

National Core Indicators Data Brief

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ABOUT NCI



What NCI Data Reveal About Service Delivery and the Respect Given to the Rights of People With I/DD

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The US Constitution, federal laws, and federal court decisions have declared that people with intellectual and developmental disabilities (I/DD) are guaranteed the same basic rights as other citizens. The CMS Home and Community-Based Services rules regarding support settings and person-centered planning¹ create an additional imperative to ensure (and document) that people exercise their rights to be full participants in their community and pursue a life of their choosing. Yet despite these protections, people with I/DD continue to experience violations of their rights. These transgressions affect their ability to live independent, autonomous, and self-determined lives.

National Core Indicators (NCI) provides a unique opportunity to capture the experiences of people with I/DD receiving public services and support. Through interviews with randomly selected service recipients, the NCI Adult Consumer Survey solicits information about services and quality of life in a range of domains, including community inclusion, employment, and choice. The survey also captures information about whether services and supports are delivered in ways that respect their rights. This brief presents those results from the 2013-14 survey.



In 1997, the National Association of State Directors of Developmental Disabilities Services (NASDDDS), in collaboration with the Human Services Research Institute (HSRI), launched a project to help state-level developmental disabilities operating agencies measure service delivery system performance. This effort, now called National Core Indicators (NCI), strives to provide states with valid and reliable tools to help improve system performance and better serve people with intellectual and developmental disabilities and their families.

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Description and Demographics of Sample

The map below shows the 39 states that participated in NCI during the 2013-14 data cycle.ⁱⁱ The data in this brief are from the 2013-14 NCI Adult Consumer Survey (ACS), which collected information from 16,370 individuals with I/DD from 31 states and one regional council.ⁱⁱⁱ

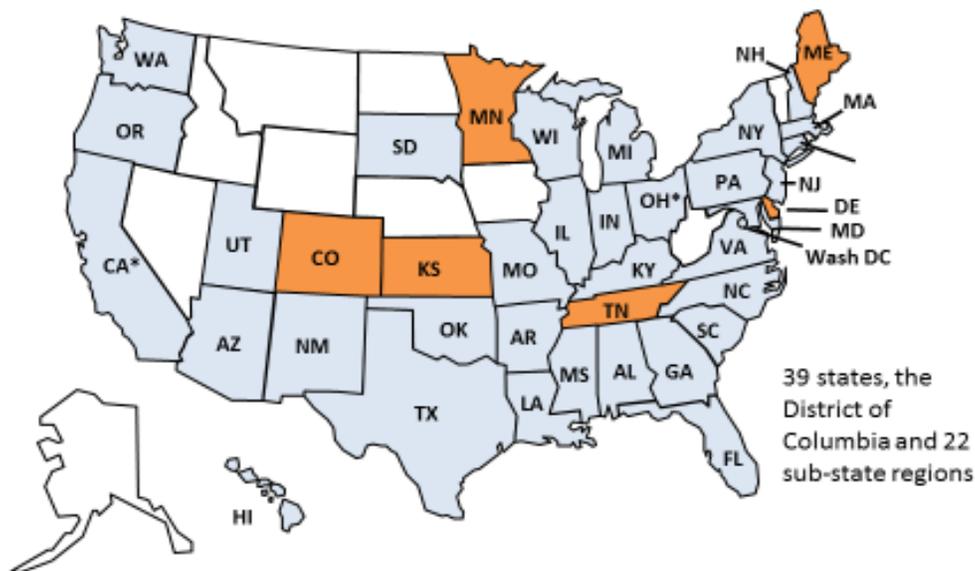
All individuals surveyed were age 18 and over and received at least one service in addition to case management. For many survey questions, the individuals receiving the services responded directly to surveyors during face-to-face interviews. In fact, Section I of the survey, which asks about personal opinions, contains questions that can only be answered by the individuals themselves.

Proxy responses are allowed for Section II, which asks questions that pertain to directly observable, measurable occurrences—such as how often the person participates in specific community events. A proxy respondent can be a family member, staff person, or someone else who knows the individual very well. Case managers or service coordinators are not allowed to respond on an individual's behalf.

Survey administrators also consult agency records or information systems for background information.

The Adult Consumer Survey includes questions that address indicators housed under the subdomain "Rights and Respect" (see Table 1 on the following page). When examined in aggregate, these questions are designed to reveal whether respondents feel that their rights are valued and whether they feel that they are treated with respect.

NCI State Participation 2013-14



■ State contract awarded in 2013-14 through AAIDD funding
CA* = Includes 21 Regional Centers.
OH* = Also includes the Mid-East Ohio Regional Council
Note: Not all states administer the ACS on a yearly basis.

TABLE 1. QUESTIONS IN THE *RIGHTS & RESPECT* DOMAIN

<i>Question</i>	<i>Section of Survey</i>	<i>Response Options*</i>	<i>Collapsed Response Options</i>
<i>Do people let you know before entering your home?</i>	Section I (no proxy responses allowed)	<ul style="list-style-type: none"> • Yes • Sometimes • No 	<ul style="list-style-type: none"> • Yes • Sometimes or no
<i>Do people let you know before entering bedroom?</i>	Section I (no proxy responses allowed)	<ul style="list-style-type: none"> • Yes • Sometimes • No 	<ul style="list-style-type: none"> • Yes • Sometimes or no
<i>Do you have enough privacy at home?</i>	Section I (no proxy responses allowed)	<ul style="list-style-type: none"> • Yes • No 	<ul style="list-style-type: none"> • Yes • No
<i>Do your staff treat you with respect?</i>	Section I (no proxy responses allowed)	<ul style="list-style-type: none"> • Yes all staff always • Sometimes or some staff • No 	<ul style="list-style-type: none"> • Yes • No, or Sometimes or some staff
<i>Can you (this person) be alone with friends or visitors?</i>	Section II (proxy responses allowed)	<ul style="list-style-type: none"> • Yes • There are rules against being alone with friends or visitors 	<ul style="list-style-type: none"> • Yes • No
<i>Do people read your mail or email without asking person first?</i>	Section II (proxy responses allowed)	<ul style="list-style-type: none"> • Yes, mail or email is read without permission • No, person reads own mail/email or others read with permission 	<ul style="list-style-type: none"> • Yes • No
<i>Are you allowed to use the phone or Internet at any time?</i>	Section II (proxy responses allowed)	<ul style="list-style-type: none"> • Yes, can use anytime • No, there are rules/restrictions on use of phone/Internet 	<ul style="list-style-type: none"> • Yes • No
<i>Have you ever participated in a self-advocacy event or meeting?</i>	Section II (proxy responses allowed)	<ul style="list-style-type: none"> • Yes • Had the opportunity but chose not to participate • No 	<ul style="list-style-type: none"> • Yes, or had opportunity • No

*Not applicable and Don't Know responses are coded as missing for these analyses.

Results

When asked about personal privacy, 89% of ACS survey respondents said that people let them know before entering their home, 84% said that people let them know before entering their bedroom, and 91% reported that they have enough privacy at home. When asked whether they could be alone with visitors at home, 77% reported they could. In terms of privacy of communications, 86% reported that they read their own mail (or someone else reads it with their permission), and 90% reported they can use the phone or Internet whenever they want.

When asked whether their staff treats them with respect, 93% answered in the affirmative. But only 32% of respondents had participated in self-advocacy meetings or had the opportunity but chose not to.

Rates by which individuals reported that their rights were respected varied significantly by state.

TABLE 2. 'YES' RESPONSES FOR RIGHTS & RESPECT

Question	Percentage of respondents	N	Range of state averages
<i>People let you know before entering your home</i>	89%	10,866	74%-98%
<i>People let you know before entering your bedroom</i>	84%	10,573	69%-95%
<i>You have enough privacy at home</i>	91%	10,508	80%-98%
<i>Your staff treat you with respect</i>	93%	10,134	77%-97%
<i>Can be alone with visitors at home</i>	77%	14,220	40%-91%
<i>Reads own mail, or others read with permission</i>	86%	13,620	64%-96%
<i>Can use phone or Internet whenever they want</i>	90%	12,600	39%-97%
<i>Participated in self-advocacy meetings or had the opportunity but chose not to</i>	32%	12,535	17%-50%

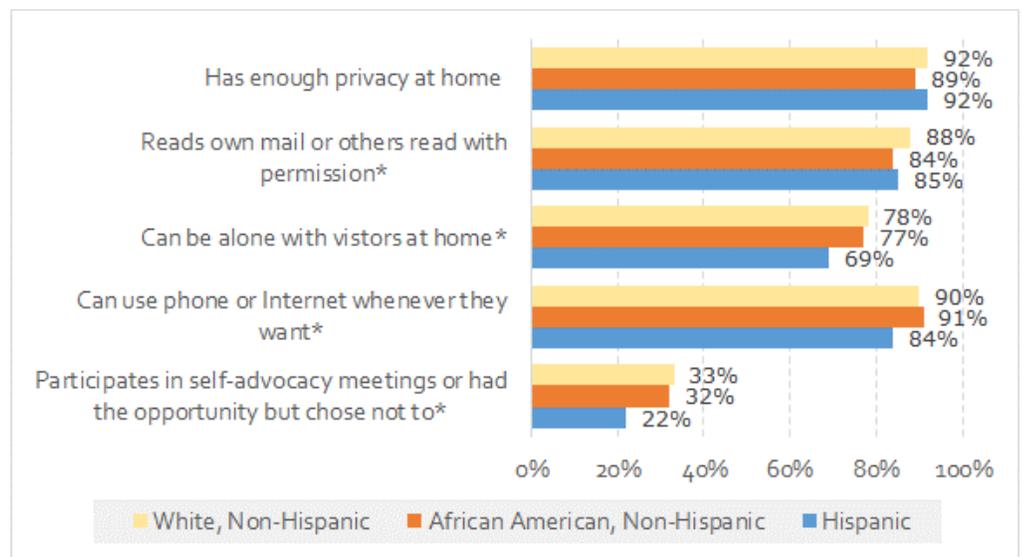
Demographics^{iv}

RACE/ETHNICITY

Individuals of different races and ethnicities reported respect for their rights at different rates.

- White, non-Hispanic respondents were significantly more likely than African American non-Hispanic or Hispanic respondents to report that they read their own mail or that others read their mail with their permission.

Figure 1. Rights Respected by Ethnicity



*Proxy responses allowed.

- African American non-Hispanic respondents were significantly less likely than Hispanic or White non-Hispanic respondents to report that they have enough privacy at home.
- Hispanic respondents were significantly less likely to report that they could be alone with visitors at home, that they could use the phone or Internet whenever they wanted, or that they participated in self-advocacy.

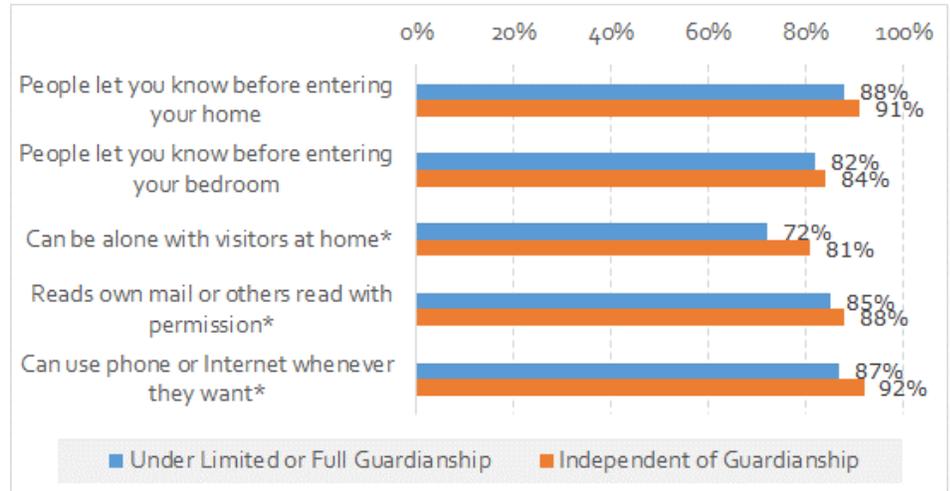
GUARDIANSHIP STATUS

Responses also varied significantly by guardianship status. Individuals under limited or full guardianship were significantly **less** likely than those independent of guardianship to report that their rights were respected. (See Figure 2.)

RESIDENCE TYPE

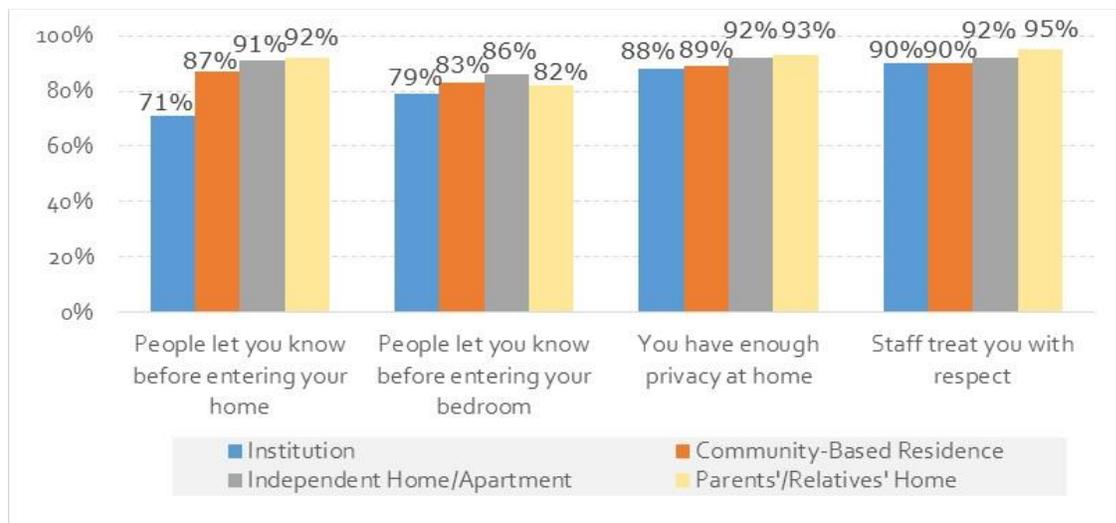
People living in institutional settings were significantly less likely than those in other residence types to report that people inform them before entering their home or bedroom. In addition, they are less likely to report having enough privacy. People who live with parents or relatives are significantly less likely than those in other residence types to report that people let them know before entering their bedroom, and significantly more likely to report that their staff treat them with respect. (See Figure 3.) These questions are all from Section I of the survey, and are therefore answered only by the individual receiving services.

Figure 2. Rights Respected by Guardianship Status



*Proxy responses allowed.

Figure 3. Rights Respected by Residence Type—Respondent Only (No Proxy Allowed)

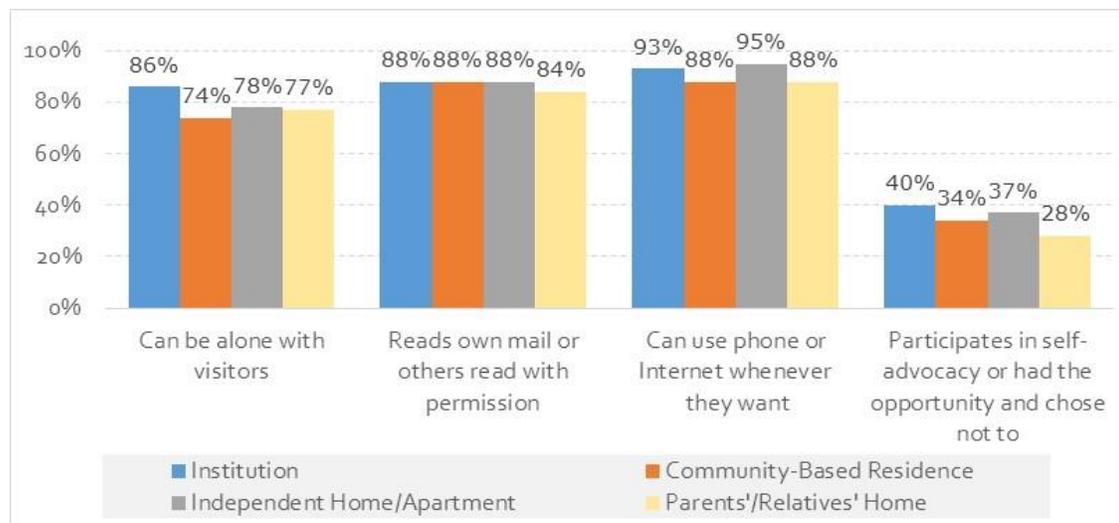


Section II of the survey (see Figure 4), which allows proxy responses, showed the following results for people residing in institutional settings:

- 86% were able to be alone with visitors
- 88% read their own mail or had others read it with their permission
- 93% could use the phone or Internet whenever they wanted
- 40% participated in self-advocacy events or had opportunity but chose not to

People living in independent homes or apartments were more likely than those in other residence types to report that they could use the phone or Internet whenever they wanted (95%) and that they participated in self-advocacy (37%).

Figure 4. Rights Respected by Residence Type—Respondent or Proxy



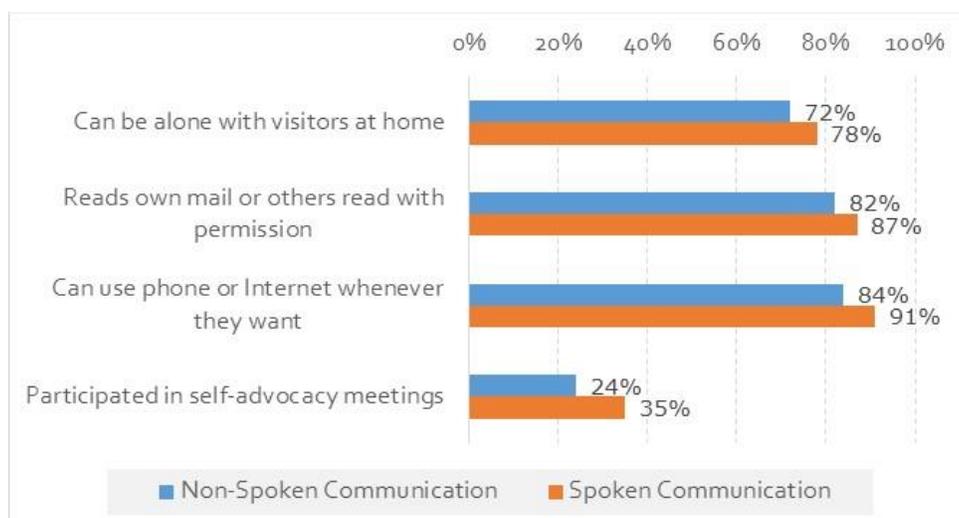
The questions in Figure 4 come from Section II of the survey, which asks about more observable, fact-based occurrences. These questions are less reliant on the recipient's subjective opinion than those in Section I, so proxy responses are allowed.

METHOD OF COMMUNICATION

Response rates to Section I of the survey (the portion that seeks only the opinions of the service recipients themselves) varied by communication method: 76% of respondents who use speech as their primary means of expression responded to Section I, whereas 24% of respondents who use some other primary method of expression responded to Section I. There were no significant differences between these two groups for the questions from this section.

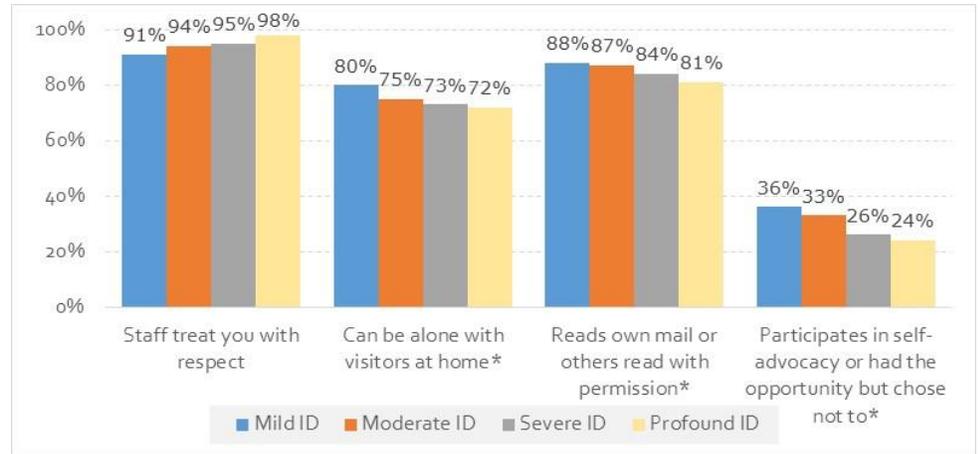
However, **there were significant** differences between those who communicate through spoken language and those who use other means when it came to Section II (see Figure 5).

Figure 5. Rights Respected by Communication Type - Respondent or Proxy



We also found significant differences between those with English as their primary language and those with a different primary language. Individuals whose primary language is not English were significantly less likely to report that they could use the phone or Internet whenever they want (80% compared to 90%). Additionally, they were less likely to report having participated in a self-advocacy meeting or having had the opportunity to participate but choosing not to (23% compared to 32%).

Figure 6. Rights Respected by Level of Disability



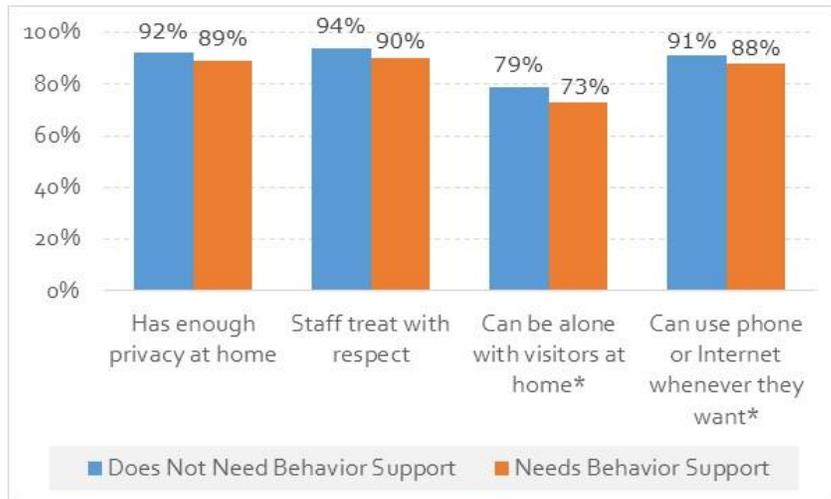
*Proxy responses allowed.

LEVEL OF DISABILITY & SUPPORT NEEDS

Responses also varied based on the respondent’s level of disability and their need for behavior support. People with more severe levels of disability were more likely to report that their staff treated them with respect. Contrastingly, the more mild the disability, the more likely one was to report that they could be alone with visitors, read their own mail (or give others permission to read it) and participate in self-advocacy.

Individuals who need some or extensive support for behavior challenges were significantly less like to report that their rights were respected. Specifically, individuals who need behavior support were significantly less likely to report that they have enough privacy at home, and that their staff is nice. In addition, they were significantly less likely to report that they can be alone with visitors or that they can use the phone or Internet whenever they want.

Figure 7. Rights Respected by Behavior Support Needs



*Proxy responses allowed.

Efforts to Preserve Rights & Respect

Direct Support Professional Training and Outcomes

Research has shown that staff training and staff stability can impact outcomes such as rights and respect for individuals receiving services. The Institute on Community Integration at the University of Minnesota collaborated with a US state to conduct a study to examine the effects of a Direct Service Professional training intervention on outcomes for individuals with I/DD receiving services. The intervention was a one-year competency-based training intervention, which included 35 hours of online training, facilitated group discussions, and on-the-job trainings. The study found that individuals whose support staff had participated in the intervention experienced significantly better outcomes in the domains of rights and respect, choice-making, relationships, and community inclusion when compared with those whose DSPs did not participate in the intervention. This study demonstrates that policy and programs directed at improving the quality knowledge and expertise of the DSP workforce have direct implications for the individual outcomes of persons receiving services, including the preservation of rights.

To that end, the College of Direct Support (CDS), with their set of web-based courses for DSPs, aims to inform and expose participants to values and approaches fundamental to building respectful and positive relationships between support workers and individuals receiving supports. In addition to providing DSPs with a foundation of best practices and professional competency to enhance staff stability and quality, CDS provides courses such as “Individual Rights and Choice,” in which DSPs learn to support individuals to express their rights and choice, and “Civil Rights and Advocacy,” in which DSPs learn about empowering individuals with disabilities to stand up for their civil and human rights.

Self-Direction/Participant Direction

Self-direction/participant direction is a service model that empowers service recipients and their families to utilize personal choice and preference in the selection, direction and management of their long-term services and supports. Self-direction represents a significant paradigm shift from a delivery system in which decisions about supports, staffing, and care are made by a professional to

Looking for ways to preserve the rights and respect of people receiving state DD services? Check out these promising programs and innovations.

one in which an individual exercises the right to make decisions about his or her care. The self-direction model, by allowing the expression of choice in the provision of services, signifies an effort to preserve the rights and autonomy of individuals receiving services. In addition, when the individual receiving services is empowered to make critical choices about who supports him or her and how, he or she can ensure that the care received is respectful of his/her rights. There are many self-direction programs around the country. The National Resource Center for Participant-Directed Services identified 95 participant-directed LTSS programs operating in 2013 for the population of adults with I/DD. For example, the IRIS program (Include, Respect, I Self-Direct) in Wisconsin is an option in which service recipients have control over an individual budget allocation and can use that budget to purchase services and supports to meet their long-term care needs.

Supported Decision Making

Supported decision making (SDM) is a model for autonomy in choice and decision-making for individuals who might otherwise be placed in more traditional guardianships. SDM is an alternative to broad and restrictive guardianship relationships in which individuals are often denied their right to make daily life choices about where to live, with whom to interact, their finances, and their healthcare. SDM relationships provide means for increasing autonomy by empowering individuals to make decisions about their lives with the encouragement of trusted friends, family members and professionals who help them understand the situations, choices and options. SDM is recognized in Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Article 12 presumes that all people have legal capacity and that governments must take appropriate action to provide people with access to the supports they need and want to make their own life decisions. SDM relationships are critical to the preservation of individuals' rights to make choices about their lives.

Person-Centered Planning

Person-centered planning is an approach to service planning that focuses on an individual's needs, wants, and ideas for the future. Person-centered planning is designed

specifically to empower people, to directly support their social inclusion, and to directly challenge their devaluation through the process of listening and learning about what is important to the individual receiving services. Person-centered planning is based on the values of human rights, interdependence, choice, and social inclusion. As such, it can play a critical role in assuring that the rights of individuals are respected within the service planning process.

HCBS Rule

The HCBS Rule^v went into effect on March 17, 2014 and created the first ever federal standards for HCBS. The Rule codifies requirements regarding the settings of HCBS

services and requires that they offer integration with the greater community; choice; privacy, dignity, and respect; freedom from coercion; and independence. These new regulations work toward the laudable goal of assuring that all people with disabilities receiving Home and Community-Based Services (HCBS) under 1915 (c), (i), and (k) waivers have full access to all aspects of community life and the opportunity to receive services in fully integrated settings. In addition, these regulations move services toward a model that is more respectful of the individuality, personal preferences, choices and opinions of individuals receiving services. These new regulations recognize the rights of all individuals to live their lives as they choose.

Notes

ⁱ <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html>

ⁱⁱ Not all participating NCI states administer the Adult Consumer Survey every year.

ⁱⁱⁱ The ACS sample from 2013-14 includes data from AL, AR, AZ, CO, CT, Washington DC, FL, GA, HI, IL, IN, KS, KY, LA, MA, MD, ME, MN, MO, MS, NC, NJ, NM, NY, OH, OK, PA, SC, TN, UT, VA and the Mid-East Ohio Regional Councils (MEORC).

^{iv} For the purpose of this data brief, only group differences that were significant at the $p < .001$ level are reported.

^v <https://www.federalregister.gov/articles/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider>

Resources

Blanck, P., Martinis, J. (2015). "The right to make choices": The National Resource Center for Supported Decision-Making. *Inclusion* 3:1 24-33 http://supporteddecisionmaking.org/sites/default/files/inclusion_blanck_maritinis_2015.pdf

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