National Core Indicators and Self-Direction: What Do the Data Tell Us?

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Introduction

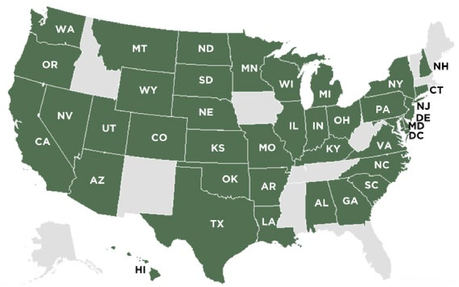
Self-Direction supports allow people with IDD to make decisions about how their services are provided including: hiring, training, supervising, scheduling, and dismissing their workers, as well as securing other goods and services.

According to the inventory of Self-Direction conducted in 2023 by Applied Self-Direction, there were 47 states with Self-Direction programs available for adults with IDD.

This brief provides an overview of data from National Core Indicators® Intellectual and Developmental Disabilities (NCI-IDD) In Person Survey (IPS) that reflects the experiences of those with IDD who use a self-directed supports option.

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.

Figure 1. Participating NCI-IDD IPS States 2024-25



Methods

The NCI-IDD IPS collects survey data on the experiences of people receiving services from their state developmental disabilities (DD) service systems. In the 2024-2025 survey cycle, 39 states administered the NCI-IDD IPS. Each state collects from people receiving case management and at least one other service. The survey is divided into 3 parts. The first part is the background section that is derived from existing records. It includes whether the individual is self-directing and options for who employs their workers:

1. Agency with choice is employer and person with IDD is co-employer
2. Person with IDD is common-law employer, fiscal intermediary (FI) functions as agent
3. Person with IDD is employer and manages all employer responsibilities

Section I of the survey can only be filled out by the individual, while section II can be filled out by the individual or a proxy. The data for this poster on experiences of Self-Direction come from the Background Section and Section II of the survey.

Results

Figure 1 shows the overall rates of self-direction among NCI-IDD respondents in the 2024-25 sample. Overall, fewer than 2 in 10 people use self-directed supports. Of the three self-direction employer models, 46% of people use agency with choice, 46% use a fiscal intermediary as their agent, and just 8% of people with IDD who self-direct manage all employer responsibilities **(Figure 2)**.

To understand the experiences of self-direction, it is important to understand who makes the decisions about the services that are self-directed. **Figure 3** shows the responses to the question of: "Who makes the decisions about the services that are self-directed?" The rates of respondents saying that someone else decides are nearly three-times higher than the rates of respondents saying that they mostly make the decisions.

Figure 1. Overall Rates of Self-Direction

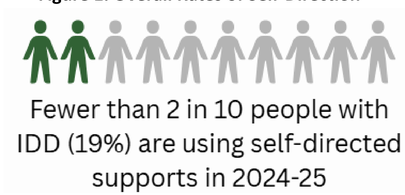


Figure 2. Self-Direction Employer Models

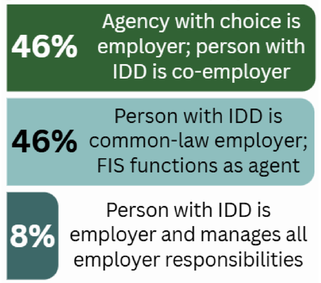
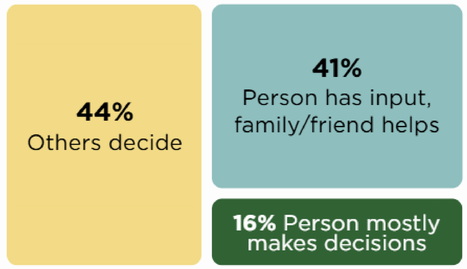


Figure 3. Who Makes Decisions About Services that are Self-Directed



Experiences with Self-Direction

Table 1 shows how people in the sample experience of Self-Direction. About 1 in 3 (34%) of respondents who are self-directing their supports need additional help with at least one area of Self-Direction. Nearly 2 in 3 (64%) of respondents say the services they want to self-direct area always available. Finally, 85% say they have the amount of control they want with services they self-direct.

Comparisons of the experiences of individuals using the Self-Direction employer model compared to those using other self-directed models and by who makes the decisions about the services that are self-directed highlight some key patterns.

Table 1. Experiences of Self-Direction		Who employs this person's support workers?			Who makes the decisions about the services that are self-directed?		
	Overall	The person manages all employer responsibilities	The person is a common-law employer; FI acts as agent	Agency with choice is employer; Person is co-employer	Person mostly makes decisions	Person has input; family/ friends help	Someone else decides
Person has at least one unmet self-direction need	34%	30%	37%	33%	42%	47%	44%
Services person wants to self-direct are always available	64%	70%	66%	64%	70%	65%	60%
Person has the amount of control they want over services that are self-directed	85%	89%	85%	82%	90%	85%	82%
			p<0.05			p<0.001	

Compared to those who use Agency with Choice or a Fiscal Intermediary, those who self-direct and manage all employer responsibilities have:

- **Significantly lower rates of unmet needs in at least one area of self-direction, and**
- **Significantly higher rates of saying they have the amount of control they want over services that are self-directed.**

Compared to those who have input or say that someone else decides, people with IDD who say that they mostly make the decisions about self-direction have:

- **Significantly higher rates of saying that the services they want to self-direct are always available, and**
- **Significantly higher rates of saying they have the amount of control they want over services that are self-directed**

Discussion

Preliminary data suggest some significant differences in self-direction experiences based on the who makes decisions about self-direction and the extent to which the person with IDD bears employer responsibilities. In short, those who have more direct control over their services, either as decision-makers or as the employer of their staff, have lower rates of unmet needs, higher rates of saying the services they want to self-direct are always available, and higher rates of saying they have the amount of control they want over the services they self-direct.

It's likely that these relationships are bidirectional. In other words, those who can more directly control their services are more likely to have better experiences, but the converse is also true. Those who advocate for any unmet needs and for the services they want may be more likely to have the skills to navigate the bureaucracy of self-direction employer models. This argues for improved resources and assistance for those considering self-direction to ensure they understand and can apply the skills necessary to both advocate for themselves and to direct their services.

Conclusions and Future Directions

It will be important going forward to conduct analyses that control for key individual characteristics to determine whether people who are not self-directing differ from those who do use self-direction. It will be important to explore any disparities or differences in both who self-directs in terms of age, racial and ethnic characteristics, and living situation including rural versus urban. Further research should also examine relationships between positive experiences of self-direction and satisfaction with case management, personal goals in the person-centered plan, and any state specific policies.

As use of self-direction continues to grow, it is essential that states can successfully monitor the quality of self-direction.

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