Service and Support Needs of Adults Aging with Intellectual/Developmental Disabilities

Testimony to the U.S. Senate Committee on Aging

Working and Aging with Disabilities: From School to Retirement

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Given the demographic imperatives of the longer life expectancy of adults with intellectual and developmental disabilities (IDD) and the aging of the baby boomers, a growing challenge exists to address this population's later life needs. People with IDD are aging at unprecedented rates and have unique health and service and support needs. They 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. Also, they may face poor access to adequate health care, as well as lifestyle and environmental issues. Furthermore, people with IDD are less likely to be employed and those that are employed or retired may need additional services and support as they reach middle and older ages. This testimony addresses the needs of people aging with IDD, including implications for employment and retirement.

These unique service needs of this population pose new challenges for existing service networks. Traditionally, the aging and developmental disabilities service systems have run on parallel tracks. Large-scale legislative changes that target long-term services and supports 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 (Factor, Heller, & Janicki, 2012).

The population of adults age 60 and older with IDD is growing dramatically and is estimated to increase from 850, 600 in the community based on the 2010 US census to an estimated 1.4 million by 2030, due to increasing life expectancy and the aging of the baby boomer generation (Factor et al., 2012). Older adults with IDD are often more vulnerable to conditions that make their old age potentially more difficult with poorer health, needs for more supports, and fewer resources than other older adults. They also have fewer opportunities to exercise their self-determination in order to have a meaningful and fulfilling life.

To understand strategies for addressing the service and support need of adults aging with IDD one needs to examine the unique aspect of aging with IDD, particularly regarding such life transitions that accompany their aging such as development of chronic health conditions, changes in family caregiving and supports, changing needs for supports in employment, and retirement from employment (Hahn et al., 2016).

Life Transitions and Aging

*Age-related changes in health***.** While the life expectancy of individuals aging with IDD is increasing, it is still lower than for the general population, particularly for those individuals with more severe intellectual and physical disabilities and certain genetic syndromes (Bittles et al., 2002; Haveman et al., 2009). For example, Down syndrome has been linked to premature aging, Alzheimer's disease, and certain organ dysfunctions (Janicki, Henderson, & Rubin, 2008). 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 (Janicki et al., 2008). People with IDD are likely to be in poorer health and experiencer earlier age-related chronic health conditions, including dementia, osteoporosis, oral disease, and diabetes (Haveman et al., 2009; Acharya, Schindler, & Heller, 2016). They are also more likely to be obese and overweight (Hsieh, Rimmer, & Heller, 2013) and experience a high rate of falls (Hsieh, Rimmer, & Heller, 2012). Sedentary behaviors and unhealthy diets contribute to greater cardiovascular disease for adults with IDD (Hsieh et al., 2016)

Health care access is often poor for adults with IDD resulting in more morbidity and earlier mortality (Haveman et al., 2010; Krahn & Drum, 2007; Perkins & Moran, 2010). For example, diagnosis of cancer occurs at a later stage and deaths from conditions that could have been amenable to health care interventions are more common among individual with IDD than in the general population (Hosking et al., 2016). They also are less likely to receive organ transplants or dialysis often due to criteria such as years of life expectancy, ability to keep a regimen, and amount of support available (Stratling & Louw, 2011). Furthermore, they may have undiagnosed conditions due to communication barriers.

Their health concerns and lifestyle differences point to the need for health promotion interventions, exercise and nutrition programs, health behavior education, and health screenings. In addition, 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 IDD.

To address multiple chronic diseases that often occur in older ages, geriatric assessments and chronic disease self-management programs play a central role in diagnosing and treating such conditions. An in-home health risk and geriatric assessment adapted for people with IDD (Aronow & Hahn, 2005; Hahn & Aronow, 2005) resulted in identification of health conditions and in follow-up checks. Wilson and Goodman (2011) adapted a chronic disease self-management program for individuals with ID and found that it was a promising practice for individuals with at least a moderate level of intellectual functioning. Given the higher prevalence of dementia in adults with Down syndrome at earlier ages (Janicki & Dalton, 2000), myriad interventions target dementia care in this population drawing on the extensive research on dementia care interventions in the general population. These include practices that increase safety, make environmental accommodations, and ensure a more positive quality of life (Jokinen et al., 2013). The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) has developed practice guidelines and a national training curriculum to enhance caregiving understanding of dementia and strategies for continued care of people with IDD and dementia. (see http://aadmd.org/ntg/education-and-training).

Other health related adaptations include falls prevention programs, such as the modified Otago program that shows promise as a method of prevention falls for adults with IDD (Renfro, Bainbridge, & Smith, 2016). An evidenced based health promotion program that has been shown to improve fitness and health of adults aging with IDD is *Health Matters: The exercise and nutrition health education curriculum for people with developmental disabilities* program which is being implemented state-wide in several states (Marks, Sisirak, & Heller, 2010).

Long-term supports and services. Adults aging with IDD are more likely than adults in the general population to have received life-long services and supports. Based on 2015 data, an estimated 71% of individuals with IDD live with their family caregiver. Of those living with their family caregiver, 24% are with caregivers aged 60+ and another 35% are with caregivers aged 41 to 59 years. Only 13 % of adults with IDD live in supervised residential settings (Braddock, Hemp, Tanis, Wu & Haffer, 2017). As of 2014, nationally, there were nearly 100,000 individuals on waiting lists for residential out-of- home services and over 216,000 estimated to be waiting for any type of long-term services and supports (Larson et al., 2017).

Parents, who often provide life-long care for their offspring with IDD, experience both their own aging and the aging of the adult with IDD. The impact of caregiving, particularly on mothers include fewer opportunities for employment and a restricted social network (Seltzer, Floyd, Song, Greenberg, & Hong, 2011) and poorer health for minority caregivers (Magaña & Smith, 2008). Many adults with IDD continue to live with aging parents until their parents are no longer able to care for them or pass away (Braddock et al., 2017). 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 (Heller & Arnold, 2010). Hence, future planning for the time when parents are no longer able to provide care becomes an important task for families and persons with IDD.

Although all states now fund family support in the form of cash subsidies and/or direct services, in 2015, national family support expenditures of $5.8 billion accounted for only 9% of total national developmental disabilities expenditures. Only 15% of families caring for a relative with a disability at home received family support (Braddock et al., 2017). The gap between need and available public resources is expected to increase with the looming demographic challenges.

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. 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 (e.g., "*The Future is Now: A Future Planning Training Curriculum for Families and their Adults Relative with Developmental Disabilities*") 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 IDD and other family members (Factor et al., 2010). However, currently there is no national infrastructure available to assist these families with future planning. Future planning must include such issues as financial, legal, advocacy, residential, vocational, and community participation.

The Research and Training Center on Family Support at the University of Illinois at Chicago (http://fsrtc.ahslabs.uic.edu/) is an example of a national center that bridges research in aging and in disability, including interventions with older caregivers of adults with IDD, into future planning as well as studies of self-directed supports for older adults and for adults with IDD and their families. An innovative project administered through an aging agency and titled "Caring for the Caregiver" was a training and support program for adults with IDD who were caring for their parents (Carbine, Buri-Kurtz, & Varick, 2010). To address the health of Latina mothers of adults with IDD, a health education program, "*By Caring for Myself I Care Better for my Family*", uses lay educators (*promotoras*) to promote improved health behaviors in these mothers (Magaña, Li, Miranda, & deSayu, 2015).

Another promising project funded, in part, by the Administration for Community Living through the Developmental Disabilities Act Projects of National Significance (P.L. 106-402, Subtitle E) is the National Community of Practice for Supporting Families developed by the University of Missouri-Kansas City, Institute for Human Development (UCEDD). A new Charting the Life Course provides a practical tool for family caregivers to identify social capital, navigate existing supports and services, find jobs in the community and generally plan for every aspect an individual's life over the course of his/her life. (see www.lifecourse.com)

Employment. While there have been many advances in knowledge about ways to support adults with IDD in employment, only 16% of people receiving services (as of 2015 National Core Indicators Data) from state IDD agencies work in integrated employment, including both individual and group supported employment (Heirsteiner, Bershadsky, Bonardi & Butterworth, 2016). According to the American Community Survey (2015) 24.8% of individuals of working age (age 24 to 64) with a cognitive disability were employed, in comparison with 34.3% of individuals with any disability, and 73.6% of people without a disability. Only an estimated 12.5 percent of the individuals with a cognitive disability were employed full-time/full-year.

The majority of persons who receive IDD services are still in facility-based and non-work settings. However, the percentage of people served in facility-based settings vary significantly by states with some states not funding facility-based programs (e.g., Vermont, District of Columbia, Maine, New Hampshire, and Massachusetts). Among adults with competitive employment, many work part-time, have low income, and few benefits (Winsor et al., 2017). There is little data available on employment of people with IDD by age. For general disability in 2016, the labor force participation rate for people with disabilities aged 65 and older was 7.6% and the unemployment rate was 6.4%, compared to the general population aged 65 and older who had a labor force participation rate of 24.2% and an unemployment rate of 3.5%.

While facility based work has declined for people with IDD, the percentage of people served in non-work settings has increased with the number of states reporting that option increasing from 18 states in 1996 to 34 in 2015. In 2015, 43% of individuals with IDD receiving day services received them in non-work settings (Winsor et al., 2017). Some of these programs have developed options that help persons with IDD engage in the community, including retirement options, such as volunteering, recreational and health promotion activities, senior center participation, and continuing education for older individuals (Sulweski et al., 2017).

Many middle age and older adults with IDD in integrated and competitive work environments may want to continue working as in the general older population. With age – related health and functioning changes they may need additional or different accommodations. This could include cognitive and assistive technology to help them remain on the job, or more customized employment (e.g., changing the type of job or task demands). It may also include more supports with transportation, as there could be changes in residential settings and family or other caregiver supports. The National Center for Transit Research (NTR) provided funding to researchers at the University of Illinois at Chicago Urban Transportation Center to develop an online tool that permits experts to evaluate accessibility by different transportation modes and use that information to improve livability.

There are many examples of middle age and older adults with IDD who with proper supports are continuing in integrated employment settings. For example, in our University Center for Excellence at the University of Illinois at Chicago we employed a self-advocacy specialist, Tia Nelis. With help in writing grants, managing fiscal issues, and other supports, she has been able to serve as a leader nationally in speaking up for the rights of people with disabilities. She has been one of the founders of the national Self-Advocates Becoming Empowered (SABE) and is now working for TASH, a national disability advocacy organization. She also provides leadership training to emerging self-advocacy leaders.

Retirement. Given that adults with IDD have very low employment rates and usually rely on government benefits, retirement may take on different meanings than for other individuals who are aging as it likely results in less financial implications. Hence, the focus of retirement becomes more of the transition from employment or IDD day program activities to socialization, health promotion, and leisure activities. For people with IDD transitioning to retirement may also mean participating in generic senior centers. Often the person with IDD has little choice in the type of activities and does not want to retire given that their social life and activities have centered around their day programs or employment which as noted above often includes segregated programs (Hahn et al., 2016).

Several programs have focused on retirement and later life activities using individualized approaches that respect the self- determination of people with IDD through education, support, and opportunities to participate in activities that are meaningful to them and desired by them. The "Person-Centered Planning for Later Life for Adults with Mental Retardation" found improvements in knowledge, leisure activities, and self-determination among older adults with IDD who participated (Heller, Sterns, Sutton, & Factor, 1996). More recently the "*Transitions to Retirement*" (Stancliffe, Wilson, Gambin, Bigby & Balandin, 2013) curriculum is using a mentored approach in which older adults volunteer to mentor adults with IDD in leisure retirement activities, which has resulted in greater social participation of the participants with IDD.

Models of Services and Supports for Adults Aging with IDD

Historical approaches. Models of services and supports for adults aging with IDD over the last four decades reflect the transformative changes in philosophies of care both in the aging and disability fields. These models include 1) segregated services, 2) services in senior network, 3) person-centered services and supports, and 4) rights based supports for full community inclusion. The segregated services, common in the 1980s included such examples as the senior activity center within a sheltered workshop, state institutions, or other large facilities. These senior activity centers often included programs developed primarily for senior centers and nursing homes, such as reminiscence therapy (Stuart, 1998).

As principles of normalization began to take hold in in the late 1980s and in the 1990s, there was an emphasis on "age appropriate" services in "generic," that is, not IDD specific settings. Hence, when adults with IDD reached a chronological age deemed as "senior" then a preferred setting was a senior setting or a nursing home. The innovative aspect was figuring out how to enhance acceptance of people with IDD into these settings by other older persons. One example was a project headed up by Ruth Roberts that provided an individualized peer mentor approach as opposed to busing a van load of people with IDD to a senior center. She paired up an elderly person with similar interests to be a peer mentor to the person with IDD who would then accompany the person to the senior center (Sutton, Factor, Hawkins, Heller, & Seltzer, 1993).

In the 1990s the notion of individualized supports and person-centered planning began to take shape. Principles of person-centered planning centered on the self-determination of adults with disabilities and the community of supports around them. One example of person-centered planning for older adults with IDD was the curriculum titled "*Person-Centered Planning for Later Life for Adults with Mental Retardation*" that provided training for the adult with disabilities in making choices, experiencing different activities in the communities, goal-setting in various domains of their lives, planning for the future, and obtaining and engaging their supports. At the same time training also occurred for the persons who the person with a disability designated as their desired circle of support (Heller et al., 1996).

With the United Nations Convention on the Rights of People with Disabilities (CRPD) (United Nations, 2006) in the twenty-first century there is an increasing emphasis on the human rights of people with disabilities. This includes the rights to full inclusion in the community, universal design, and supported decision-making as reflected in the Medicaid Home and Community- Based Services Final Rule (2014). While each era brings new models and approaches, the older ones continue to exist in many places. For example, there are still segregated settings being built for people with IDD and dementia (Janicki, 2011). As new models evolve we need to make sure to examine best and promising practices and their outcomes to inform policies and practices that bridge aging and disabilities (Sutton et al., 1993).

Bridging aging and disability policies. In the United States, there are now many opportunities for common ground between the aging and the disability service networks. At the national level, the Administration for Community Living (ACL) within the Department of Health and Human Services, has recently united both the developmental disabilities and the aging networks under its umbrella. ACL has several initiatives that encompass both aging and disability, including the Aging and Disability Resource Centers, Lifespan Respite Care Act programs, the National Family Caregiving Support Program, and the National Alzheimer's Project Act (NAPA). The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) has been successful in promoting the inclusion of people with IDD in the NAPA initiatives so that now several states have funding from the ACL to provide training and support to people with IDD who develop dementia (http://aadmd.org/NTG).

Conclusion and Recommendations

As people with IDD reach middle age and older age, there is an increasing need for supports to assist them to have fulfilling lives. Addressing age related health needs, family support, and community participation interacts with the ability of people with IDD to lead productive lives which could include employment and retirement as they age. With changes in health, it is critical that greater efforts are made to increase preventive care and health promotion activities. Employee health promotion programs and attention to prevention and health promotion by managed care organizations can help address the health care needs of people with IDD if done carefully and with input from people with disabilities and their advocates. Increased supports for families are integral to helping the many adults with IDD who are living at home with family members. For adults aging with IDD as well as for other aging adults, assistive and cognitive technology and universal design increase in importance. Similarly, inclusive transportation assistance (in both rural and urban areas) is needed to help individuals participate in the community, including employment, access health care services, paratransit, and other community based supports. Challenges will occur as there is more pressure on community based systems to supply a work force that can support people aging with and into disability. There is a growing recognition of supportive decision-making and interdependence between people across generations. Finally, a need exists for research on better ways to bridge aging and disability.

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