

Time for a Plan: The Urgency for Families of Older Adults with I/DD

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Introduction

Older adults with intellectual or developmental disabilities (I/DD) face unique health challenges and complexities in their daily lives. Although many require long term services and supports,¹ these supports tend to be provided only by family caregivers; often parents who are themselves aging.² This is of great concern in Arizona, the state with the greatest percentage of adults with I/DD in the country living in their family home.³

In 2000, the World Health Organization identified older people with I/DD and their aging family caregivers as vulnerable groups who should be prioritized in programs and policy.⁴ Sixteen years have passed. While these issues are even more urgent today, they remain largely unaddressed. Not only must adults with I/DD plan a future in which parents will eventually be unavailable to help, the stresses on family members caring for aging loved ones with I/DD have been shown to be especially acute. By their mid-60s, parents of adults with I/DD, compared to parents of adults without a disability, report lower marital stability, reduced leisure time, greater limitations in parental activities of daily living, poorer mental health, and a lower health-related quality of life.⁵

The needs of both aging adults with I/DD and their caregivers should be assessed to ensure the state is responsive throughout every life stage. To that end, ASU's Morrison Institute for Public Policy (MI) conducted six focus groups on behalf of the Arizona Developmental Disabilities Planning Council (ADDPC) – three with adults with I/DD 40 years of age and older and three with their caregivers – in Flagstaff, Phoenix, and Tucson. Forty participants shared their personal experiences with aging, how they planned for their futures, barriers they have encountered, and what has helped them reach their goals. The results reveal consistent themes and highlight new ones that warrant attention from policymakers.

I'm 86. I can't take care of myself. I get cleaning services for me, but they won't clean her [my daughter's] room. They won't clean her bathroom. I have to hire someone to clean, because I can't do it. I live on social security. We live on a thousand dollars a month. I don't know how. I mean, we just scavenge and everything we have is old. It's hard. I don't think DDD (Division of Developmental Disabilities) realizes what—I have no family. They keep saying, "Well, we'll take care of her," but how? How will they take care of her?

-Parent of daughter with Down syndrome (DS)/Alzheimer's disease (AD)

Arizona's Growing Aging I/DD Population

According to the Centers for Disease Control (CDC), average life expectancy in the U.S. is 78.8 years.⁶ Like the rest of the population, life expectancy for people with I/DD has grown over the past 50 years, although it fluctuates by disability. The mean age at death ranges from the mid-50s (for those with more severe disabilities or Down syndrome (DS)) to the early 70s for adults with mild/moderate I/DD.⁷

In 2014, there were 337,122 Arizonans with cognitive disabilities comprising 5.3% of the state's age 5+ population – the highest number ever recorded. The total number of people with cognitive disabilities increased 32.4% since 2006, almost twice the rate of Arizona's 18% population growth.⁸ While the risk of specific cognitive disabilities increases with age, there are increasingly more young adults with cognitive, or intellectual disabilities, who require more supports. The 18-34 age group has grown most rapidly since 2004 at a rate of 68.9%; the next largest growing age group is 50-64 at 52.8%. Those 65 and over with cognitive disabilities have increased by 40.8%.

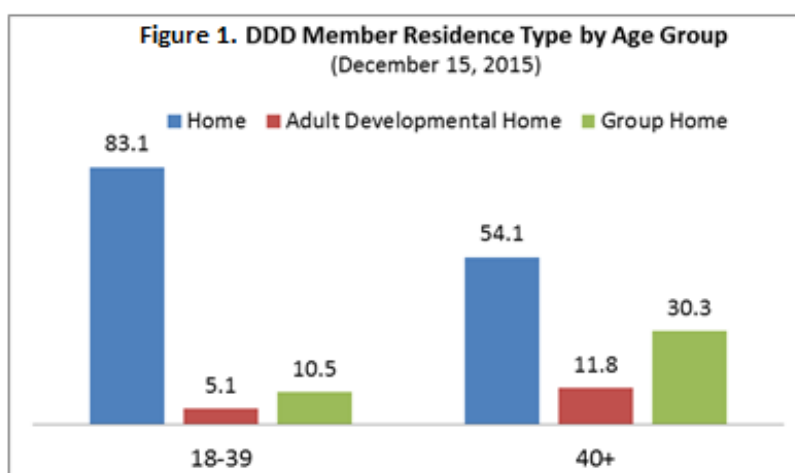
This growth in the number of Arizonans with cognitive disabilities over the age of 40 will require a change in how supports are provided. Specifically, people with DS have an increased risk for acquiring Alzheimer's disease (AD) and related dementias. AD is an irreversible, progressive brain disorder that slowly destroys memory and thinking skills, and eventually the ability to carry out even the simplest tasks. Autopsy studies show that by age 40, the brains of almost all individuals with DS have significant levels of abnormal protein deposits considered AD markers. But despite the presence of these brain changes, not everyone with DS develops AD symptoms. Therefore, it is important that caregivers and professionals recognize the signs of dementia in people with DS and know the resources and supports available.⁹ In addition, some DDD support coordinators have been trained by the state's Division of Aging and Adult Services (DAAS) on aging issues and AD to ensure all aging members with I/DD are receiving the services they need to maintain safety and the opportunity to age in place.

The Centers for Disease Control and Prevention (CDC) defines aging in place as "the ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level."¹⁰ Aging in place allows individuals of all abilities and ages to continue living in the community setting of their choice and provide for any necessary assistance through an individualized combination of formal and informal supports. Governments also find savings in home-and-community-based care rather than institutional care. Aging in place encompasses the full range of physical, functional, and psychosocial health concerns that contribute to successful aging for all people, with and without disabilities.¹¹

Prioritizing aging in place is critical in state services, preventing unnecessary institutionalization. Yet, in 2012, there were 12,424 Arizona residents in nursing homes; 20.4% of them were under the age of 65, well above the 15% national average for this age group. Arizona also has the highest percentage of residents with mild or no cognitive impairment living in nursing homes (48.1%) – 36.3% of these residents have limitations in three or fewer daily living activities. These statistics underline the need for more supports to age in place.

While only 5% of Arizona's Division of Developmental Disabilities (DDD) members are 55 and over, 14%, or 4,998 members with I/DD, are 40 and over and are at an increased risk of health issues. According to DDD, Arizona's aging caregiving population is also directly impacting the provision of services. In the majority of cases, the adult with I/DD has always lived at home with his or her parents. When health issues arise with the primary caregiver(s), there is often no other family or friend able to provide care. For those with access to DDD services, the agency has to identify emergency placement for this member who has never been away from home. Once the member is placed, he or she becomes depressed and either isolates or lashes out because of this life-altering event. Even if there is someone named to provide care in the event of an emergency, the individual with I/DD who has never been away from home still encounters tremendous stress.

It is no surprise then that DDD members age 40+ are more likely to live out of the family home than those 18-39 (Figure 1). Very few live in institutions or nursing homes; almost one in three live in group homes. Prior research finds that most caregivers of adults with I/DD would like them to continue to live in their family home after they are gone; however there are barriers in planning for many.¹²



Aging with DD: Voices and Experiences

The majority of adults with I/DD who attended the focus groups ranged in ages with most in their mid to late 40s and early 50s. The oldest was 63. Some had cognitive disabilities, some did not; however, disabilities overall were significant, requiring day-to-day supports. The caregivers who attended were typically ages 50 and over and included guardians, spouses, and parents. Their ages ranged between 40 and 86. While there may have been differences in age and circumstance, there were common themes consistent across all six focus groups.

Theme #1: There is a lack of activities for older adults with I/DD.

The consensus by families and providers is that services and activities do not meet individualized needs for adults with I/DD as they age. When discussing their health, a group member with I/DD said, “I’m retiring, but I have Down syndrome. It’s very...messes my brain. I can’t think...” Many complained of not having energy or being able to do the things they used to do. These new limitations are challenging for individuals with I/DD who have always been taught independence and self-determination. Increasingly, the freedom of having a job and living on their own that they worked so hard to achieve are called into question when their health begins to deteriorate.

Many of the families corroborated the declining health of their son or daughter with I/DD, and the majority reported having difficulties keeping them active with the limited options available.

I have a daughter who’s 45, and she’s worked all her life. Now the last, oh, two years, three years, she hasn’t worked. She’s going to the daycare center. That’s a huge change, ‘cause she really thrives on working. Now she’s going mentally down, down, down...she really wants to be more active, because she isn’t... Well, now she’s been diagnosed with Alzheimer’s. She’s Down syndrome.

But just as disability differs for each individual, so does the aging process. While out-of-home activities are too active for some, in-home activities are not active enough for others. A parent said with others nodding in agreement, “They [older adults with I/DD] think young. They’re very ambitious. They’re very vital. They want someone to exercise with. They want someone to do things with like that. There doesn’t seem to be any caregivers that will fit that bill.” In response, some family members were fearful over what would happen if their adult with I/DD had to stop working.

While senior centers operated through Area Agencies on Aging (AAA) can fill the gap for social activities, they are often underutilized among individuals with I/DD and older family caregivers. Senior center staff members often don’t have training in I/DD, or families are not made aware of these services. There continues to be aging, disability, and I/DD service silos

that need to be bridged to assure all individuals are able to be included in their communities throughout their life, regardless of age, health or disability.

Senior Centers: An Untapped Resource among People with I/DD and Their Caregivers

More than 150 local centers across the state provide a system of services and resources to age in place for individuals who are 60 and over or who have disabilities. Adults have a variety of opportunities of support through recreation, social, education, health and wellness, advocacy and social services. The centers also provide information on senior programs and resources, minor home appliance replacement/repair for seniors and senior discount programs. Meals are also served at no charge. Some sites offer transportation.

Theme #2: Older adults with I/DD and their families experience a decline in social support.

Additional health diagnoses have made it difficult for individuals with I/DD and their family members to participate in community activities. As a result, the social support network, often intertwined with activities, is not accessed as frequently at a time when it is needed the most. A couple of parents discussed why these social groups are so important: “So, yeah, once she quit going to the dances and going bowling, now I have no social life ‘cause I can’t visit with the ladies. So, hey, girl. I’m still in the program.” Another parent stated, “I feel like half my life is spent in her social life arranging everything.” When that goes away, they all feel a huge void and a loss of social connections.

Increasingly, adults with I/DD depend on their primary caregivers as they age. But the focus groups find, and there is additional evidence to suggest,¹³ that many adults with I/DD and their aging caregivers have a mutually supportive relationship involving both practical tasks and emotional support. At times, the adult with I/DD may take on domestic tasks such as cleaning or cooking that used to be carried out by the aging caregiver who is no longer able to complete these tasks. Further, many who solely rely on family members to help solve problems with minimal outside activities or supports cannot imagine – and don’t want to imagine – life without them. The thought of future planning brings up intense anxiety, which makes it more difficult to discuss, as shown by this individual with DS:

Me and my sister have been talking about this thoroughly and to the point where I don’t want to talk about this— cuz she’s—we’ve been trying to talk about this and it’s like—I know it’s real, but it’s touchy—because—I know, but my sister keeps on going to the ER a lot—she’s having problems. Major.

Those who are already executing their future plan and living independently encounter frustration with support staff. As soon as they develop a friendship and a rhythm with their direct care worker, he or she leaves. These losses are hard emotionally and physically as the individual not only has to “start all over” with a new direct care worker, they lose someone they consider “a friend” in the process. This also makes it challenging for new workers and support coordinators to know individuals with I/DD well enough to identify if there are age-related changes that require different services, resulting in a lack of continuity.

Peer mentors provide positive role modeling, exhibit strong coping and problem-solving skills, and share the benefit of their knowledge about community resources and how to deal with aging issues and other problems. They can also provide an informal community of trust. For example, while adult developmental homes (e.g., placement in an outside family home) are an option for respite, some caregivers feel uncomfortable placing their adult with I/DD with strangers. They are interested in building a community of peer support for respite care in which families and adults with I/DD know one another.

Theme #3: Families do not feel that the state system prioritizes the needs of aging adults with I/DD.

Many older caregivers are facing their own health limitations and worry about the future of their loved one. Despite their worries, caregivers consistently report not having a concrete emergency plan in place, even after speaking to agencies about their concerns. Further, the need for out of home short-term respite is high. Specifically, many worry about what will happen to their loved one if there is a crisis.

To prevent unnecessary stress for themselves and their adult with I/DD, some families want to “try out” a residential option. However, many stated their support coordinators said that wasn’t an option. DDD would not comment on this finding.

Even when there is a plan in place, some report difficulties with implementation. After her friend passed away, a trustee discussed her perceived lack of assistance in having her friend’s daughter with moderate I/DD live with her. The state did not recognize the decline in her friend’s daughter’s health, which impacted her ability to fulfill the emergency plan.

For much of the last four years Felicia¹⁴ had to be in adult developmental homes, because there just wasn’t the support out there for us for her to be in my home with the hours that I worked. So what I ended up doing was sort of semi-retiring... I think the one thing that is most challenging for us is the whole attendant care habilitation assessment process. I think the tool that the division is using is so unrealistic in terms of the time frames that they afford people to do certain tasks... The division has assessed that as long as she’s living with me she needs 19 hours of support a week....But the assessment tool itself, if you were to look at it, they allot five minutes

for preparing breakfast and cleaning up afterwards. You know, just the time frames are very unrealistic. Especially working with someone who needs time to process as Felicia does.

Understanding how formal supports are administered and what informal supports are available can help determine if an emergency plan is sustainable over the long term.

Theme #4: Naming the trustee or guardian is a big concern.

Those who have a plan still worry about the person caring for their son or daughter and how well he or she will be cared for. Their top concern is finding someone who can communicate with the doctor for individuals with I/DD who cannot express themselves clearly. Many parents have named siblings as the guardian or caregiver since they know the adult with I/DD well and can advocate for them. But still parents worry about the life the adult with I/DD will have without them. Will the siblings make the right decisions?

The plan is for her to go live with her brother, which isn't too good of a fit because he really doesn't know how to take care of her..that's kind of limited with her...he thinks she should be able to do more than she does. And I'm worried about her in his house because his floors are all hard tile and if she was to have a seizure, you know, she'd have to be sure to have her helmet on in his house.

Some who were not in the DDD system worry about what will happen if their plans fall apart and the state steps in to provide care.

We have set up a trust. We've got some people named, but they're not that far away from our age. I just shudder to think of them being turned over to a governmental agency for care, cuz I know exactly what's gonna happen. They're gonna be warehoused and destroyed, and that's basically the end of their life.

There is simply no certainty among these family members that their loved ones will be properly cared for, especially if their adult with I/DD has relied on only them their entire life.

Highlighting Solutions to Effectively Plan Ahead

Many families in Arizona with an adult child with I/DD aren't eligible, or aren't accessing, DDD services, but still require care and support. It is critical that individuals with I/DD and their family members learn about aging and disability services inside and outside the DDD system and build informal supports to create a more sustainable and resilient plan over the long term.

Developing Resilient Plans

Resiliency is the ability to recover from a challenge, thrive with a sustained purpose, and grow in a world of turmoil, change, and chronic condition.¹⁵ Resilience thinking finds ways to

solve problems that leave individuals feeling stronger than they would have been without encountering crises. This notion of resilience is often not discussed in relation to people with disabilities and future planning. But this strength-based, holistic approach has the potential to transform planning and services for people with disabilities by focusing on the development of resilience in people's lives. Individuals who were not before resilient can learn resilience.

Individuals with I/DD who learn how to advocate for themselves, engage in meaningful activity, and remain connected to others as they age are practicing resilience. They have a bright outlook about their futures and have taken steps to plan. For example, older individuals with I/DD who were involved in self-advocacy groups tended to be busier with volunteerism, work, and socializing with friends. They stated they did "fun things," and helped each other with problems. They have friends who are not direct care staff. In fact, they learn from their friends about meaningful activities in which to engage as they age. These supports fill in gaps when a parent is no longer there.

Traits of Resilience in Disability & Aging¹⁶

Optimism and effective coping styles: Responses to crises are often seen from the "silver lining" than from despair. These factors were more important to obtaining happiness in aging than perfect health.

Personal connections: Happily engaged with family, friends, close-knit communities, or at paid or unpaid work.

Sense of purpose: Involved in an activity or a function that gives life meaning. This factor affects optimism and how one looks to the future.

Knowledge: Awareness of rights; knowledge of formal and informal resources.

Power and control: Self-advocacy; the ability to affect change in one's social and physical environment in order to access health, educational and community resources.

However, resilience is the exception to the norm. A 2015 MI poll shows the majority of Arizonans with disabilities (51%) are not speaking up for themselves, and 60% of providers feel the formal system does not do a good job maximizing client independence. To develop an effective plan and build resiliency, both the family caregiver and individual with I/DD should participate in self-advocacy training when offered across the state. Older adults with I/DD build connections with others with disabilities so they can socialize, talk through problems, and learn how to lead self-determined lives. The state's five centers for independent living also train on self-advocacy, as well as independent living (<http://www.ilru.org/projects/cil-net/cil-center-and-association-directory-results/AZ>).¹⁷

Building a Community of Care

Resilience planning should start before the problems associated with aging become apparent in both the person with I/DD and the family caregiver. Resilience planning engages a person-centered approach to ensure that future care scenarios honor the choices and preferences of the individual with I/DD as well as those of his or her parents, siblings, extended family members and friends. Parents plan as though they are no longer there - promoting their adult's independence and sense of power and control, which is important to resilience.

A mother of a 50 year old daughter with moderate I/DD and autism who engaged in resilience planning was one of the few participants who had peace of mind about her daughter's future. She spoke about the plan she created with her daughter who is living in her own apartment and working in the community:

She has habilitation workers five days a week, Monday through Saturday, to help her with grocery shopping, cooking, all of those kinds of things, and just social kinds of activities that she's involved in...She has a sister that lives here. She has two nephews that live here. The whole reason we moved here was so they would—I mean, her sister's known her all of her life, but her nephews, so they would get to know who she is. Because ultimately they will be the ones making decisions...

There are informal steps families can take immediately to start planning ahead. They can reach out to others to build a community of support for themselves and their loved one with I/DD. This will not only help them with the stress of caregiving, but will also give the adult with I/DD the opportunity to become comfortable with others. It is important to use a team approach when discussing and creating the plan and always to keep the person's interests, preferences, and skills as the main focus. The more people know about the desires and interests of the adult with I/DD, the more likely these interests will continue to be encouraged. In addition, if future residential plans are informally arranged, parents and family caregivers should “test” their emergency plans, by having their loved one stay over at the trustee's house periodically. This will also help in transitioning the adult with I/DD.

Training and Caring for the Caregivers

Eighty percent of caregiving is provided by families, which helps individuals with disabilities live in the community. In Arizona, there are 855,000 caregivers providing over \$9 billion of care to those with a disability, representing about 14% of the general population¹⁸ – 30% of these 855,000 caregivers are ages 56 and older, according to a 2015 poll of Arizona voters. This work is appreciated by Arizonans; the same poll shows that 79% of Arizonans think that family members who help care for someone with a significant disability should receive financial assistance from the federal government.

Arizona's DDD program directly supports families through various mechanisms. It offers case management services for the DDD member "from cradle to grave." It allows primary family members to serve as paid personal assistants, and provides families with 600 respite hours per year and short-term respite through adult day care centers, adult developmental homes (e.g., adult foster homes), and in-home support. It also can provide home modifications and adaptations to ensure that the person with I/DD is safe in their home.

In addition, there are programs through DAAS that are vastly underutilized by the I/DD community but provide additional support. The Family Caregiver Support program (FCSP) through DES provides a greater variety of services, including case management, counseling services and support groups, caregiver training, respite, and home modifications¹⁹/supplemental provisions through AAAs. In FY 2014, the FCSP served 21,000 caregivers.²⁰

Another underutilized resource is the volunteer driven FCSP Partners in Service database. It was created for family caregivers, individuals living with a disability, and older adults to access supportive services at no charge. These agencies offer trained caring volunteer services free-of-charge for individuals, family caregivers and adults living with disabilities to help them to continue living in their own homes.

But despite the existence of these resources, many individuals with I/DD and their families don't know about them. Failure to receive needed information and support services, including respite, training, and other caregiver-targeted supports, contributes to early or unnecessary out-of-home placements for people with I/DD.

To promote safety, well-being, and aging in place, several training programs and curricula have been developed for both formal caregivers and family members of people aging with I/DD,²¹ including some that are specific to dementia. Caregivers are trained in how to physically adapt the home, how to tailor social and recreational opportunities to changing needs/abilities, and how to provide health and behavioral support in safe and appropriate ways.

Care Partners Reaching Out (CarePRO)

The Alzheimer's Association Desert Southwest Chapter received a grant from ADDPC to extend the CarePRO program to persons caring for loved ones with I/DD who are also coping with Alzheimer's disease and related dementias. CarePRO is a series of skill-building workshops that provides education about dementia and its impact on families. The workshops engage seven to ten caregivers, training them in ways to manage stress and techniques to help them cope with the disease and communicate better with loved ones. The program also includes personalized telephone "coach" calls that help caregivers implement the new skills introduced in the workshops. Respite care for the person with I/DD and dementia is available so caregivers may attend the sessions.

Prioritizing Financial and Legal Planning

It is never too early for legal and financial planning. Planning for individuals and family members includes developing a special needs trust (a trust which protects government and disability benefits) and taking action on residential planning.²² This type of planning decreases caregiver burden, increases choice-making of individuals with disabilities, increases discussion of plans with individuals with disabilities, and overall resiliency. However, state agencies and federal programs are not prioritizing future planning when they allocate resources and develop programs. Many families need help planning housing, finances, personal assistance, and quality of life, among other issues.

The following resources can assist individuals and families in becoming legally and financially prepared.

1. With the recently authorized ABLE accounts²³, people with disabilities will for the first time be able to accrue up to \$100,000 in savings without losing access to Social Security, Medicaid, and other government benefits. A recent MI poll indicated that 76% of people with disabilities would set up an ABLE account if given the opportunity. This year Arizona passed legislation that will begin to set up these accounts, but they will not be available until next year. Until then, families will be able to shop around to find a state program that best suits their needs. To be eligible for an ABLE account, an individual must have a disability that originated before the age of 26. Funds in the accounts can be used to pay for education, health care, transportation, housing and other expenses. Interest earned on savings in the accounts will be tax-free.
2. The Arc and the Center for Future Planning (<https://futureplanning.thearc.org/>) provides a web-based tool to help families build a sound a sustainable plan for their loved one with I/DD.
3. ADDPC funded several guides to help individuals with I/DD and their families in planning:
 - The Sonoran University Center on Excellence in Developmental Disabilities created “[Future Care Planning: A Roadmap for Family Caregivers](#).” It is a planning workbook for individuals with I/DD and family members designed to elicit thoughts and discussion about future care needs.
 - The Arizona Center for Disability Law authored the “[Legal Options Manual](#).” The purpose of this manual is to advise people with disabilities, their families and caregivers about options available when an adult with a disability needs the assistance of someone else in a legally recognized fashion to help manage one or more facets of his or her life.

NEXT STEPS FOR ARIZONA

DDD has promoted inclusion in place by supporting individuals living with their families, but the limited options available still exclude older adults with I/DD from community spaces. Services for I/DD remain inherently specialized and are predominantly segregated from the mainstream. That needs to change in light of the growing number of older adults with I/DD and their aging caregivers. Aging family caregivers are increasingly likely to suffer health problems and to have support needs of their own, often resulting in a mutually dependent relationship with their loved one with I/DD. As a result, the needs of both caregivers and individuals must be considered together in future policies.

State long term care resources are available through various agencies, yet many families are not aware of them, and they are often limited. In response, the National Community of Practice, funded by the Administration on Intellectual and Developmental Disabilities, proposes a set of strategies that will help create a comprehensive state infrastructure responsive to aging concerns of the family caregiver and adult with I/DD.²⁴ They include:

- ✓ Providing education and training on how to access and develop options, opportunities and practices, as well as services and supports within and outside of disability services;
- ✓ Establishing connections to other families and to self-advocates;
- ✓ Creating collaborative processes to plan, explore, problem-solve and support a vision for the future for their family member with a disability and entire family system, starting early and continuing across the lifespan;
- ✓ Learning about local funding for goods and services specific to the support and/or caregiving role for the person with I/DD across the lifespan (e. g., respite, home modifications, cash assistance, assistive technology);
- ✓ Planning for crisis prevention/intervention for families and other caregivers;
- ✓ Training to enhance the family's ability to advocate for services and policies.

These strategies will require the collaboration of different agencies, programs, and services in Arizona. To ensure coordinated service delivery, program staff will require training in aging with I/DD and interagency services and supports. In addition, existing programs and services should be tailored with this population in mind. For example, residential planning should include a transition component that allows individuals to adjust to the idea of life without their primary caregiver.

Advancing successful aging in place and resilience planning goes beyond simple service provision. It's a holistic, multi-faceted approach that requires "a whole village." Planning should start now.

NOTES

- ¹ Ryan A., Taggart L., Truesdale-Kennedy M. & Slevin E. (2014) Issues in caregiving for older people with intellectual disabilities and their ageing family carers: a review and commentary. *International Journal of Older People Nursing* 9, 217–226. doi: 10.1111/opn.12021
- ² Factor, A., Heller, T., & Janicki, M. (2012). Bridging the aging and developmental disabilities service networks: Challenges and best practices. Chicago, IL: Institute on Disability and Human Development, University of Illinois at Chicago.
- ³ UCP Case for Inclusion, 2015, <http://cfi.ucp.org/state-scorecards/>
- ⁴ World Health Organization (2000) Ageing and Intellectual Disabilities– Improving Longevity and Promoting Healthy Ageing: Summative Report. World Health Organization, Geneva.
- ⁵ Williamson, H.J. & Perkins, E.A. (2014) Family Caregivers of Adults with Intellectual and Developmental Disabilities: Outcomes Associated with U.S. Services and Supports. *Intellectual and Developmental Disabilities*, 52(2). DOI:10.1352/1934-9556-52.2.147
- ⁶ <http://www.cdc.gov/nchs/fastats/life-expectancy.htm>
- ⁷ Bittles A. H., Petterson B. A., Sullivan S. G., Hussain R., Glasson E. J. & Montgomery P. D. (2002) The influence of intellectual disability on life expectancy. *The Journals of Gerontology Biological Sciences & Medical Sciences* 57, M470–M472.
- ⁸ Based on IPUMS data for population ages 5 and over.
- ⁹ The following link from the Alzheimer's Association introduces articles, fact sheets, videos, and books on DS and dementia: (http://www.alz.org/library/downloads/downsyndrome_rl2014.pdf).
- ¹⁰ <http://www.cdc.gov/healthyplaces/terminology.htm>
- ¹¹ Laura Jackson, Tom McVeigh, Robin Rust, Christy Miller, April 2015. Aging with Intellectual and Developmental Disabilities: Trends and Best Practices, <http://dmh.mo.gov/dd/manuals/docs/agingwithidd.pdf>
- ¹² Taggart L., Truesdale-Kennedy M., Ryan A. & McConkey R. (2012). Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. *Journal of Intellectual Disabilities* 16, 217–234.
- ¹³ Taggart et al., 2012.
- ¹⁴ All names are changed to preserve anonymity.
- ¹⁵ Edwards, E., Hall, J., & Zautras, A. (2013). Resiliency and aging. *Arizona Geriatric Society*, 18, 1, 27-28.
- ¹⁶ Adapted from McFadde, E., 2014, Aging in Place or Aging and Displaced? A Multi-Site Comparative Case Study of Power, Subjectivity, and Community Resiliency in Public Housing Governance (dissertation); and Grant, G., Ramcharan, P. and Flynn, M. (2007), Resilience in Families with Children and Adult Members with Intellectual Disabilities: Tracing Elements of A Psycho-Social Model. *Journal of Applied Research in Intellectual Disabilities*, 20: 563–575. doi: 10.1111/j.1468-3148.2007.00407.x
- ¹⁷ Centers for independent living are consumer-controlled, community-based, cross-disability, nonprofit agencies that provide an array of independent living services to support individuals with disabilities of all ages to live in the community.
- ¹⁸ Lynn Feinberg, Susan C. Reinhard, Ari Houser, and Rita Choula, Valuing the Invaluable: 2011 Update The Growing Contributions and Costs of Family Caregiving, AARP Public Policy Institute, <http://assets.aarp.org/rgcenter/ppi/lrc/i51-caregiving.pdf>
- ¹⁹ For older adults with I/DD, families and service providers have the challenge of adapting the environments so that persons can maintain function and continue desired activities as long as possible. Environmental interventions (EI) to adapt or modify home/living environments, and assistive technologies (AT), have shown positive effects on function for adults with I/DD.
- ²⁰ The respite program is available to those with I/DD who do not receive DDD respite funds.
- ²¹ Janicki, M. P., McCallion, P., & Dalton A. J. (2000). Supporting people with dementia in community settings. In M. P. Janicki & E. F. Ansello (Eds.) *Community supports for aging adults with lifelong disabilities* (pp. 387-414). Baltimore, MD: Brookes Publishing Company.
- ²² Heller, T., Caldwell, J., & Factor, A. (2007). Aging family caregivers: Policies and practices. *Mental Retardation and Developmental Disabilities Research Reviews* 13(2), 136.
- ²³ <https://www.irs.gov/Government-Entities/Federal-State-&-Local-Governments/Tax-Benefit-for-Disability-IRC-Section-529A>
- ²⁴ <http://supportstofamilies.org/>



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