



DATA HIGHLIGHTS

Older Caregivers • Employment Goals • Guardianship
Health and Safety • Parents with Disabilities • Self-Advocacy

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What are Data Highlights?

Every month, National Core Indicators (NCI) releases a data highlight. This compendium includes six of NCI's latest highlights.

- Each data highlight details a specific data point, discusses why that point is important, and how states can further examine the issue.
- The data highlights are intended to share further resources for people interested in learning more about a specific issue.

These highlights are made available to our partner organizations to disseminate throughout our networks through newsletters, websites or other platforms. **If your organization would like to receive these highlights in the future, contact Dorothy Hiersteiner at dhiersteiner@hsri.org**

National Core Indicators™ Data Highlight

What can states learn from state and national NCI results about the ages of family caregivers and the implications for future service demands?



The 2016-2017 National Core Indicators™ Adult Family Survey Data indicate that 60% of caregivers responding were between the ages of 55 and 74, and 11% were 75 years and over. In one state, 22% of the respondents were caregivers over 75.

Why does it matter? Many people with disabilities are living with aging caregivers. Demand for state-funded supports and services is expected to swell as caregivers experience age-related support needs. In 2015, the Family Information Systems Project (FISP) reported that 199,641 people with intellectual and developmental disabilities (I/DD) were waiting for one or more Medicaid home and community-based waiver service. The total number of people with I/DD getting services and supports would have to have grown by 23% nationally to serve all the people on waiting lists. More than half of states reported over 1,000 people on waiting lists and, of those, 15 states reported that 76,682 people were waiting for services to move out of the family home. In the 2017 The Arc FINDS survey, 1 in 4 caregivers reported that their family member was waiting for a least one service and 20% said that their family member had been waiting for more than 10 years. Families with aging parent-caregivers are not in a position to wait.

Questions to ask: What other data do you have in the state for forecasting support needs as caregivers age? estimate future demand for out of home placement? Do you survey your waiting list to determine ages of caregivers and the sustainability of their ability to care for their family member? Are there significant unmet needs among those waiting for services? Are there racial and ethnic disparities? Does your state provide any outreach to people on the waiting list? Do you assist families on the waiting list to network with other families and plan for the future? Do you assist families to gain access to natural supports?

Want to know more?

- How many people with IDD are waiting for long-term supports and services? <https://fisp.umn.edu/chart-gallery/waiting>
- *State of Caregiving in the I/DD Community*, Arc (2017). www.thearc.org/FINDS
- Burke, M.M. & Heller, T. (2016). Disparities in unmet service needs among adults with intellectual and other developmental disabilities. *Journal of Applied Research in Intellectual Disability*, Volume 30 (5), pp. 898-910.

National Core Indicators™

Data Highlight



What can states learn from state and national NCI results *people who want a paid job in the community but may not have employment as a goal in their individual plan?*

Data in the 2016-2017 National Core Indicators™ Adult Consumer Survey indicate that 47% of those responding didn't have a paid job in the community but wanted one. Of those who wanted a job, only 40% had employment as a goal in their individual plan.

Why does it matter? NCI data have shown over the past few years that only about 19% of people with intellectual and developmental disabilities (I/DD) in the national sample have a paid job in the community. The fact that only about half of those who want a job have an employment goal in their individual plan suggests that a targeted strategy to include more employment goals during the planning process would improve work opportunities and expand the numbers of people with I/DD who have who are employed.

Questions to ask: How do case managers in your state introduce employment during the individual planning process? Are people without jobs given yearly opportunities to explore potential occupational options? Do case managers in your state work with families to discuss any concerns about pursuing a job for their family member; understanding how to talk about the dignity of risk. Does the individual plan include information about “social capital” that the individual and family may have that could lead to employment? Have case managers received training regarding best practice in supporting people to find jobs. Are you taking advantage of the ABLE Act to assist people to put funds aside for such needs as education, housing, transportation, employment training and support, and assistive technology? Do you case managers understand how to explain and access available resources through vocational rehabilitation programs?

Want to know more?

- *Real Jobs for Real People.* <https://www.realworkstories.org/>
- *Working in the Community: The Status and Outcomes of People with Intellectual and Developmental Disabilities in Integrated Employment – Update 3 (2018).* Human Services Research Institute and the Institute for Community Inclusion. <https://www.nationalcoreindicators.org/resources/data-briefs/>
- *Carter, Erik. What Matters Most: Research on Elevating Parent Expectations (2015).* <https://nasddds.org/resource-library/employment/employment-resource-documents/what-matters-most-research-on-elevating-parent-expectations/>
- *Financial Literacy & Capability.* <http://www.leadcenter.org/financial-literacy-capability>
- *SELN Guidance for case managers*
- *A Purpose in Life: Why Employment First Matters to Self-Advocates*
- *Self-Advocates Becoming Empowered (SABE) and Green Mountain Self-Advocates (2018)* https://www.nasddds.org/uploads/documents/sabe_EF_2018_%28002%29.pdf

National Core Indicators™ Data Highlight



What Does NCI Data Tell Us about the Guardianship Status of Adults with Intellectual and Developmental Disabilities? *

The 2015-2016 Adult Consumer Survey Data indicate that 51% of participants in the Adult Consumer Survey had a partial or full guardian.

Why does it matter? People with guardians are not able to marry, enter into contracts, get a driver's license, sign a lease, make purchases and exercise other choices without the approval of a guardian. People who have guardians cannot participate fully in their own lives.

Questions to ask: Are there alternatives to guardianship in your state?
Are families and individuals in your state familiar with supported decision-making?

Want to know more?

- *Texas Guardianship law (2015) – requires exploration of alternatives to guardianship, supported decision-making and allows individuals to maintain ability to make personal decisions*
- *National Guardianship Association Revised Standards – Requires guardians to facilitate individual choices and preferences*
- *American Association on Intellectual and Developmental Disabilities and The Arc Joint Statement on Guardianship*
- *Website: www.supporteddecisionmaking.org*

* *National Core Indicators, Adult Consumer Survey 2015-16 Final Report. Human Services Research Institute and National Association of State Directors of Developmental Disabilities Services.*
www.nationalcoreindicators.org

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Data Highlight



How can states learn from state and national NCI results to reduce and manage the risk of abuse, neglect and exploitation of adults with I/DD?

The 2016-2017 Adult Consumer Survey Data indicate that 20% of respondents felt afraid in at least one setting such as in their home, day program, at work, walking in their neighborhood, and/or in transport. State results ranged from a low of 5% of people reporting the felt afraid in at least one setting, to a high of 36% of people reporting the same.

Why does it matter? The proportion of people feeling afraid may be associated, at the systems level, with the potential for abuse, neglect or exploitation. Research indicates that risk of harm can be mitigated by ensuring that people have friendships and relationships beyond paid staff, experience respect from staff and others, are afforded privacy, have control of over decision-making, are included in their communities, and are knowledgeable about their rights. (Bolded mitigation factors represent NCI Data)

Questions to ask: Does your quality system track or flag these potential risk factors using NCI and other data? What strategies does your system use to ensure that people learn how to prevent and report abuse, neglect, exploitation? How does your system support or assure access to healthy social networks? How can person centered assessment and planning contribute strategies to help when someone does feel afraid at home, at work, or in their neighborhood?

Want to know more?

- *Predictors of Abuse and Neglect: A hypothetical case illustrating how states can use NCI data to address important issues* https://www.nationalcoreindicators.org/upload/core-indicators/Abuse_Neglect_Case_Example_formatted_Final.pdf
- *Friendship Matters! Improving Health and Well-Being by Supporting Relationships* <https://ici.umn.edu/products/impact/291/11.html>
- *Incident Management Systems and Mortality Reporting in Select State I/DD Systems*, NASDDDS, 2017 <http://www.nasddds.org/resource-library/quality/incident-management-systems-and-mortality-reporting-in-select-state-i-dd-sy/>
- *Promoting and Sustaining Quality Improvement in I/DD Service Systems*, Presentation by Emily Lauer and Steve Staugaitis PhD, 2018 https://www.nasddds.org/uploads/files/230_Staugaitis_and_Lauer.pdf
- *Ensuring Beneficiary Health and Safety in Group Homes Through State Implementation of Comprehensive Compliance Oversight*, DHHS Office of the Inspector General, ACL, and Office for Civil, 2018. <https://www.acl.gov/aging-and-disability-in-america/joint-report-ensuring-beneficiary-health-and-safety-group-homes>

* National Core Indicators, Adult Consumer Survey 2016-17 Final Report. Human Services Research Institute and National Association of State Directors of Developmental Disabilities Services.

** Disability Justice, <http://disabilityjustice.org/justice-denied/abuse-and-exploitation/>

National Core Indicators™ Data Highlight



What can states learn from NCI™ results about people with disabilities who are parents?

In the 2017-2018 National Core Indicators In-Person Survey, 4.5% of respondents were reported to be parents.

Why does it matter? As a field, we continue to move towards a society in which people with I/DD engage in all aspects of the human experience, including intimate relationships and parenting. Up until recently – and perhaps still happening in some states, children of parents with disabilities were referred to the state child welfare agency and were brought into state care to be fostered or adopted.¹ Though this practice is no longer the default response, the standard menu of supports in most states does not include services specifically aimed at parents with disabilities. There are also legal issues that parents with disabilities may be more likely to face including questions about guardianship, and medical consent issues surrounding pregnancy and the health of their child. For those individuals who may decide not to raise a child, the availability of adoption opportunities and counseling are necessary resources.

Questions to ask: Is your state aware of the number of people supported in the I/DD system who are parents? Can people with I/DD who are parents access services that are tailored to meet their unique needs? Are there collaborative efforts among state agencies to provide educational opportunities for potential and current parents with disabilities regarding child care and other important aspects of child rearing? Are parents with disabilities aware of supports through Maternal Child Health programs and Women Infant and Children's Nutrition? Are residential supports for people with I/DD available for new or young mothers. Is support available to accompany pregnant women to their doctor appointments, and to follow diet and other health instructions? Are support groups available for parents with disabilities where they share experiences and learn from others? Do prospective parents have access to advocates as they navigate the medical establishment and beyond? For parents who are employed, do their employers provide parental leave? How can your state make supported decision available for parents with I/DD?

Want to know more?

- *How many people with IDD are waiting for long-term supports and services?* Center for Advanced Studies in Child Welfare (2013). *The Intersection of Child Welfare and Disability*. University of Minnesota, School of Social Work. http://cascw.umn.edu/wp-content/uploads/2013/12/Fall2013_CW360_WEB.pdf
- Christopher and Dana Reeves Foundation (2016). *Parenting with a Disability: Know Your Rights Toolkit*. http://s3.amazonaws.com/reeve-assets-production/Parenting-Booklet-Digital_Finalv2.pdf
- Disabled Parents Project, Brandeis University, <https://www.disabledparenting.com/>; <https://disabledparenting.com/community/forum/disabled-parenting-message-boards/>
- The Arc (2011). *Parents with Intellectual Disability*. <https://www.thearc.org/what-we-do/resources/fact-sheets/parents-with-idd>
- The Association for Successful Parenting (TASP) <http://achancetoparent.net/>
- The National Research Center for Parents with Disabilities. <http://heller.brandeis.edu/parents-with-disabilities/>
- Through the Looking Glass, <https://www.lookingglass.org/national-services/national-center>
- Women Infant and Children's Nutrition. <https://www.fns.usda.gov/wic/about-wic-wics-mission>

¹ McConnell, D. & Sigurjonsdottir, H.B (2010). *Caught in the Child Protection Net* In G. Llewellyn (Ed), *Parents with Intellectual Disabilities: Past, Present and Futures* (pp. 17-188). Malden, MA: Wiley-Blackwell.

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Data Highlight



What can states learn from NCI™ results about people's involvement in self-advocacy activities?

In the 2017-2018 National Core Indicators In-Person Survey, 24% of respondents said they had the opportunity to participate in a self-advocacy meeting. This means that they either participated or had been given the opportunity to participate and said no. State results during that cycle ranged from a high of 45% to a low of 12%. Those who reported having the opportunity to participate in self-advocacy meetings were significantly more likely to have had at least some input in critical life choices such as choosing their home, their housemates, their staff, their schedule, what to buy with spending money and what to do in their free-time.

Why does it matter? The mission of self-advocacy organizations is to help people with intellectual and developmental disabilities (I/DD) to speak for themselves, to understand their rights, and to make important decisions about their lives. Self-Advocates Becoming Empowered (SABE)'s mission captures this aim: "To ensure that people with disabilities are treated as equals and that they are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves; opportunities to make new friends, and to learn from their mistakes." If states aim to support more people to self-direct, to be active participants in their individual plans, and to be involved in civic life, participation in self-advocacy organizations is one way to develop the necessary skills. Self-advocates can also provide much needed feedback and comments on key program documents, bulletins, and pending policy changes.

Questions to ask: Does your state or local organization provide resources to support self-advocacy organizations? Are families aware of the positive benefits of involving their family members in self-advocacy organizations? Are young people with I/DD introduced to self-advocacy organizations as part of their transition from school to adulthood? How does your state agency encourage or motivate providers of services to support people to attend self-advocacy meetings? How do the disability coalitions in your state assure they include self-advocacy organizations? When testimony is needed for legislative, regulatory or Medicaid program changes, how does your state seek out self-advocacy organizations for input? Does your state or local agency assure a self-advocacy agencies have membership on state advisory and/or quality committees?

Want to know more?

- *How many people with IDD are waiting for long-term supports and services?* The Arc. Position Paper on Self-Advocacy. www.thearc.org/who-we-are/position-statements/rights/self-advocacy
- Human Services Research Institute. The Riot (newsletters written by self-advocates, and self-advocacy resources). www.theriotrocks.org
- Institute on Community Integration, Self-Advocacy On Line, University of Minnesota. <https://ici.umn.edu/products/view/559>
- Institute for Human Development, University of Missouri-Kansas City; and Institute on Disability and Human Development, University of Illinois at Chicago (2012). Advising Through Self-Determination — An Information Guide for Advisors. <https://www.nasddds.org/self-advocacy/advising-through-self-determination-an-information-guide-for-advisors>
- Self-Advocates Becoming Empowered (SABE). www.sabeusa.org.
- Self-Advocacy Resource and Technical Assistance Center (funded by the Administration on Community Living). <http://selfadvocacyinfo.org/>

