dementia and an intellectual disability geared toward direct care staff, families, and other primary workers.	Administration on Developmental Disabilities, Universities, Developmental Disabilities Nurses Association
#19	Organize and deliver a national program of training using workshops and webinars, as well as other means, for staff and families.	American Academy of Developmental Medicine and Denti-stry, American Association on Intellectual and Develop-mental Disabilities, Developmental Disabilities Nurses Association, Universities' academic and research centers
#20	Develop and produce an education and information package for adults with an intellectual disability to help them better understand dementia.	American Academy of Developmental Medicine and Dentistry, Developmental Disabilities Nurses Association, Universities' academic and research centers

Co-Chairs

Matthew P. Janicki, Ph.D. and Seth M. Keller, M.D.

APPENDIX 7
STATE PROFILES OF ADRCS SERVING PEOPLE WITH DEVELOPMENTAL DISABILITIES

Georgia

Georgia's ADRC program is referred to as the Aging and Disability Resource Connection. Local ADRCs are housed in Georgia's twelve Area Agencies on Aging and provide statewide coverage. The ADRC brochure and website videos specifically promote outreach to people with developmental disabilities and their families. The brochure features a photo of an older man with a developmental disability on the cover, and two of the ADRC website's four videos explain how it can address prominently describe the ADRC as a resource for individuals with developmental disabilities and their families. Two videos focus on people with developmental disabilities. The state ADRC website lists the contact information for each ADRC, the counties comprising its service area, and the names and contact information the Aging and Developmental Disabilities Specialist.

The 12 ADRCs use the "No Wrong Door" model. In addition to the statewide ADRC Advisory committee each local ADRC must establish its own Advisory committee whose members must include people with disabilities. Each ADRC collaborates with the one or more of the six Department of Behavioral Health and Developmental Disabilities regional offices that operate in their planning and service area. The ADRC funds four full-time developmental disabilities specialists that are located in the regional DBHDD offices and who are each assigned to three ADRCs. Their contact with the AAA ADRC aging specialist forges the linkage between the two service systems. At the local level people with developmental disabilities and their families are more likely to contact the regional DBHDD office. If they initially contact the AAA, staff will find out if they are known to the DD system, and depending on their needs, may transfer. Regardless of where people with disabilities enter the system, they are still included in the ADRC data base. One of the benefits of collaborating with the AAAs is that people who with I/DD who have an urgent need for services the greater propensity to apply for services under the Aging HCBS waiver if the person qualifies due to the shorter waiting list. The ADRC model also enables both service systems to address the older parent's need for services and income supports as well as the needs of their relative with a disability.

One of the biggest challenges that staff in both networks experience is learning the culture of the other service system. The specialists are catalysts of culture change that teach staff in one service system how the other system operates. They also collaborate on providing staff cross-training on aging and developmental disabilities. The Atlanta Advocacy organization, all About Developmental Disabilities developed a coalition building toolkit to foster aging and developmental disabilities partnerships at the ADRCs.

Texas

Texas has nine regional ADRCs that jointly cover about one-third of the state. The assistant commissioner for Access and Intake is responsible for coordinating access to services and supports provided through area agencies on aging, MR authorities, and community services for individuals who are over the age of 60 and those with a disability, including: intellectual, developmental and physical disabilities. In addition, Access and Intake provides guardianship services. Services and supports provided through Access and Intake programs provide individuals with assistance in accessing medical, social, educational and other appropriate information, services, and supports, which allow them to maintain their independence, achieve quality of life, and maintain a level of community participation. Access and Intake oversees hundreds of contracts with in-home and community service providers to ensure consumers have a full array of services available.

The Central Texas ADRC and the Connect to Care Dallas County ADRC served 964 and 332 persons with developmental disabilities respectively, far surpassing the combined client volume of the other ADRCs. The Dallas County ADRC Connect to Care is housed at Metrocare, which is the gatekeeper for county developmental disabilities and mental health services. (www.connecttocaredallas.org) has a web-based self-referral form that can be completed online. The Central Texas ADRC website (www.ctadrc.org) also is web-based. Clicking on the "contact us" or the link to the Central Texas AAA opens an email form to complete and send to the ADRC. The Central Texas ADRC home page provides the address and hours of the ADRC office, but does not include a telephone number. The Texas Department of Aging and Disability Services ADRC website does list the address, phone number and website URLs for each local ADRC.

Metrocare is the lead agency for the ADRC. There is not a written agreement that designates partner agencies' specific responsibilities although there is a general memorandum of understanding that partner agencies will work together collaboratively. Metrocare and the Dallas Area Agency on Aging were both involved in the initial planning process and are advisory board members. The ADRC was publicized by disseminating brochures to its network of service providers. The ADRC also makes frequent presentations at education sessions for mental health mental retardation authority staff. Staff at both agencies participated in cross-training and attend monthly meetings to discuss current and future activities. The ADRC serves a relatively large number of people with developmental disabilities compared to the other sites because Metrocare is the point of entry for people seeking developmental disabilities services. Area Agency on Aging staff are not co-located at the ADRC. However, they staff the ADRC eight hours a month. The ADRC uses VoIP phones that accommodate three-way calls and warm transfers between the ADRC and the AAA offices so the ADRC appears as a seamless operation. Developmental disabilities services and programs have been added to the 2-1-1 information and referral phone line which is a collaboration of the Area Agency on Aging and the Texas 211 contractor. The ADERC does not have access to the data base, but can quickly access need resources by phone or email. The ADRC obtains

feedback on its activities through follow-up calls and evaluation surveys with all clients. The ADRC evaluation board reviews the findings and provides feedback. The ADRC advisory board addresses issues that arise among service providers. Best practices that foster collaboration across service systems include:

- The mix of service providers on the ADRC Advisory Board and their active participation and oversight of the Dallas ADRC.
- Monthly Lunch and Learn meetings that were implemented in the first year enable the developmental disabilities and aging communities to jointly learn about the services each network provides.
- For the ADRC's 2011-2012 strategic plan, the Area Agency on Aging is expanding the coalition of aging and disability providers to ensure diverse representation and participation in the service area.

Community service agencies in both the aging and developmental disabilities service networks present two challenges that we must address: 1) concerns about competition for funds and 2) understanding that the ADRC was not established to replace them but to be a catalyst for collaboration across the service networks.

Arizona

AZ Links is the state's network of seven aging and disability resource centers that serve 9 counties. The network is administered by the Division of Aging and Adult Services within the Department of Economic Security. ADRC partners include the developmental disabilities district offices and the Centers for Independent Living. Individuals can contact the developmental district office directly. If they complete the AZ Links on line screening tool, it goes to the Area Agency on Aging and is forwarded to the developmental disabilities district office. these populations have one-stop access to a plethora of information to assist them in maintaining their independence, and that people know of private section options for long term care so as to prevent or delay reliance upon publically funded long term care for as long as possible. Local ADRC start-up occurred sequentially and partner agency staff attended training to learn about Medicaid eligibility and each of the three service systems. Currently, there is no shared data base of service resources or management information system for sharing client data among the three partner agencies at each ADRC. Partner agencies submit their client demographic data to the Division of Economic Security, which prepares the Semi Annual Report. Partner agencies at each local ADRC have the capacity to make warm transfers of client phone calls to expedite screening and information inquiries.

The most requested service by people with developmental disabilities and their families is community residential services. The Maricopa County (Phoenix) developmental disabilities district office established a "Premier Unit" to address the needs of individuals with disabilities age 50+ who are living with older parents. They have developed a formal assessment protocol and revisit families every quarter. There is no waiting list for people who need long-term care services if they are Medicaid eligible.

Alaska

In 2004 ADRC grant was awarded to the Housing Finance Corporation. That didn't work out and in 2008 it was transferred to the Division of Senior and Disability Services, which oversees local ADRC activities. The ADRCs have a statewide Advisory Council. The lead organization at each ADRC site has its own board of directors which function as an advisory committee on ADRC activities. The ADRCs contract with Alaska 211 is to provide benefits counseling and address basic information and referral needs.

Most people with I/DD seeking waiver funded services continue to apply through the 12 regional STAR offices (Short-Term Referral and Assistance) programs which are the gatekeepers for HCBS waiver services and nursing home placement. There is talk of reorganizing the STARS and incorporating some of them with the ADRCs

Wisconsin

Wisconsin has 72 counties which all operate under a state statute that established regulations for the Community Integration Program which provides community services to older people and people with disabilities. CIP started in 1991. In 2000, WI started the Family Care Program and incrementally expanded it to all counties by 2008. The ADRC assesses an individual's functional and financial eligibility for services. The I&A staff spend time with consumers explaining their long-term care options. The ADRC enrolls people in the program and follow up with them. WI Family Care and partnership programs are administered by eleven Managed Care Organizations (MCOs). The average capitation rate for the eleven MCOs is $2,800 per month. The client's ability to have a choice of MCOs depends on where s/he lives. In Milwaukee there are three MCOs. Many counties contributed funds to their LTC program so there was no wait list for services.

In Wisconsin, the ADRCs are funded by the legislature. A cap was placed on the number of people who can receive Medicaid waiver services based on the enrollment as of 7/1/2011. Consequently, there are now waiting lists for waiver programs because the attrition rate of service users is less than the growth of people on the waiting lists. The state wanted to make waiver HCBS an entitlement program, this was put on hold because of the state's poor economy. ADRCs do not serve people who solely have psychiatric disabilities unless there is a coexisting cognitive or physical impairment. About 40% of individuals with developmental disabilities have a mental health condition. Milwaukee operates two ADRC. The ARC serves older people and younger adults with physical disabilities. The DRC serves people with I/DD.

Wisconsin has a county system with a County Human Services Board, which has to approve the ADRC and explain the transition to the local community. The state sent letters to all waiver participants and each ADRC also publicized the change. Outreach is a large part of the ADRCs' role. Every current waiver participant has to receive options counseling. There are close to 3,000 enrollees in IRIS and 30,000 on other waivers.

The ADRC does not have a statewide advisory group. Each local ADRC has a board comprised of members from each target group and ethnic group. Each county still

operates as an ADRC so the model is No Wrong Door rather than Single Point of Entry. People with TBI are classified as having a developmental disability if the onset occurred before age 21. If the onset occurred later, they are classified as having a physical disability. CILs are considered service providers and some have taken on a larger role.

The Long Term Care Division Office of Resource Development provides training and technical assistance to the ADRCs. There is a staff of 17 plus 6 individuals that work out of their home and travel to the ADRCs to improve processes, provide training and technical assistance, review contract language, and work with the board.

Benefits. Establishing rapport with families regardless of their disability and income status; developing a data base of service resources; following up on referrals whose benefits to clients have been documented by research. Counties are developing good relationships with MCOs.

Challenges. One of the struggles was getting people with I/DD and county case managers to understand that the ADRC was the point of contact. Also, the cost of residential services, especially for people with I/DD is rising.

Best Practices. Information and Access staff provide accurate and high quality information. The value of the outcome should be measured. Regional quarterly meetings and the annual statewide meetings provide opportunities to share information and innovative practices infuse the knowledge of regional staff.

APPENDIX 8
EXAMPLES OF UCEDD COLLABORATIONS WITH ADRCS

Institute on Disability, University of New Hampshire

The New Hampshire UCEDD has been a collaborator with the state's ADRC network of Service Link Resource Centers since the ADRC initiative was first funded. The UCEDD is on the ADRC Advisory Board and provides training and technical assistance to ADRC staff and other stakeholders. The UCED attributes positive collaboration with New Hampshire's ADRCs to working "in the trenches" with the state unit on aging, ADRC site managers, caregiving specialists, and long term care counselors to assess their information and training needs. Consequently, the UCEDD has trained ADRC staff on providing caregiver support and long-term options counseling to all populations they serve. The UCEDD is also a resource on developmental disabilities and has educated ADRC staff how to utilize person-centered planning to identify consumer support needs and to develop service plans. The UCEDD has benefitted from its role by being included in other grant-funded activities. It is currently working with the New Hampshire Alzheimer's Association to enhance the network of community supports to better serve individuals in the early stage of Alzheimer's disease and related disorders and to provide training to clinicians, care providers, individuals, and their families and to embed these trainings in the Service Link ADRC network.

Institute on Disability and Human Development, University of Illinois at Chicago

The Illinois UCEDD has a long-term collaboration with Illinois ADRC program. It evaluated the outcomes of Illinois initial two ADRCs, including one site that serves people with developmental disabilities, during their first three years of performance for the Illinois Department on Aging. IDHD developed the formal evaluation plan and assessment tools, oversaw data collection, prepared the final report and presented the findings at national conferences with Illinois Department on Aging and ADRC staff. IDHD also provided staff training on aging with a long-term disability to a third ADRC location. The Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTCADD) housed at the Illinois UCEDD is a listed as a resource for ADRCs on ADRC Technical Assistance Exchange Website. The UCEDD serves on the Illinois Department on Aging ADRC Advisory Group.

Center for Human Development, University of Alaska Anchorage

The Alaska UCEDD is a member of the ADRC advisory group and is currently evaluating two ADRC initiatives for the state Division of Senior and Disabilities Services: 1) the expansion of ADRC sites and 2) piloting the Coleman Model of Care Transitions Intervention for people with chronic health conditions to reduce the likelihood of readmissions after their hospital discharge. ADRC staff serve as the model's Transition Coach to teach patients and their family specific self-management skills such as developing a medication regimen, effectively tracking and communicating their health status and care needs, and also will provide follow-up reinforcement and evaluation. The UCEDD also will train hospital discharge planners to use person-centered planning in developing discharge plans with patients. The UCED has a long-term collaborative

relationship in writing grant proposals with the Division of Senior and Disabilities Services were written into the proposals to conduct the project evaluation. The ADRC proposal was one of these grant "partnerships." “Alaska is a small town. Everyone one knows everyone else and we partner pretty easily due to limited capacity.”

Iowa’s University Center for Excellence on Disabilities, University of Iowa The Iowa ADRC initially was a web-based resource LifeLongLinks that linked to COMPASS and Iowa’s two other Information and Referral programs. The Iowa UCEDD was involved in the ADRC start-up because it operates COMPASS (Iowa’s statewide information and referral service for Iowans with disabilities). The UCEDD incorporated COMPASS resources into the ADRC I & R data base and trained staff about the service needs of people with disabilities and their families and about Iowa’s disability service system.

Wyoming Institute for Disabilities (WIND), University of Wyoming
The Wyoming Institute for Disabilities (WIND) collaborated with Wyoming Independent Living, Rehabilitation (WILR), a Center for Independent Living (CIL) to write the grant proposal to establish Wyoming’s ADRC and open the pilot site Resource Center at WILR in Casper. WIND was responsible for administration of the ADRC grant as well as for project evaluation and for systematic feedback for the entire project; development of a marketing plan and production of marketing materials; increasing responsiveness of the ADRC by building the capacity of an existing online database of human services, Connect Wyoming, as the information and referral source for the ADRC. The ADRC served “seniors” age 50 and older and people with physical and developmental disabilities age 21 and older. The latter were included only because of WINND’s insistence. During its five years of operation, the ADRC serve 1275 people. The majority of consumers were people with physical disabilities. People with developmental disabilities accounted for only 0.6% of the clients. When the grant period ended, the AoA regional office awarded the grant to the Aging Division in the Wyoming Department of Health to establish a virtual statewide ADRC that people could contact via a toll-free number and using the internet.

Center for Persons with Disabilities, Utah State University
The UCEDD was a collaborator in establishing the Utah ADRC.

UCEDDs also have contributed research reports, training curricula, and issue briefs to the ADRC Technical Assistance Exchange website. Examples are:

> Issue Brief - Long Term Support for Individuals with Mental Retardation/Developmental Disabilities (Iowa UCEDD)
>
> Implementation of Consumer-Directed Services for Persons With Intellectual or Developmental Disabilities (MN UCEDD)
>
> Aiding Older Caregivers of Persons with Intellectual and Developmental Disabilities: A Tool Kit for State and Local Aging Agencies (IL UCEDD)

APPENDIX 9
INFORMATION SOURCES

Patricia Bordie, ADRC Grants Coordinator, Texas Department of Aging and Disability Services

Sherry Chantharaj, Connect to Care (Dallas County ADRC)

Roger Webb, Executive Director, Texas Council for Developmental Disabilities

Jill Ginn, The Arc of Indiana

Jade Luchauer, Director of Client Services Bureau of Developmental Disabilities Services, Indiana Family and Social Services Administration

Laura Connors, ADRC State Program Coordinator, Massachusetts Rehabilitation Commission

Faith Behum, Disability Policy Specialist, Massachusetts Developmental Disabilities Council

Cheryl Harris, State ADRC Coordinator, Georgia Division of Aging Services

Allan Goldman, Atlanta Regional Commission (Area Agency on Aging)

Sue Burgess, Atlanta Regional Commission (Area Agency on Aging)

Maria Lee, Region I, Georgia Department of Behavioral Health and Developmental Disabilities

Kelda Barstad, Alaska Aging and Disability Resource Centers Program Manager, Division of Senior and Disabilities Services

Roxann Lamar, Research/Evaluation, University of Alaska at Anchorage Center for Human Development

Jutta Ulrich, Arizona Links (ADRC) Project Director, Arizona Department of Economic Security, Division of Aging and Adult Services

Neal Minogue, ADRC Quality Specialist, Wisconsin Department of Health and Family Services

Dennis Harkins, Director (Retired), Wisconsin Bureau of Developmental Disabilities Services

Charlotte McHenry, Vice President of Community Services, West Central Florida ADRC

Marilyn Wilson, Project Director (Retired), Waisman Center UCEDD, University of Wisconsin-Madison

Katherine Foley, Director, LEAP ADRC, Ohio

Greg Link, Project Officer National Lifespan Respite Care Program, Administration on Aging

Robert Hornyak, Director, Office of Performance and Evaluation, Administration on Aging

Joseph Lugo, Aging Services Program Specialist, Administration on Aging

Elizabeth Leef, Aging Services Program Specialist, Administration on Aging

Carrie Blakeway, Project Manager, The Lewin Group

Joe Caldwell, Director, Long Term Services and Supports Policy, National Council on Aging

Ruth Katz, Office of Disability, Aging and Long-Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services

Suellen Galbraith, Senior Policy Advisor, ANCOR