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What Do NCI Data Tell Us About the Characteristics and Outcomes of Older Adults with IDD?

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For people with intellectual and developmental disabilities (IDD), transitions from one stage of life to another require thoughtful planning and support in order to ensure that people with IDD can continue to live a quality life according to their own preferences and needs. Whereas some of these critical life junctures have received increased attention in recent years, such as the shift from school to work, the transition when people enter their later years has received comparatively less attention. Yet, as more and more people receiving public support begin to age, it is important for policymakers, providers, and advocates to understand their unique support needs so that the transition is a success and people are able to enjoy their later years.

As we release this brief, the global community is grappling with COVID-19, a virus that appears to affect older adults more severely than other age groups. Older adults with IDD are now facing additional challenges, both related to the virus and to the steps needed to avoid the illness (social distancing and quarantine). Though this brief was written before the COVID outbreak, it offers information about the characteristics, outcomes and health status of older adults with IDD that will prove helpful to those working to support them during difficult times.

Using National Core Indicators® data, this data brief describes the characteristics of older adults with IDD and what is known about their outcomes. We also provide suggestions for public managers, providers, and other stakeholders regarding how they might use this information to plan for and support older adults with IDD.

As discussed in this brief, some older adults with IDD have health challenges in addition to those experienced by the general population.

Background

The generation born between 1946 and 1964 makes up a substantial portion of the world's population—and nearly 20% of the American public. In the US, we often refer to this generation as the “Baby Boom generation,” since birth rates across the world spiked following the end of World War II. The population with IDD born during those years—five to seven decades ago—has lived through significant social and cultural change. In 1946, for instance, the first year of the baby boom, there were few publicly funded family and community services, and large institutions housed thousands of people with IDD. In subsequent decades, policy shifts have supported greater access to community supports, legal protections, and greater choice and control over services. And in their own lives, Baby Boomers with IDD have experienced many life transitions—from early years into school through adolescence and into the many phases of adulthood. Now, as with Boomers in the general population, they are at another stage of life transition: moving into their older years.

The number of older adults in the United States continues to grow. The population age 65 and over increased 33% from 2006 to 2016, growing from 37.2 million to 49.2 million, and it is projected to almost double to 98 million in 2060.¹ Currently, one in every seven individuals in the US is over 65, and approximately one in five is over age 55.

Likewise, the numbers of people with IDD over 55 are also growing. This increase is in part the result of a growth in the average lifespan of people with IDD which is now similar to the general population,² with the mean age at death ranging from the mid-50s (for those with more severe disabilities or Down syndrome) to the early 70s for adults with mild to moderate IDD.³ The increase in life expectancy may be attributed to better medical care and health surveillance as well as improved living conditions. The number of adults with IDD age 60 years and older is projected to nearly double from 641,860 in 2000 to 1.2 million by 2030 when all of the Baby Boom generation will be over 65.⁴

As people with IDD age, some will have health challenges in addition to those experienced by the general population. For instance, people with cerebral palsy may experience additional functional limitations, people with Down syndrome are more likely to experience the onset of Alzheimer's disease at an earlier age, and people on the autism spectrum are more likely to have gastrointestinal complications. People with gait and ambulation issues may be more susceptible to falling, and osteoporosis (fragile bones) associated with aging increases the risk of serious injury from a fall.⁵

Moreover, given the shifts in models of support and care that have occurred in their lifetimes, many older adults with IDD have previously lived in an institution. Thoughtful planning for these individuals can support aging in place as a feasible option and avoid re-institutionalization in a

nursing home as a person’s needs increase. And as in the general population, older adults with IDD will need support for end-of-life planning and advance care directives. Like people in the general population, people with IDD need assistance to ensure they can secure adequate housing, get access to specialized health and wellness services, participate in their communities, and ensure that they are safe and secure. However, adults with IDD are at greater risk of abuse, neglect, and other violence against them than the general population. And as they age and develop more functional and cognitive limitations, they may be even more vulnerable to abuse, neglect, and exploitation.⁶

According to the American Association for Intellectual and Developmental Disabilities, agencies that are organized to serve people with IDD are not necessarily equipped to provide such assistance and “have historically not planned for the challenges faced by older people with intellectual and/or developmental disabilities”⁷ and are not prepared to address these unique needs, including providing education and training on mitigating the risk of elder abuse and neglect for a potentially more vulnerable population of older people.

Understanding how to provide services and supports to older adults with IDD requires further research and exploration. The intention of this brief is to provide some insights, using National Core Indicators data from 2017-18, into the characteristics and outcomes of older adults with IDD with the hope that it will add to a growing body of knowledge.

National Core Indicators Data on Older Adults with IDD

To explore the characteristics and outcomes of older adults with IDD, we analyzed NCI[®] In-Person Survey data that was collected in 2017-18 by 35 states and the District of Columbia. Of the 25,671 survey respondents, 25.1% were over age 55 (“older adults” for the purposes of this analysis). As shown below, for this analysis we divided the survey sample into four cohorts:

NCI Survey Respondent Cohorts and Distribution

Age	Frequency	Percent of sample
Under 55	19,149	74.9%
55-64	4,065	15.9%
65-74	1,826	7.1%
75+	522	2.0%
Total	25,562	100%

2018 National Health Interview Survey (NHIS)

To determine whether the needs of older NCI respondents with IDD varies from the needs of the aging general population, we compared NCI data with results from the 2018 National Health Interview Survey (NHIS).⁸ NHIS is the principal source of information on the health of the civilian noninstitutionalized population of the United States.

For all NHIS data, we have included the **confidence interval** in parentheses next to the relevant percentage. If the NCI data falls outside of this interval, it means that the NCI data are **statistically significantly** different from the NHIS data. In this analysis, most of the NCI data are statistically significantly different from the NHIS data.

However, when NCI data show a statistically significant over- or underrepresentation when compared to the general public, **differences in NCI sampling versus NHIS sampling should be considered**. For example, NCI data are collected from adults receiving at least one service in

addition to case management from the state system of developmental disabilities supports. Some states limit their samples to certain programs or waivers, while some states include the entire population of adults receiving DD services (for more see [2017-18 In-Person Survey PART II: History, Methodology, Appendices](#)).

Trends in NCI data

As shown in Figures 1 and 2, the population of older adults in the NCI sample grew during the last 10 years of NCI data collection.

Figure 1. The proportion of people over age 55 increased from 2007-08 to 2017-18.

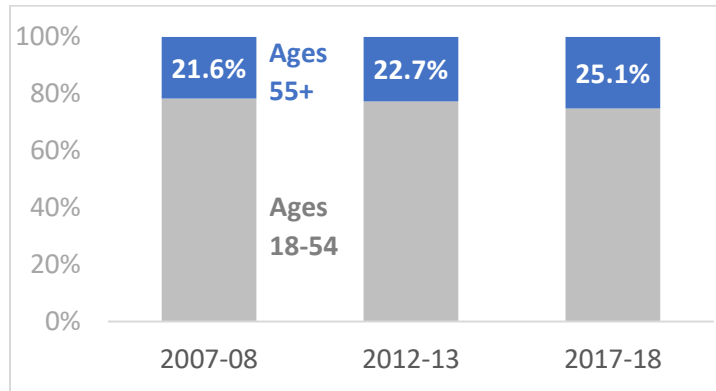
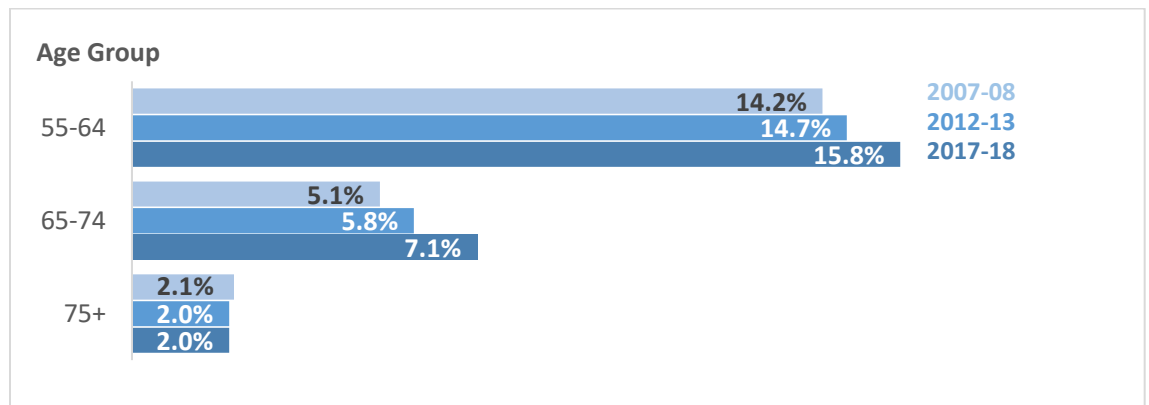


Figure 2. Populations in the older adult age categories grew from 2007-08 to 2017-18, with the exception of the “75 and older” category.

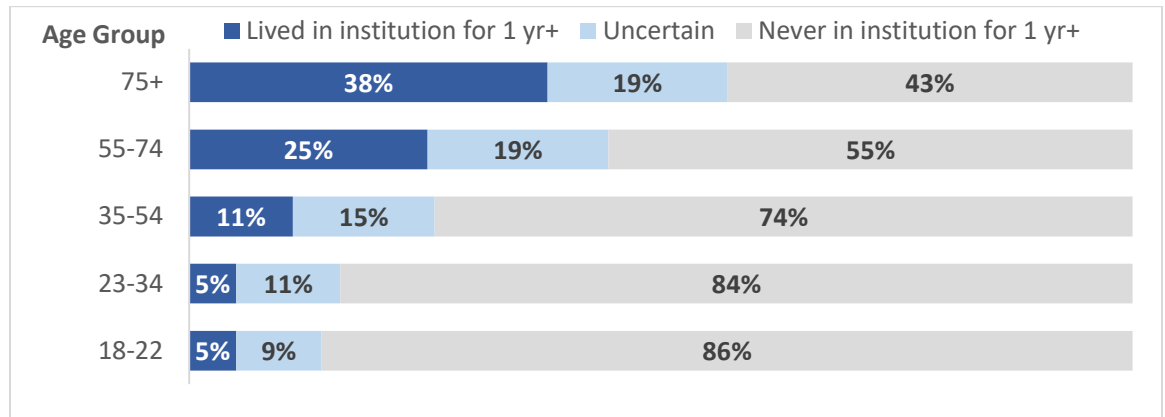


Caregivers are also aging: 64% of caregivers who responded to the 2018-19 NCI Adult Family Survey^a were between the ages of 55 and 74, and 11% were 75 years and over. In two states, 13% of the respondents were caregivers over 75.

Given the shifts in models of support and care that have occurred in their lifetimes, many older adults with IDD have previously lived in an institution. As shown in Figure 3, based on NCI In-Person Survey data from the 2017-2018 data cycle, 38% of people over age 75 who were living in the community had previously lived in an institution, as had 25% of those who were between the ages of 55 and 75.

^a The Adult Family Survey is a separate NCI survey in which respondents are relatives/guardians and live with an adult receiving services from the state developmental disabilities service system

Figure 3. 38% of NCI respondents over age 75—and 25% of those between the ages of 55 and 75—had lived in an institution longer than a year at some point in life.



Demographics

Age. Older adults with IDD (those over 55) represent only 25% of the NCI population. The national portion of the general population over age 55 is 37.4%. In Table 1, you can see that the NCI data points fall outside the NHIS 95% confidence intervals. This means the NCI data are statistically significantly different from the NHIS data. Those over age 55 may be underrepresented in the NCI dataset when compared with the general population.

Table 1: NHIS Age Groups Compared to NCI Age Groups

Age	NHIS	NHIS 95% Confidence Interval	NCI
Under 55	62.6%	(61.9-63.3%)	74.9%
55-64	16.9%	(16.5-17.3%)	15.9%
65-74	12.2%	(16.5-17.3%)	7.1%
75+	8.3%	(8.0-8.6%)	2.0%

Weighted Percentage Denominator: 249,448,868 (adults 18+ in the US)

NHIS 2018 Sample Universe (US population of 2018): 322,903,933

Race. Seen in Table 2, older adults (55+) in the NCI data are more likely to be non-Hispanic white when compared to the comparable age group in the general public (NHIS data). The proportion of non-Hispanic black respondents in the older age groups in the NCI sample roughly approximates the proportion in the NHIS sample. (Notably though, non-Hispanic black respondents are overrepresented in the younger age groups in the NCI data.) Hispanic respondents to NCI are significantly underrepresented in the older cohort when compared to the NHIS data (See Table 3).

Table 2: Race by NCI Age Group

Age	NHIS: non-Hispanic white	NCI: non-Hispanic white	NHIS: non-Hispanic black	NCI: non-Hispanic black	NHIS: non-Hispanic all other race groups	NCI: non-Hispanic all other race groups	NHIS: N	NCI: N
Under 55	57.8% (56.1-59.5)	63.9%	13.5% (12.5-14.5)	17.4%	8.6% (7.8-9.4)	6.5%	32,124	18,920
55-64	70.6% (68.7-72.4)	75.7%	11.7% (10.6-12.9)	15.7%	6.0% (5.2-6.9)	3.0%	9,950	4,045
65-74	75.0% (73.1-76.8)	82.6%	9.8% (8.8-10.9)	11.1%	6.1% (5.3-7.1)	3.2%	7,820	1,811
75+	79.1% (77.1-80.9)	86.6%	8.4% (7.3-9.6)	8.2%	4.8% (3.9-5.7)	2.4%	5,092	520

Table 3: Ethnicity by NCI Age Group

Age	NHIS: Hispanic	NCI: Hispanic	NHIS: N	NCI: N
Under 55	20.1% (18.7-21.6)	12.2%	32,124	18,920
55-64	11.6% (10.4-13.0)	5.6%	9,950	4,045
65-74	9.1% (7.9-10.4)	3.1%	7,820	1,811
75+	7.8% (6.6-9.1)	2.8%	5,092	520

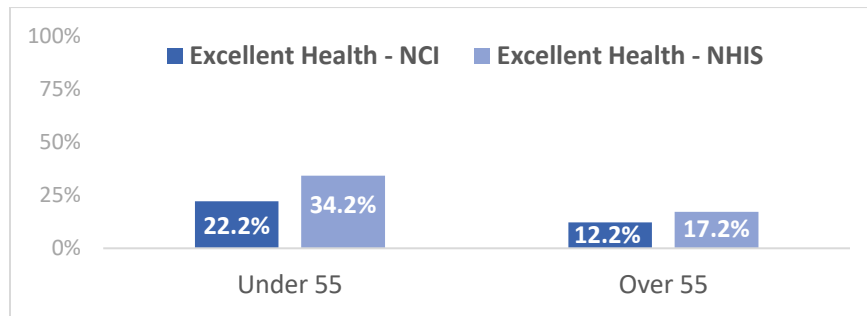
Gender. The NHIS sample is majority female in all age groups. In the NCI data, the younger cohorts are majority male. However, the 75+ age group is majority female. This may mean that the NCI sample is under-representative of females.

Table 4: Gender by NCI Age Group

Age	NHIS Male	NCI Male	NHIS Female	NCI Female	NHIS N	NCI N
Under 55	49.4% (49.0-49.9)	60.2%	50.6% (50.1-51.0)	39.8%	32,124	19,104
55-64	48.3% (47.5-49.1)	55.3%	51.7% (50.9-52.5)	44.7%	9,950	4,056
65-74	46.9% (46.0-47.7)	51.0%	53.1% (52.3-54.0)	49.0%	7,820	1,822
75+	41.8% (40.6-43.0)	48.9%	58.2% (57.0-59.4)	51.1%	5,092	522

General Health Status. In NCI, those under age 55 are more likely to self-report excellent health. However, when compared to the general population, those in the NCI sample both under and over 55 are less likely to report excellent health.

Figure 4: Excellent Health Status by NCI Age Group



Co-occurring conditions. The older age cohorts in the NCI data are significantly more likely to be reported to be diagnosed with mood and anxiety disorders. As may be expected, the proportions of the sample that are reported to have limited or no vision or hearing loss (severe or profound) goes up as age increases.

Comparisons to the NHIS sample should be made with caution, since the questions are not identical. NHIS asks about whether the person is “LIMITED IN ANY WAY in any activities because of physical, mental or emotional problems.” If the answer is yes, the NHIS asks what causes the limitation. To make the data comparable to the NCI data, we included people who reported to be and those reported NOT to be limited in any way in any activities because of physical, mental or emotional problems in the denominator when calculating the NHIS percentages.

When compared to the general public, mood, anxiety, psychotic, or other mental health diagnoses are overrepresented in the NCI sample in all age cohorts. Similarly, vision problems and hearing problems are also overrepresented in the NCI sample.

Table 5: Co-occurring disabilities

Age	NHIS: Depression/ anxiety/ emotional problem causes limitation (N=9273)	NCI: Mood, anxiety, or behavior diagnosis (N=24637)	NHIS: Vision/ problem seeing causes limitation (N= 9273)	NCI: Diagnosis of limited or no vision (N=24300)	NHIS: Hearing problem causes limitation (N=9273)	NCI: Diagnosis of hearing loss, severe or profound (N=24113)
Under 55	26.2% (24.3-28.2)	42.7%	7.2% (6.1-8.5)	8.8%	2.9% (2.3-3.7)	4.9%
55-64	15.1% (13.3-17.1)	50.7%	8.3% (6.9-9.9)	11.2%	3.6% (2.9-4.6)	7.6%
65-74	9.1% (7.6-10.7)	48.7%	7.6% (6.4-9.0)	13.6%	4.8% (3.9-6.1)	11.0%
75+	4.5% (3.6-5.5)	45.2%	9.5% (8.3-11.0)	15.0%	10.2% (8.7-11.8)	18.1%

NCI Data (Without Comparisons to General Public)

There were several relevant NCI measures that did not have comparable data points within the NHIS data. These data points are presented in this section.

Other disabilities The cohort under age 55 is much more likely to be reported to have a diagnosis of autism spectrum disorder and similarly more likely to have a diagnosis of cerebral palsy when compared with the older cohorts. The proportion of the sample reported to have Down syndrome goes down as age goes up, which is not surprising given early onset Alzheimer's in this group of participants and a shorter life expectancy.

Table 6. Other Disabilities

Age	Autism Spectrum Disorder (N=24663)	Cerebral Palsy (N=24790)	Down Syndrome (N=22562)
Under 55	25.6%	16.6%	9.7%
55-64	7.6%	12.2%	7.4%
65-74	4.4%	12.7%	2.5%
75+	2.3%	13.4%	1.1%

Other Conditions. In the NCI sample, the incidence of cardiovascular disease, diabetes, cancer, high blood pressure, and high cholesterol increases as age increases. The incidence of Alzheimer's or other dementia also increases: 19% of people over age 75 (nearly one in five) are reported to have Alzheimer's disease or another dementia.

Table 7: Other Conditions by Age Group

Age	Cardiovascular disease (N=24,302)	Diabetes (N=24,464)	Cancer (N=24,553)	High Blood Pressure (N=24,204)	High Cholesterol (N=23,610)	Alzheimer's or other dementia (N=24,453)
Under 55	5.4%	8.5%	1.3%	14.8%	13.1%	1.1%
55-64	11.3%	18.3%	4.3%	37.6%	35.7%	6.4%
65-74	17.2%	21.2%	6.1%	44.9%	39.4%	8.5%
75+	24.8%	23.6%	12.5%	49.7%	44.6%	19.0%

Preventive Health Screenings. Perhaps not surprisingly, the NCI data indicate that proportions of respondents who received vision exams, hearing tests, flu vaccines and/or mammograms in the past year increase as age increases.

Table 8: Preventive Screening by Age Group

Age	Vision exam in the past year (N=20,889)	Hearing test in past year (N=16,520)	Flu vaccine in past year (N=19,902)	Women age 40+ mammogram in past year (N=4,120)
Under 55	54.4%	52.2%	68.8%	68.5%
55-64	66.7%	65.9%	85.6%	81.8%
65-74	68.4%	67.6%	90.3%	72.1%
75+	71.2%	75.6%	92.3%	60.7%

Where People Who Are Aging Live. In the NCI sample, those over age 55 are significantly more likely to live in an ICF/IID, nursing facility, or other institutional setting than those under age 55. They are also significantly more likely to live in a group residential setting as opposed to an individual setting. Those over 55 are significantly less likely than the younger cohort to live with family or parents. As stated previously, in their lifetimes, those in the NCI sample who are over 55 are significantly more likely to have lived in a state hospital or state developmental center for people with IDD, a private ICF, and/or a nursing home for longer than a year than those under age 55.

Table 9: Living Arrangement by Age Group

Age	ICF/IID, nursing facility or other institutional setting	Group residential setting (e.g., group home)	Own home or apartment	Parents/relatives home	Foster care or host home	N
Under 55	3.7%	25.7%	16.7%	50.0%	3.8%	18684
55-64	10.6%	45.0%	24.9%	13.9%	5.7%	3955
65-74	10.6%	53.5%	22.7%	7.8%	5.5%	1764
75+	13.7%	56.5%	17.1%	5.0%	7.7%	504
TOTAL	5.5%	31.5%	18.5%	40.2%	4.3%	24907

Table 10: Residence by Age Group

Age	Longer than a year in State hospital or state developmental center for people with IDD	Longer than a year in a Private ICF	Longer than a year in a nursing home	N
Under 55	3.0%	2.0%	0.6%	18,979
55-64	14.0%	5.0%	2.1%	4,023
65-74	20.0%	6.0%	3.7%	1,805
75+	25.0%	10.0%	4.3%	520

Medication. Respondents over the age of 55 are significantly more likely to take medications for mood or anxiety disorder. Respondents over the age of 55 are significantly less likely to take meds for behavior challenges.

Table 11: Medication By Age Group

Age	Takes meds for mood, anxiety, psychotic	N for mood anxiety psychotic meds	Takes meds for behavior challenges	N for behavior meds
Under 55	45.0%	12,314	21.2%	12,310
55+	55.3%	4,120	16.5%	4,098

Mobility Impairments. In the NCI sample, the need for mobility assistance increases as age increases.

Table 12: Mobility by Age Group

Age	Moves self around environment without aids	Moves self around environment with aids or uses wheelchair independently	Non-ambulatory, always needs assistance	N
Under 55	81.3%	10.3%	8.4%	19,004
55-64	72.1%	19.0%	8.9%	4,034
65-74	60.1%	27.8%	12.0%	1,804
75+	42.4%	42.6%	15.1%	515

What People Do During the Day. As age increases, people in the NCI sample are less likely to have a paid community individual or group job or a job in a community business that primarily hires people with disabilities. Participation in an unpaid community activity also goes down as age goes up, while participation in paid and unpaid facility-based activities goes up but decreases again after age 75.

Table 13: Employment by Age Group

Age	Paid community job*	Unpaid community activity	Paid facility-based activity	Unpaid facility-based activity
Under 55	18.2%	21.2%	13.8%	35.6%
55-64	11.4%	20.9%	17.6%	46.2%
65-74	6.2%	18.4%	14.7%	50.7%
75+	1.5%	15.1%	8.0%	49.3%

* In an individual, group, and/or community business that primarily hires people with disabilities

Transportation. There is no statistical significance in the differences between the percentages of people in each age cohort who reported almost always being able to get where they need to go. However, the percentage of those who report that they are almost always able to get places when they want to do something outside of the home—like going to see friends or going to do something fun—declines as age increases.

Table 14: Transportation by Age Group

Age	Almost always able to get places to do something enjoyable*	N
Under 55	84.5%	12,698
55-64	81.4%	2,661
65-74	81.0%	1,198
75+	79.0%	333

*Like going out to see friends, for entertainment or to do something else fun

Relationships. As age goes up, NCI respondents are less likely to have friends who are not family or staff.

Table 15: Friendship by Age Group

Age	Has friends who are not staff or family	N
Under 55	78.8%	12,787
55-64	75.6%	2,680
65-74	71.8%	1,211
75+	70.9%	340

Community Inclusion. Those over age 55 are less likely to have done the following activities in the community at least once in the past month:

Table 16: Community Participation by Age Group

Age	Shopping	N	Entertainment	N	Out to Eat	N	Out to Religious or Spiritual Practice	N
Under 55	90.1%	18,600	75.2%	18,598	86.9%	18,624	41.1%	18,432
55+	87.2%	6,210	70.5%	6,215	84.4%	6,221	38.3%	6,175

Summary

This review of the characteristics and outcomes for people in the NCI 2017-2018 In Person Survey sample who are aged 55 and above suggests that this cohort:

- Is smaller than the general population
- Is less like to say they are in excellent health than those who are under 55
- Reflects a declining number of individuals with Down syndrome
- Is more likely to be white than the general population
- Is more likely to have sensory deficits
- Is more likely to have limited mobility
- Is less likely to be on the autism spectrum
- Has more of a problem finding transportation to do things for fun
- Is more likely to have mood and anxiety disorders
- Is more likely to live in a group setting and to have spent time in state hospital
- Is less likely to have friends
- Is less likely to be involved in the community

State IDD systems will increasingly face the challenges presented by a growing number of individuals who are living longer lives. The overview presented here suggests that these individuals will require supports tailored to their changing needs that take into consideration their health challenges, quality of life, wellness, and community involvement.

What Are the Policy Implications?

What we know about people with IDD who are aging—both based on the NCI data and existing research—suggests that public systems, providers, and advocates need to ensure the availability of adequate supports tailored to the changing needs of older participants. One important step is to facilitate access to community programs geared to older adults in the general population—including senior centers and other resources geared to socialization, nutrition, wellness, housing, and benefits counseling. Yet, efforts to bridge the gap between systems that serve older adults and those that serve people with IDD have been minimal despite federal efforts beginning in the 1980s and 1990s to incentivize such collaboration, including legislative changes, federal grants, and the development of memoranda of understanding (MOU) at the federal and state level between developmental disabilities and aging agencies. According to Heller, Factor, and Janicki in a 2012 report, these efforts were undermined over time by changing leadership and changing federal and Congressional priorities. Renewed efforts between aging and IDD agencies will be required to bring about a sustainable partnership to make individuals with IDD welcome in generic aging programs.

Many people with IDD who are aging will experience changes in their physical and cognitive abilities. To tailor supports to meet these changing needs, assessment protocols geared to older individuals will be important. In addition, lifespan planning tools such as those used in Charting the LifeCourse can be helpful in anticipating the supports that will be required as individuals age and in identifying generic, community, and service system resources. Supported Decision-Making may also assist these individuals to make important life decisions including end-of-life decisions and advance directives.

Dementia in later years is also an issue for people with IDD, especially for individuals with Down syndrome for whom the onset of Alzheimer's starts 20 years earlier than for the general population.⁹ Jokinen et al. (2013) in *Guidelines for Structuring Community Care and Supports for People With Intellectual Disabilities Affected by Dementia* note that the first step in treating Alzheimer's is to maintain the individual's quality of life. The authors recommend shared initiatives "across agencies and organizations that involve the aging, disability, and dementia care systems, whether for family supports, day respite, residential, or other supports and services" (page 40).¹⁰

Older adults can also benefit from a range of technological advances including but not limited to remote monitoring, communication devices, GPS trackers, medication organizers and dispensers with timers or enabled with remote monitoring, security systems, home sensors, and voice activated assistants. To ensure that individuals can receive technological support through HCBS waivers, person-centered service plans should include goal(s) linked to the need for a specific device and the steps necessary to ensure that the individual has the ability to use it. Low-interest loans may also be available from federally funded assistive technology centers.

As individuals age, mobility issues may necessitate home modifications or relocation to more accessible housing. As part of person-centered planning, support coordinators should anticipate mobility challenges and explore the availability of federally funded low-income rent supplements for older adults as well as housing available through the HUD Section 202 program.

Direct support professionals (DSPs) play an important role in supporting individuals to make the transition to retirement. According to Sedlezky (2010)¹¹, DSPs need to be knowledgeable about the following five aging-related areas: 1) awareness of physical and mental health changes,

2) supporting aging in place, 3) retirement and later-life social networking, 4) grieving and loss, and 5) end-of-life planning.

Additional issues affecting older adults that DD managers, advocates, providers and other stakeholders should be examining include how to help individuals to make the transition to retirement, how to support wellness programs, and how to attend to the needs of aging caregivers.

State DD systems should be prepared to examine their policies, programs, and practices to ensure they can adequately support people with IDD and their families as they age. One successful approach is discussed below, under Promising Practices.

Conclusions

The needs of older adults with IDD should be anticipated and planned for in advance. This requires shifting to planning formats that take into consideration the supports needed across the lifespan. One successful approach to such planning is being employed by The Community of Practice (COP) for Supporting Families of Individuals with Intellectual and Developmental Disabilities which is working with six states to develop systems of support for families throughout the lifespan of their family member (<http://supportstofamilies.org/>). The COP is supported by the National Association of State Directors of Developmental Disabilities Services, and the University of Missouri Kansas City-Institute on Human Development (UMKC-IHD), and the Human Services Research Institute (HSRI). The COP website includes valuable resources regarding the application of Charting the Lifecourse tools <http://www.lifecoursetools.com/planning/>.

Questions? Comments? Contact Us

For additional information on the National Core Indicators (NCI) initiative, public reports, and past data briefs, please visit: www.nationalcoreindicators.org.

We welcome your feedback and questions. If you want to discuss this report or have questions about the NCI project, please contact: Dorothy Hiersteiner, NCI Project Coordinator, at dhiersteiner@hsri.org

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