National Core Indicators and Self-Direction:

What do the data show?

April 2025

Prepared by: Lindsay A DuBois, Valerie Bradley, Dorothy Hiersteiner, Stephanie Giordano, Laura Vegas, and Rosa Plasencia

Executive Summary

This brief examines data from National Core Indicators Intellectual and Developmental Disabilities (NCI-IDD) In-Person Survey (IPS) and National Core Indicators Aging and Disabilities (NCI-AD) Adult Consumer Survey (ACS) to shed light on the populations of people self-directing their supports and their experience of self-direction. These two self-direction data sets show that there are notable differences both among each survey population and between NCI-AD and NCI-IDD respondents. These include differences in demographics (e.g., diagnosis, race and ethnicity, level of disability) of those who use self-direction and differences in their experience of self-direction. The experiential differences also vary by personal characteristics, such as mode of communication and age. This brief concludes with recommendations for public managers as they consider how to expand service users' access to self-direction.

Background

Self-direction allows older adults and people with disabilities to make decisions about how their services will be provided including hiring, training, supervising, scheduling, and dismissing their workers, as well as securing other goods and services. In other words, self-direction places more decisions about supports and services in the hands of individuals. In this way, self-direction provides an important opportunity to exercise self-determination and control.

Self-directed supports in human services first emerged in California nearly 70 years ago.[1] By the mid-1990s, self-direction became a service delivery option in home and community-based services (HCBS). Since 2003, self-direction has been a service option for all states under federal home and community-based services (HCBS) Medicaid waivers that serve older adults, people with intellectual and developmental disabilities, people with physical disabilities, autistic individuals, individuals with serious mental illness, individuals living with HIV/AIDS, and individuals with acquired brain injury. According to the inventory of self-direction conducted in 2023 by Applied Self-Direction, there were 260 self-direction programs across the country in 2023 serving a total of 1,520,267 individuals; this number represents a 23% increase between 2019 and 2023.[1]

Several important factors explain the growth of self-direction between 2019 and 2023. Federal policy and regulatory initiatives (e.g., the Affordable Care Act, the Centers for

Medicare & Medicaid (CMS) HCBS Settings Final Rule) provided opportunities to states to enhance the availability of self-direction. For example, when the COVID-19 pandemic significantly disrupted the provider networks around the country, Appendix K of the HCBS waiver application afforded states flexibilities to broaden rules around self-direction and pay family members to provide supports. Another factor escalating the uptick in self-direction has been the continuing direct care workforce crisis. The 2023 NCI State of the Workforce in IDD survey of 3,934 provider agencies employing 325,591 direct support professionals (DSPs) who support adults with IDD found that the average turnover ratio among was 40%. According to the 2023 NCI State of the Workforce Aging and Disabilities (AD) survey of 1,324 provider agencies employing 88,855 direct support workers (DSWs) who support the AD population, the average turnover ratio was 48%. Hiring family members can compensate for staff support shortages.

This brief provides an overview of data from National Core Indicators that reflects the experiences and characteristics of those with disabilities and older adults who self-direct their HCBS supports. The analysis provides a national overview of the characteristics and experiences of people with IDD, older adults, and people with physical disabilities who self-direct (e.g., in terms of age, race/ethnicity, gender, level of disability, etc.).

Of note, the implementation of self-direction, including opportunities to participate in self-direction, can vary widely. Across states, there are differences in which state agency oversees self-directed HCBS, the types of people participants can hire to provide their supports, services that may be self-directed, and more. Some of these variations may account for differences in use and experiences with self-direction. For the purposes of this analysis, we are focusing on national level data related to the populations receiving supports from their state aging and disabilities and developmental disabilities service systems. For more information about how self-direction services are administered in the United States, see Appendix A.

Methods

The data for this analysis come from 2022-2023 NCI-IDD In Person Survey (IPS) and the NCI-AD Adult Consumer Survey (ACS). The NCI-IDD IPS collects survey data on the experiences of people receiving services from their state developmental disabilities (DD) service systems, and the NCI-AD ACS solicits the experiences of older adults and people with physical disabilities receiving services from their state aging and disability

service systems (AD systems). In the 2022-2023 survey cycle, 33 states administered the NCI-IDD IPS to 25,424 participants, and 18 states administered the NCI-AD ACS to 15,455 participants.

For this analysis, we used bivariate associations to characterize the population that uses self-directed supports and their experiences with self-direction along various personal factors in both the NCI-AD ACS and NCI-IDD IPS surveys.

Findings

Descriptives and Demographics

Table 1 reports the use of self-directed supports among NCI-AD and NCI-IDD survey respondents overall, and by selected demographics. There are notable differences both between and within NCI-AD and NCI-IDD populations. The proportion of NCI-IDD respondents who used a self-directed supports option is about half that of the NCI-AD sample. Although most states offer self-direction for people with IDD, the option is sometimes only available on specific state waivers and/or for specific waiver services. Previous research finds that people with IDD utilize self-direction in lower numbers compared to other disability populations.[2,3]

In both survey populations, use of self-directed supports is lower among older respondents, which could be related both to a reluctance to give up legacy services, unwillingness to take on responsibilities of self-direction, or the fact that self-direction is not possible in many residential settings where older people are more likely to live. There appear to be differences by race and ethnicity between the NCI-IDD and NCI-AD surveys in the rates of participation in self-direction supports options. For example, Hispanic respondents to the NCI-AD ACS have much higher rates of self-direction than Hispanic respondents to the NCI-IDD IPS. Also, within both survey populations, there are notable racial/ethnic differences in the use of self-direction (e.g., among American Indian/Alaska Native respondents on NCI-IDD and NCI-AD, Asian and Pacific Islander respondents on NCI-AD). These differences may be due to a number of factors that merit further study.

Table 1. *Use of self-direction by survey population and selected demographics*

	NCI-AD 2022-23	NCI-IDD 2022-23
Overall percent of respondents who use self-directed supports	34%	17%
Age group		
18-44	33%	22%
45-64	36%	10%
65+	29%	5%
Gender		
Female	34%	17%
Male	33%	17%
Race/ethnicity		
American Indian/Alaska Native	44%	22%
Asian	46%	16%
Black	32%	12%
Pacific Islander	41%	20%
White	33%	19%
Hispanic	40%	9%
Other	20%	16%
Preferred language		
English	33%	18%
Spanish, Chinese, Tagalog, Vietnamese, ASL, or other	56%	9%
Preferred means of expression		
Spoken	33%	16%
Gestures, sign language, communication aid/device, or other	43%	19%

Experience of Self-Direction

Differences by survey population

Examining differences in the demographic characteristics of those who participate in self-directed supports options and those who don't can prompt state systems to examine possible differences in access to and uptake of self-directed supports. Along with an analysis of demographics of those using self-directed supports options, it is essential to explore any differences in the experience or quality of self-directed supports. Table 2 showcases measures of the experience of self-direction for NCI-AD and NCI-IDD respondents who use self-directed supports.

Table 2. *Experience of self-direction by survey population*

Experience	NCI-AD 2022-23	NCI-IDD 2022-23
Who makes the decisions about services that are self-directed?		
Person mostly makes the decisions	60%	14%
Person has input and family/friends help	25%	40%
Someone else makes decisions	15%	46%
Person has enough help deciding how to direct their services	94%	85%
Person can make changes to the services and support they self-directed if needed	94%	90%
Person has amount of control they want with the services they self-direct	91%	84%
The services and supports the person wants to self-direct are always available	78%	65%
Person gets information about their budget and services from their financial management service (FMS)	52%	81%
The information from the FMS is easy to understand	78%	70%
The person needs help with at least one part of self-direction (e.g., getting staff paid, findings or keeping staff, managing benefits for staff)	34%	49%

There are several notable differences between NCI-AD respondents and NCI-IDD respondents; for example, NCI-IDD respondents are more likely to report that someone else makes the decisions about services than do their NCI-AD peers (46% vs 15%). This finding may reflect, in part, the high rates of guardianship among people with IDD, which constrains the decisions they are legally allowed to make. Almost half (47%) of respondents to the 2022-23 NCI-IDD IPS were reported to have guardians. Many states also provide the option for participants to have a representative act on their behalf and make decisions related to self-direction.[4] Additional factors, such as family involvement in service planning, availability of natural supports, cultural beliefs, and age may be related to who has more opportunity to make decisions about the services that are self-directed.

5

Likewise, NCI-IDD respondents are less likely than their NCI-AD peers to report that the services and supports they want to self-direct are always available (e.g., having the services available when needed and having enough staff to hire) (65% vs 78%). Finally, almost 50% of NCI-IDD respondents report that they need help with at least one part of self-direction, compared to 34% of NCI-AD peers. This could be related to the fact that fewer people with IDD say that the services and supports they need are always available, but further study is needed into the specific areas of unmet need for the different populations.

Differences in experience of self-direction by demographic characteristics

Within the NCI-AD and NCI-IDD populations, experiences with self-direction for respondents from different demographic groups also vary. Tables 3 and 4 showcase examples of notable similarities and differences in the experiences of self-direction across surveys within specific subgroups. Table 3 shows differences for those who use non-spoken communication methods such as gestures, sign language, communication aid/device, or other; Table 4 shows differences across age groups.

Differences by communication

Among NCI-AD and NCI-IDD respondents, 3% and 20%, respectively, use non-spoken forms of communication. Of note, those who use non-spoken forms of communication (gestures, sign language, communication devices) have higher rates of using self-directed supports in both the NCI-AD and NCI-IDD survey when compared with those who use spoken communication.

Within each survey population, there are several significant differences in experiences of self-direction for those who use non-spoken communication relative to those who use spoken communication. For example, in both the NCI-AD and NCI-IDD populations, those who use non-spoken communication have much lower rates of reporting that they make decisions about the services that are self-directed when compared to those who use spoken communication, and much higher rates of reporting that someone else makes the decisions. Among those who use spoken forms of communication, 60% of NCI-AD respondents say that they mostly make decisions about the services that are self-directed, while just 17% of NCI-IDD respondents do. This difference is significantly smaller between surveys for those who use non-spoken forms of communication, at 12% and 6% for NCI-AD and NCI-IDD respectively.

NCI-IDD respondents who use non-spoken forms of communication, compared to peers who use spoken communication, are significantly less likely to say they have enough help deciding how to direct services (82% vs 87%). Those respondents who use non-spoken forms of communication, compared to those who use spoken communication, are also significantly less likely to say that they have the amount of control they want with the services they self-direct (86% vs 81%). Both NCI-IDD and NCI-AD respondents who use non-spoken communication have significantly lower rates of saying that the services and supports they want to self-direct are always available. Of note, individuals with communication differences may require the use of a proxy-respondent to have equitable participation in the NCI surveys; while we did not exclude information reported by proxies for the self-direction questions, proxy-response may differ from self-response.

Differences by age group

Table 4 shows that older NCI-AD and NCI-IDD respondents use self-directed supports at lower rates than their younger peers. In both the NCI-AD and NCI-IDD, there are several significant differences in the experience of self-direction across age groups; while the relative percentages for each measure often differ between NCI-AD and NCI-IDD respondents, the patterns across age groups are somewhat similar.

For example, middle-aged respondents (45-64 years old) in both surveys have the highest percentages of indicating that they mostly make the decisions about the services that are self-directed (NCI-AD: 73.2%; NCI-IDD: 24.7%) and the lowest rates of saying that someone else makes the decisions (NCI-AD: 5.1%; NCI-IDD: 38.5%). Relative to older peers, NCI-AD and NCI-IDD respondents who are ages 18-44 also have significantly lower rates of saying the services and supports they want to self-direct are always available (70.8% on the NCI-AD survey, and 63.5% on the NCI-IDD survey), and significantly higher rates of saying that they need help with at least one area of self-direction (45.2% and 50.3% on the NCI-AD and NCI-IDD respectively).

These findings provide some important information for public managers who are seeking to understand and improve their self-direction supports. The data demonstrate that there are differences in who can get access to self-direction, as well as in the experiences of self-direction both across and within survey populations. NCI-AD respondents who self-direct their supports appear to have higher rates of direct choice and control, compared to NCI-IDD respondents who self-directed their supports. These differences within and between populations point to the importance of further research to understand what factors contribute to these differences.

Table 3. Experience of self-direction by preferred means of communication

Experience	NCI-AD 2022-23		NCI-IDD 2022-23	
	Uses spoken communication	Uses non-spoken communication	Uses spoken communication	Uses non-spoken communication
Who makes the decisions about the services that are self-directed?^*				
Person mostly makes the decisions	60%	12%	17%	6%
Person has input, and family/friends help	26%	33%	45%	27%
Someone else makes the decisions	13%	56%	38%	67%
Person has enough help deciding how to direct their services *	94%	92%	87%	82%
Person can make changes to the services and support they self-directed if needed	95%	82%	91%	89%
Person has amount of control they want with the services they self-direct*	91%	93%	86%	81%
The services and supports the person wants to self-direct are always available^*	82%	60%	66%	60%
Person gets information about their budget and services from their financial management service (FMS)	54%	63%	81%	81%
The information from the FMS is easy to understand*	78%	82%	69%	74%
The person needs help with at least one part of self-direction (e.g., getting staff paid, findings or keeping staff, managing benefits for staff)	32%	43%	48%	51%

^ denotes significant difference ($p<0.05$) between those who use spoken communication and those who use non-spoken communication in NCI-AD
* denotes significant difference ($p<0.05$) between those who use spoken communication and those who use non-spoken communication in NCI-IDD

Table 4. *Experience of self-direction by age group*

Experience	NCI-AD 2022-23			NCI-IDD 2022-23		
	Ages 18-44	Ages 45-64	Ages 65+	Ages 18-44	Ages 45-64	Ages 65+
Who makes the decisions about the services that are self-directed?^*						
Person mostly makes the decisions	50%	73%	51%	13%	25%	19%
Person has input, and family/friends help	27%	22%	12%	41%	37%	27%
Someone else makes the decisions	23%	5%	21%	47%	39%	54%
Person has enough help deciding how to direct their services	94%	93%	95%	85%	88%	93%
Person can make changes to the services and support they self-directed if needed	93%	94%	94%	90%	92%	93%
Person has amount of control they want with the services they self-direct	88%	92%	92%	84%	87%	86%
The services and supports the person wants to self-direct are always available^*	71%	83%	76%	64%	70%	78%
Person gets information about their budget and services from their financial management service (FMS)*	52%	54%	48%	82%	74%	66%
The information from the FMS is easy to understand*	81%	77%	79%	71%	63%	72%
The person needs help with at least one part of self-direction (e.g., getting staff paid, findings or keeping staff, managing benefits for staff)^*	45%	34%	30%	50%	45%	35%

^ denotes significant difference (p<0.05) between those who use spoken communication and those who use non-spoken communication in NCI-AD
* denotes significant difference (p<0.05) between those who use spoken communication and those who use non-spoken communication in NCI-IDD

Limitations

While this brief is intended to provide preliminary insights into self-direction, we acknowledge that one of the limitations is that the methods of analysis were focused on bivariate analysis rather than multivariate modeling. Nevertheless, states can use the data from this brief to think about policies (e.g., alternatives to guardianship) and procedures (e.g., training for families and participants) in their state that may impact who accesses self-directed supports, and their experiences within self-direction programs.

Additionally, this analysis of NCI data on self-direction does not examine the model of self-direction being used. For example, the data do not indicate whether a person is utilizing self-direction only to direct their transportation services, or whether the person is utilizing self-direction to direct and manage all of their services and supports. The data also do not indicate whether the person is using an employer authority or budget authority model. Therefore, although this analysis can examine the experiences of those who participate in self-direction, we cannot make assumptions about their level of engagement in the direction and planning of their supports.

Conclusions and Future Directions

This analysis indicates that access to and utilization of self-direction varies by population group and demographic characteristics. Additionally, this analysis shows that, of those who are using a self-directed supports option, the experience of self-direction varies by population and personal characteristics.

The disparities in access and experience of self-direction suggest some implications for public managers regarding improvements in the self-direction infrastructure to ensure equitable opportunity to self-direct their services and supports. Suggestions include:

- Ensure that people who are self-directing have access to support brokers/independent facilitators to support them through the process.
- Develop plain-language resources for participants and families about the mechanics of self-direction as well as the services and supports that can be self-directed.
- Develop training for service coordinators/case managers regarding how to introduce and support self-direction.

- Seek advice on system improvements from people who are self-directing regarding what's working and what's not working well.
- Initiate outreach to racial and ethnic groups to ensure that the process of self-direction is respectful of culture.
- Use existing data on self-direction available through the NCI-IDD IPS and NCI-AD ACS to identify areas for improvement and to target efforts to attract individuals who typically do not seek to self-direct.
- Integrate data collection requirements into FMS contracts to track the status of the self-direction workforce in terms of turnover, characteristics, etc.

Additional research should look at whether people who have positive experiences with self-direction also have more positive outcomes including community participation, employment, respect for rights and other quality of life indicators. By contrast, public managers should also identify factors that contribute to a poor experience of self-direction in order to expand self-direction.

Acknowledgements

Suggested citation: DuBois, L.A., Bradley, V., Hiersteiner, D. & Giordano, S. (2025). National Core Indicators and Self-Direction: What Do The Data Show?[White paper]. https://idd.nationalcoreindicators.org/survey-reports-insights/

Appendix A: How does Medicaid Self-Direction work?

In the U.S., those eligible for Medicaid services are eligible for self-direction through a variety of authorities including Section 1915(c) HCBS Waiver, Section 1915(i) State Plan Benefit, Section 1915(j) Self-Directed Personal Assistance State Plan Option, Section 1915(k) Community First Choice State Plan Option, and Section 1115 Demonstrations. Self-direction can take two forms: budget authority and employer authority. Under employer authority, "the participant is supported to recruit, hire, supervise, and direct the workers who furnish supports. The participant functions as the common law employer or the co-employer of these workers. When the employer authority is utilized, the participant rather than a waiver provider agency carries out employer responsibilities for workers[5]."

> **Minimum CMS State Requirements for Self-Directed Waiver Programs**
>
> - Person-centered planning process
> - Service plan
> - Information and assistance
> - Financial Management Service
> - Quality assurance and continuous quality improvement system
> - Individualized budget (if applicable)

Within both models, participants are given the use of a Financial Management Service (FMS). There are two main FMS models; the Fiscal/Employer Agent model (F/EA), and the Agency with Choice (AwC). In the budget authority model, the participant is the common law employer of workers and the F/EA serves as the "employer agent. The F/EA pays workers and vendors on the participant employer's behalf and withholds, calculates, deposits and files federal taxes for the employer and employee including Social Security and Medicare Taxes. With budget authority, the individual can determine the rate of pay for employees and can purchase goods and services.

In the employer model or AwC model, a Medicaid provider agency serves as the fiscal intermediary and partners with self-directing employers/participants. In this co-employment model, the agency serves as the employer of record but the individual trains, supervises and manages the support staff. The provider agency pays the worker, including withholding, filing and paying federal and state income and employment taxes,

as well as providing a worker's compensation policy. In both models, all payroll and purchases are made within the participant's budget based on an individual service plan.[6]

Though there are federal guidelines for Medicaid self-direction—particularly when self-direction is supported by home- and community-based waivers[7]—state systems have broad discretion in determining how self-direction supports options can operate in each state. For example, states can determine what services and supports can be self-directed depending on the waiver population, the characteristics and numbers of fiscal employer agents, amount of the individual budget, types of staff training, and the staff that can be hired (e.g., in the state of Washington, self-directed staff must be members of a union).

This lack of overall standards means that state self-direction programs vary widely insofar as the numbers of people self-directing and the degree and nature of support and assistance available to the individual who is self-directing. State-level data that can showcase the experiences and outcomes of those using self-directed supports is imperative to inform best practices for self-direction service delivery.

Figure 1. *Self-Direction Roles and Process*
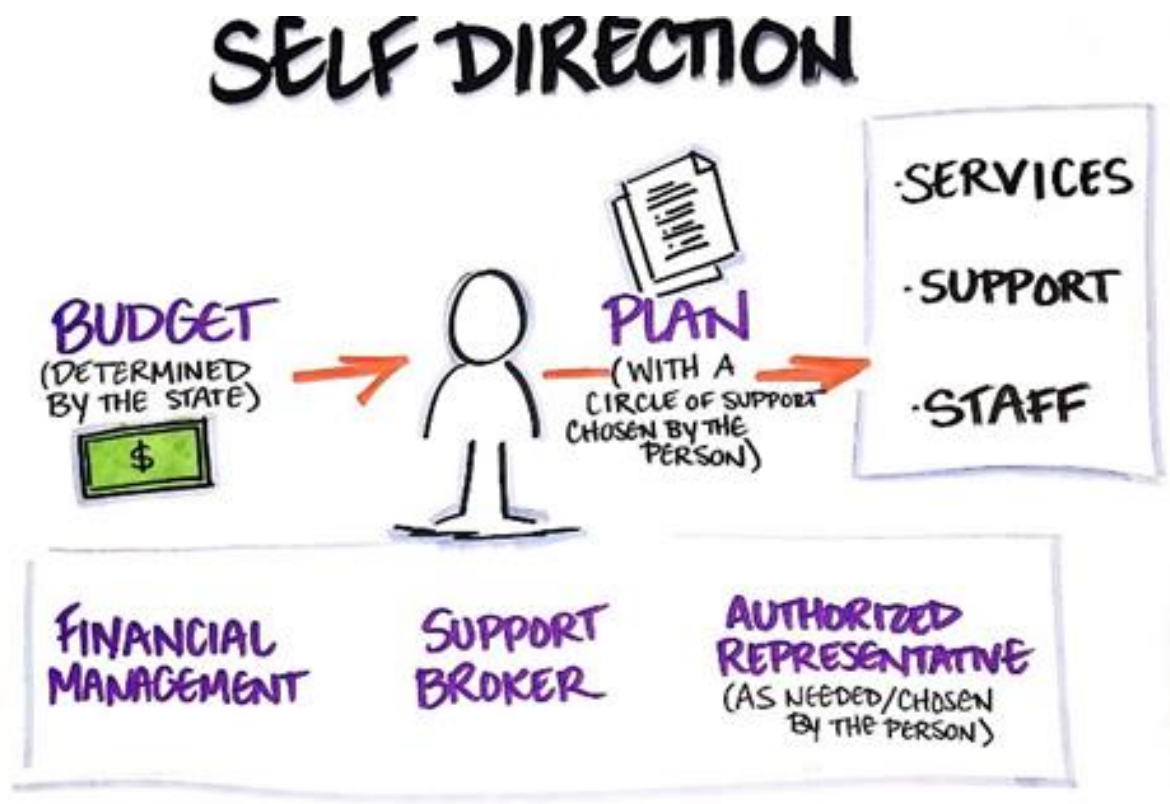
Source: Bradley, V., Fenton, M. & Mahoney, K. (2022). Self-Direction: A Revolution in Human Services. Suny University Press, p. 3.

References

[1] Murray, K., M. Morris, M. Edwards-Orr, et al. (2024) National inventory of self-directed long-term services and supports programs for the 2023 AARP LTSS state scorecard, Washington, DC: AARP Public Policy Institute.

[2] Friedman, C. (2025), Self-Direction in Medicaid Home- and Community-Based Services. J Policy Pract Intellect Disabil, 22: e12531. https://doi.org/10.1111/jppi.12531

[3] Cherry, E. Stancliffe, R.J., Emerson, E. & Ticha, R. (2021) Policy Implications, Eligibility, and Demographic Characteristics of People with Intellectual Disability Who Access Self-Directed Funding in the United States, Intellectual and Developmental Disabilities, 99(2):123-140.

[4] "Key Components of Self-Directed Services – HCBS," Centers for Medicare and Medicaid Services, www.medicaid.gov/medicaid/long-term-services-supports/downloads/hcbs-key-components.pdf. Accessed 28 Feb. 2025.

[5] "Understanding Budget Authority in Self Directed Home and Community Based Services" (2024) Division of Long Term Services and Supports, Medicaid Benefits and Health Programs Group, Centers for Medicaid and Chip Services. https://www.medicaid.gov/home-community-based-services/downloads/undrstnd-bdgt-athry-slf-drcted-hcbs-may-2024.pdf Accessed 17 Apr. 2025.

[6] Financial Management Services in Participant Direction: What are the Different Models?" National Resource Center for Participant Directed Services. https://pb.appliedselfdirection.com/api/files/xdr1oqesscyfjmm/5cwzl6zzbb9i9vp/FMS%25%32%30Models.pdf Accessed 17 Apr. 2025

[7] Self-Direction for Home and Community Based Services. Medicaid and CHIP Payment and Access Commission. https://www.macpac.gov/wp-content/uploads/2024/12/05_December-Slides_Self-Direction-for-Home-and-Community-Based-Services.pdf. Accessed 17 Apr. 2025