BARRIERS AND CATALYSTS TO SELF-DIRECTED SERVICES AND SUPPORTS FOR ADULTS WITH DISABILITIES

Results of the 2018 I/DD Provider Survey
on Self-Directed Supports and Services

Sponsored by the Spark! Initiative
an Optum Group

Developed by the National Leadership Consortium on Developmental Disabilities
of the University of Delaware

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The Spark! Initiative

Spark! Initiative, an Optum Group, is comprised of representatives of more than 25 organizations focused on developing a variety of resources for the general public to support and empower adults with intellectual and developmental disabilities to live self-directed lives. Optum developed the Spark! Initiative to bring together leaders in government, non-profits, and private sectors to discuss solutions to better support people with I/DD.

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The National Leadership Consortium on Developmental Disabilities

Leadership, Values and Vision: Transforming Lives and Organizations

The goal of the National Leadership Consortium is to assure the quality and commitment of the next generation of leaders for government and nonprofit organizations serving people with developmental disabilities. Drawing upon the experience of the principals of the Leadership Consortium in heading two of the largest disability associations nationally, the Consortium is dedicated to building a corps of quality leaders and to the promotion of sound, values-based leadership practices.

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Executive Summary

Agencies providing services to adults with intellectual and developmental disabilities (I/DD) are undergoing a decades long shift from congregated approaches toward community-based, integrated, and person-centered supports. This transformation in service delivery models has been propelled by the self-determination movement, which advocates for people with I/DD have the right to control every aspect of their lives and live with dignity. Such advocacy has influenced federal policy and allocation of funds for self-directed services through Home and Community-Based Services Medicaid waivers, which are becoming more widely utilized.

When self-directing their services, adults with I/DD exercise employer and budget authority, sometimes with the assistance from a family member, support broker, counselor, and/or a fiscal intermediary. This transfer of control from case managers, service providers, or state employees to the person with I/DD has many provider agencies struggling to adjust their services due to an array of systemic, economic, political and attitudinal barriers. Better understanding of how service agencies are navigating this shift will assist in the transition and ensure appropriate service delivery.

The *I/DD Provider Survey on Self-directed Services and Supports* investigated how providers are currently supporting adults to lead self-directed lives, and the barriers and catalysts to such supports. Responses from 475 professionals working at all levels of service provider agencies across the nation point to agency, community, and systemic factors that are hindering and helping the process of providing self-directed supports. Key findings include:

Top 3 Barriers to Providing Self-Directed Services and Supports:

1. State policies, regulations, funding and service definitions
2. Federal policies, regulations, funding and service definitions
3. Family attitudes, knowledge and involvement

Top 3 Facilitators to Providing Self-Directed Services and Supports:

1. People who receive support—their attitudes, ability and opportunity
2. Provider agency leadership or staff attitudes, beliefs and skills
3. Provider agency policies, structures and practices

Participants were asked, "If you had a magic wand and could fix ONE factor instantly, which would you fix?" Their top three answers were:

1. State policies, regulations, funding and service definitions
2. Federal policies, regulations, funding and service definitions
3. Community systems, opportunities and attitudes

Successful Strategies Associated with Agency Capacity to Deliver Self-Directed Services

- Self-direction principles and language clearly included in agency: policies and handbooks; and written service plans and goals
- Agencies providing tools and support to people with I/DD about how to manage their own service dollars and spending money
- Agencies providing tools and support to people with I/DD about how to choose their leisure activities
- Agencies providing staff formal training about how to facilitate self-directed services
- Agencies providing staff tools and support about: how to assist people with I/DD to manage their own service dollars and spending money; and how to assist people with I/DD to be truly in control of their services

Services and Supports: Where We've Been and Where We're Going

There are approximately 4.7 million people with intellectual and developmental disabilities (I/DD) in the U.S.[i]. An estimated 29% use formal I/DD services and supports. Those services utilize 76% of federal-state Medicaid spending for supports and services[ii].

Over the past several decades, there has been a significant change in the field's assumptions about how to provide quality services and supports for adults with intellectual and developmental disabilities. This change has been characterized by a shift away from the traditional models of service delivery, where supports were previously decided and managed by professionals from state and provider agencies, to services that are designed with and by the people with disabilities who choose them.

SELF-DIRECTED SERVICES
Federal Definition

The Centers for Medicare and Medicaid Services describes self-directed Medicaid services as allowing participants to, "have the responsibility for managing all aspects of service delivery in a person-centered planning process. Self-direction promotes personal choice and control over the delivery of waiver and state plan services, including who provides the services and how services are provided…Participants may also have decision-making authority over how the Medicaid funds in a budget are spent." [ix]

TRENDS IN AGING

A compounding factor influencing service trends is the enormous aging population, affecting both people with I/DD and their families. People with I/DD are aging and living considerably longer than previous generations, creating a demographic shift that challenges existing service networks to support people who are at a higher risk for developing chronic health conditions at younger ages, tend to have poor access to adequate health care, and are less likely to be employed.

Further, as the baby boom generation continues to age, many family members of people with I/DD who were previously in support roles, now need services themselves, creating even more strain on the services system. In 2011, approximately 25% of those caregivers were older than 60 while 35% were between 41 and 59; today, those numbers have increased significantly.

As the field continues to rely less on institutional services, the aging trends for both people with disabilities and their family members will have significant impacts on agency's capacity to provide individualized, self-directed services.

Medicaid waivers, a primary funding source for supports and services for people with intellectual and developmental disabilities, encourage the shift from institutional and congregate settings, such as intermediate care facilities, clinic and rehabilitative services, sheltered workshops and segregated day centers, toward more individualized and community-based services. Specifically, within the Medicaid 1115 and 1915 waivers, Home and Community Based Services (described below) are designed to enhance the growth of self-directed services. As the landscape of services for people with I/DD continues to change, the need to enhance systems and provider infrastructure to develop, transition to and sustain self-directed services is becoming more urgent.

Today, only 13% of people with I/DD receiving formal services currently live in supervised residential settings, while the remaining 87% live with a family caregiver, alone, or with a roommate [ii]. People with I/DD living in public institutions and nursing facilities with more than 16 people have decreased by almost half in the past 16 years, down from 126, 312 people to 69, 557[ii]. Yet the way services are provided has failed to keep up with the shift to more individualized supports. Ultimately, self-direction extends the control that people with intellectual and developmental disabilities have over the design and maintenance of their services, allowing for more personalized supports that are integrated into people's chosen homes and communities.

Spearheaded in the 1990's by the Robert Wood Johnson Self Determination Demonstration projects[iii], Advocacy and legislative efforts continue to push for community based and integrated support services. For instance, the Centers for Medicare and Medicaid Services' Home and Community Based Services (HCBS) waiver programs have allowed states to develop and provide non-institutional service delivery methods, as long as they remain cost-neutral[iv]. Each year, the number of HCBS waiver participants increases nationally; and over

the past two decades the number of waiver participants increased from 122,410 in 1994 to 741, 285 in 2014[iv]. In 2015, 656,195 people in the U.S. were on HCBS waiver wait lists[v]. The HCBS waiver program accounted for 70% of the nearly $50 billion funded by federal, state and local Medicaid for I/DD services in 2015[iv].

Self-direction is the premier model of HCBS service delivery for adults with intellectual and developmental disabilities. Service agency administrators, along with the people with I/DD and the families they support, repeatedly report higher satisfaction with the flexibility and individualization provided through self-directed services[vi, vii]. Further, researchers consistently find that the more individualized services are, the better quality of life outcomes people with I/DD experience[viii].

What are Self-Directed Services and Supports?

Self-directed services assure responsiveness to diverse goals and needs and support people with I/DD in environments that encourage personal autonomy and control[ix]. Self-directed service options vary widely, ranging from more limited employer authority (i.e., the ability to hire, manage, and dismiss workers such as direct support professionals) to more comprehensive models that include budget authority (i.e., the ability to have access to a flexible budget to purchase goods and services that are authorized in the individual plan of care), and not all options are offered in every state[x]. In many states, the person with I/DD receives assistance with employer and budget authority from a family member, a support broker or counselor, and/or a fiscal intermediary. Unlike traditional models, where case managers who are employees of the state or service agencies are the decision-makers, with self-direction, support brokers and other staff are employees of the participant and collaborate with them and their families to provide guidance and supports[xi].

THE SELF-DETERMINATION MOVEMENT
A Distinction of Terms

Self-Determination vs. Self-Direction

Although the policy innovations in self-direction (i.e., individual budgeting, person-centered planning, support brokerage, fiscal intermediaries, and employer authority) support individuals with disabilities to engage in self-determined behavior, self-direction and self-determination are not synonymous. The American Association on Intellectual and Developmental Disabilities describe self-determination as a right for people with disabilities to become "contributing, valued, and respected members of their communities and live lives of their own choosing." The concept of self-determination is much broader than self-direction and refers to management of all aspects of one's life, not just services.

Person-Centered Services vs. Self-Directed Services

The National Association of State Directors of Developmental Disabilities Services describes person-centered practices as "ways of planning, providing, and organizing services rooted in listening to what people want and helping them live in their communities based on their choices." Self-directed services are more specific than person-centered services in that they empower people with disabilities to have budget and employer authority. Both should be led by the desires of the person being supported, however, a service provider could deliver person-centered services without meeting the criteria of those services being self-directed.

Utilization of Self-Directed Services

Little is known about the actual utilization of self-directed services. In 2011, there were nearly 300 self-directed supports programs serving people with all types of disabilities (not limited to intellectual and developmental disabilities) in the U.S.[xii]. This figure is double the previous amount measured 10 years earlier[xiii]. The National Resource Center for Participant Directed Services at Boston College estimated that between 0 and 12% of people with disabilities utilized self-directed services in 2011[xiv]. Recent National Core Indicators results support these figures, in 2015, 10% of service users interviewed were using self-directed services[xv].

Benefits of Self-Directed Services

When people with disabilities have more control over their services, it has a profoundly positive impact on their lives. People utilizing self-directed services have been found to be less likely to experience out-of-home placement at an institution or nursing home[xvi, xvii], and report fewer unmet needs for social/recreational services, vocational services, dental care, and advocacy[xviii, xix]. Self-direction has been linked to better medication management, and better oral, dietary, and general health conditions[xx], as well as higher quality of life outcomes all around for people utilizing self-directed services compared to those in congregated settings[xxi]. People who receive self-directed services also report increases in performance toward their personal and services goals[xxii]. Finally, self-directed services also positively impact family wellbeing. For instance, families often feel empowered when transitioning from agency-directed services to individualized, flexible supports[xxiii].

SELF-DIRECTED SUPPORTS What Is The Difference?

Traditional Services and Supports	Self-Directed Services and Supports
Services are designed for people based on diagnoses and previous data collected about the person and plans written for the person. People using supports have little or no say in choosing their services	People who use services are an integral part of selecting and designing their services, based on personal goals, interests and support needs. People have authority over their services and can change their minds about which services will be provided
Services are provided for groups of people with disabilities, often with similar diagnoses	Services are provided individually
Agencies control people's schedules, money, food/ diet and personal relationships	People using services have full control over their own schedules, money, diet and personal relationships and can receive supports in any of these areas if they choose
Direct Support staff are selected by the agency and are directed and supervised by an agency superior, service plans and behavioral plans	Direct Support staff are often selected by or with the person using services, they are directed and supervised by the person using services within the boundaries of the support provided
People are supported in day habilitation or prevocational centers, sheltered workshops or enclaves. They often make below minimum wage and are required to participate in activities and work that they did not choose.	People are supported to explore, gain and maintain meaningful employment and volunteer opportunities that align with their interests and goals; for working age people the focus is on a career. Support is sometimes provided on the job with others who have gathered because of similar interests and expertise, rather than a disability label.

While the evidence in favor of self-direction is strong, information about how to best implement these services is lacking. Pressing trends to convert agencies that support people with intellectual and developmental disabilities from congregate settings to individualized, self-directed models may require additional supports for providers to transition successfully. While some provider agencies across the nation have made the switch, others struggle to deliver flexible, individualized, and person-directed services due to an array of systemic, economic, political and attitudinal barriers[xxiv]. To provide the necessary supports, better understanding of how service agencies are navigating this shift will assist in the transition to ensure effective and appropriate service delivery.

Provision of Self-Directed Services and Supports: What We Know

While research and anecdotal evidence strongly favors self-directed services[xxv], information about how to best implement these services is just beginning to emerge. The Human Services Research Institute recently conducted interviews with experts from six state developmental disabilities agencies who had significant experiences with developing self-direction options to investigate their success. The interviews were part of an evaluation of self-directed services. Interviews revealed that successful self-directed programs had: clear and simple programs with a modest number of self-direction options; clear and organized policies and procedures; self-direction specialists who were proficient in helping people decide on self-direction and then operationalize those plans; support from peer mentors and experienced family members; and additional supports for participants who did not have a large network of involved family and friends[xxvi]. Other components that are posited to influence the quality of life outcomes in self-directed services include: frontline and managerial practices that reflect values of self-direction; culture; organizational characteristics; policies and processes; sufficient resources; and external environment[xxvii].

While some provider agencies across the U.S. have successfully created or transitioned to self-directed services, others struggle to deliver flexible, individualized, and person-directed services due to an array of systemic, economic, political and attitudinal barriers[xxviii]. To provide the necessary supports, better understanding of how service agencies are navigating this shift will assist in the transition to ensure effective and appropriate service delivery. The Spark! Initiative's *I/DD Provider Survey on Self-Directed Services and Supports* sought to fill the gap in knowledge by collecting data at the provider level about the factors that hinder and facilitate self-directed services and supports.

I/DD Provider Survey on Self-Directed Services and Supports

The *I/DD Provider Survey on Self-directed Services and Supports* was initiated by the Spark! Initiative, an Optum Group, which is comprised of representatives of more than 25 organizations focused on developing a variety of resources and strategies to address barriers and support a national shift towards self-directed services and supports. Optum developed the Spark! Initiative to bring together leaders in government, non-profits, and private sectors to discuss solutions to better support people with I/DD. Out of the initial Spark! Initiative, a workgroup identified the need to better understand the supports and barriers that agencies providing services to people with I/DD face today. To address this, Optum funded a research team from the National Leadership Consortium on Developmental Disabilities at the University of Delaware to develop and disseminate a national survey of service providers to better understand how providers are currently supporting adults to lead self-directed lives and the barriers and catalysts to such supports.

SELF-DIRECTED SERVICES
As Defined in this Project

Individualized self-directed services for this project are defined as "those in which adults with intellectual/ developmental disabilities are in charge of decisions affecting their lives, including control over: their budget and spending decisions, where they live, who (if anyone) they live with, the agency and people who facilitate and deliver their services, their interests and goals, their schedule, the kind of work they do, what they do for fun, what/when they eat, how and with whom they spend their time, etc. People who receive Individualized Self-Directed Services do not need to live alone but they must manage their supports and have control over their own lives with the supports they want/need to be successful."

Project Overview

Goals of this survey: The goals of this survey are to support the field's overall understanding about self-directed service provision across the U.S. Specifically, the *I/DD Provider Survey on Self-Directed Services and Supports* was designed to enhance knowledge about:

- The characteristics and approaches at the program and agency level that lead to successful implementation of self-directed supports
- Barriers that exist to providing individualized supports at the program and agency level
- The relationship between types of services (community living, residential, supported living, day and employment support, case management, resource coordination, and support brokering) and successful implementation individualized supports
- The relationship between types of services (community living, residential, supported living, day and employment support, case management, resource coordination, and support brokering) and barriers to implementing individualized supports
- Supports that are needed at the agency level to successfully implement self-directed supports

The survey was designed by researchers at the National Leadership Consortium after conducting a literature review to better understand how self-directed services and supports have been evaluated to date. Specifically, the literature review focused on national and local research to better understand the internal and external factors that have been measured regarding self-directed services and supports. The survey was designed to supplement recent research and included questions about barriers and facilitators to self-direction, agency practices of self-direction, and individual values about self-direction. Responders were asked to rank barriers and facilitators to better understand what holds agencies back from or assists them in providing self-directed services. They were also asked to share agency practices and values around self-direction, to better understand how agencies operate to provide self-directed services and supports. The table below outlines the types of questions asked.

Survey Focus	Focus of Indicators
Barriers and Facilitators to Self-Direction	Federal policies, regulations, funding and service definitions
	State policies, regulations, funding and service definitions
	Managed Care Organizations' policies, structures and practices
	Community systems, opportunities and attitudes
	Board of Directors' attitudes, tradition and leadership
	Service Coordination/Case Management attitudes and processes
	Provider agency policies, structures and practices
	Provider agency leadership or staff attitudes, beliefs and skills
	Family attitudes, knowledge and involvement
	People who receive support – their attitudes, ability and opportunity
Agency Practices of Self-Direction	Language (*written policies, vision/mission statement, job descriptions, service plans/goals, online marketing materials/website, quality monitoring processes)*
	Support (*board of directors, executive director/CEO, managers/supervisors)*
	Staff Training *(to assist people with I/DD to be in control of their service dollars, services, work, leisure activities)*
	Training of People Supported *(to be in control of their services dollars, services, work, leisure activities)*
Values about Self-Direction	Opinions and ideas about the best types of services for people with disabilities
	Opinions and ideas about the choice and control that people with disabilities should have over their lives
	Opinions and ideas about the capacity of people with disabilities to self- direct

Pilot Survey

A pilot survey was conducted to evaluate the content and style of the initial survey designed by the research team with input from the Spark! team. Twenty-five potential pilot participants were contacted to give feedback about the initial survey draft. Potential pilot participants were identified experts in the field and selected from a pool of professionals who had previously worked with the National Leadership Consortium or Spark! team. The pilot participants matched the target population from the survey in that they were from provider agencies that were dispersed among the different regions of the U.S, provided a variety of services, and were of all sizes.

Potential pilot participants were sent requests to be part of the pilot group via email in early March, with nine participants confirming that they would participate. All 25 potential pilot participants were emailed the pilot survey with instructions in mid-March. Pilot participants were given approximately three weeks to review the survey. During the review process, two additional pilot participants were added at the recommendation of other pilot participants. Ultimately, feedback was received from 13 pilot participants. Feedback came in the form of written comments throughout the pilot survey, written comments on an additional comment sheet given to pilot participants, and through an online meeting with pilot participants on April 4. Based on feedback received and in consultation with the Spark! team on April 12, minor revisions were made to the pilot survey to eliminate some repetitive questions, revise the format of some questions and the survey title, and correct survey skip pattern issues.

Survey Recruitment and Methodology

Potential survey respondents were recruited through the 17 national partners of the National Leadership Consortium, most[1] of the Spark! group members and the National Leadership Consortium listserv that includes more than 2,000 graduates, faculty and partners of the Leadership Consortium training and development programs. The web-based survey was distributed nationally via email, organizational websites, and social media with the hopes of attracting service providers from across the country.

For this initial survey, purposive and snowball sampling was employed to gather as many responses as possible who fit the criteria for responding (respondents had to be working for an agency that directly provides services to adults with I/DD). Although these sampling methods have important implications for the representativeness of survey results, researchers and the Spark! team determined that the initial goal of the survey was to develop a better understanding of the barriers and catalysts to self-directed services from as many professionals as possible. We recommend that future surveys recruit a random selection of a nationally recommended sample to validate the results found in this project.

Throughout the recruitment process, National Leadership Consortium researchers reviewed the distribution of responding agencies regionally and by service type. In areas where response rates were lower, researchers conducted an online search of direct service agencies and state provider associations. When possible, contact information was collected, and the survey was sent directly to agencies in areas that were underrepresented.

The online survey was distributed and opened on April 16, 2018 and remained open until July 31, 2018, during which time data was collected. The survey was open for a total of 106 days. Recruitment materials were developed for each partnering organization and partners were asked to distribute and remind their listservs several times over the course of the three months. Further, the National Leadership Consortium distributed the survey and sent six reminders periodically to encourage potential responders. Finally, the survey was advertised through the American Association of Intellectual and Developmental Disabilities (AAIDD) annual conference,

[1] One Spark! member did not distribute the survey due to a potential conflict of interest.

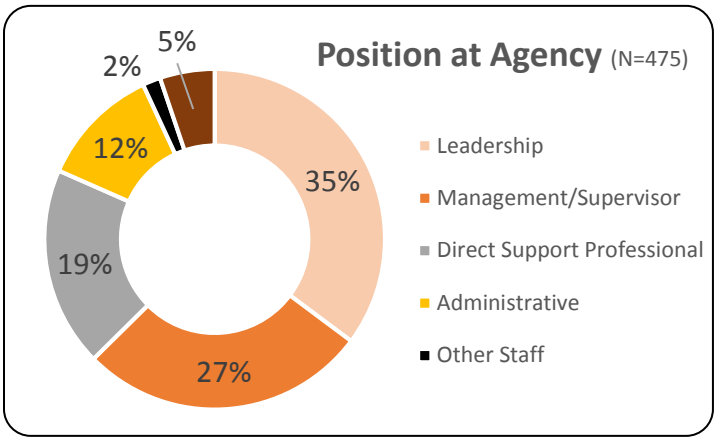
the Arc NCE Summer Leadership Institute and the Reinventing Quality conferences. We estimate that more than 12,000 potential responders received the survey between April and July.

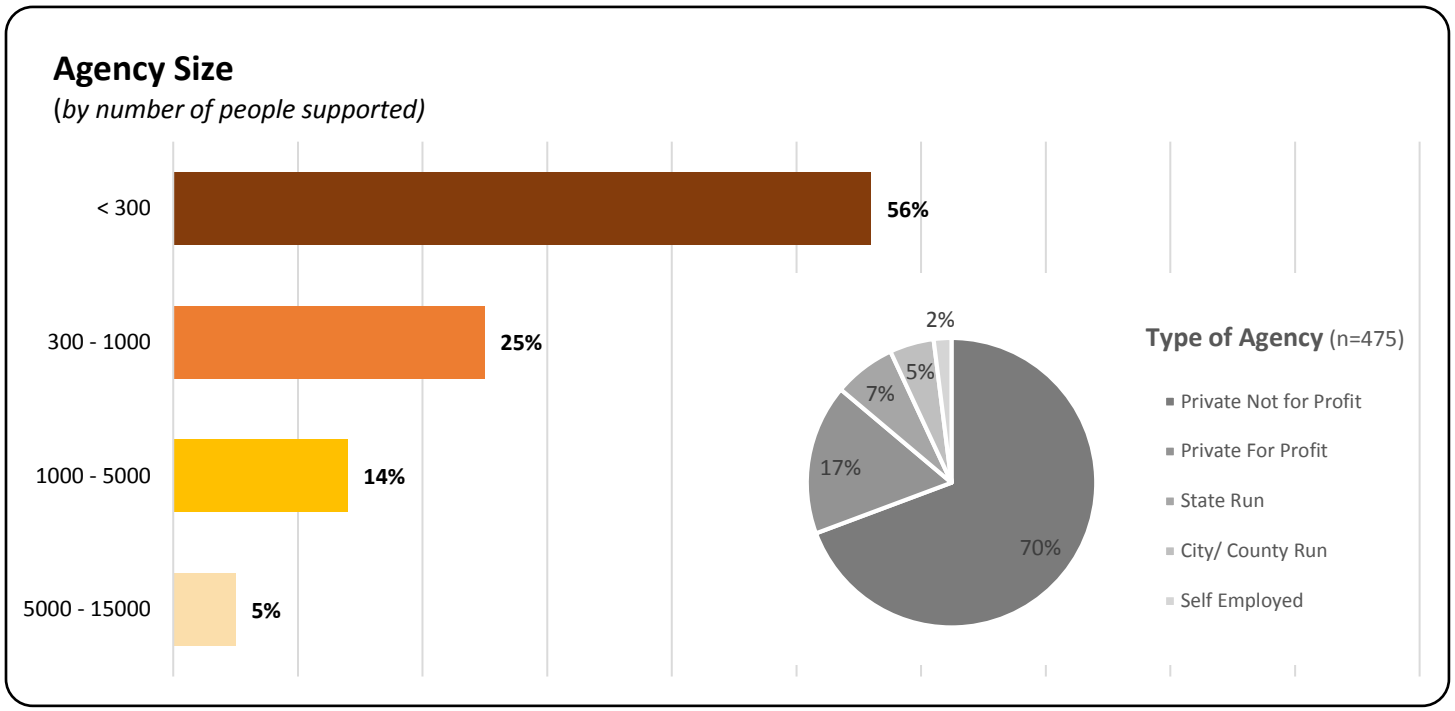
Survey Respondents

A total of 1,119 potential respondents opened the survey. Seventy-eight (78) respondents were diverted from completing the survey because they did not work for agencies that directly provide services to adults with I/DD. Eleven (11) respondents were excluded because they did not work in the U.S., and 555 respondents were excluded because they did not meet the minimum criteria for completion of the survey (i.e., completing enough of the survey to provide sufficient information about the main purpose of the survey; identified barriers to self-directed service delivery). Ultimately, the data from 475 respondents met the minimum criteria for the completion of the survey and were included in the analysis for this project.

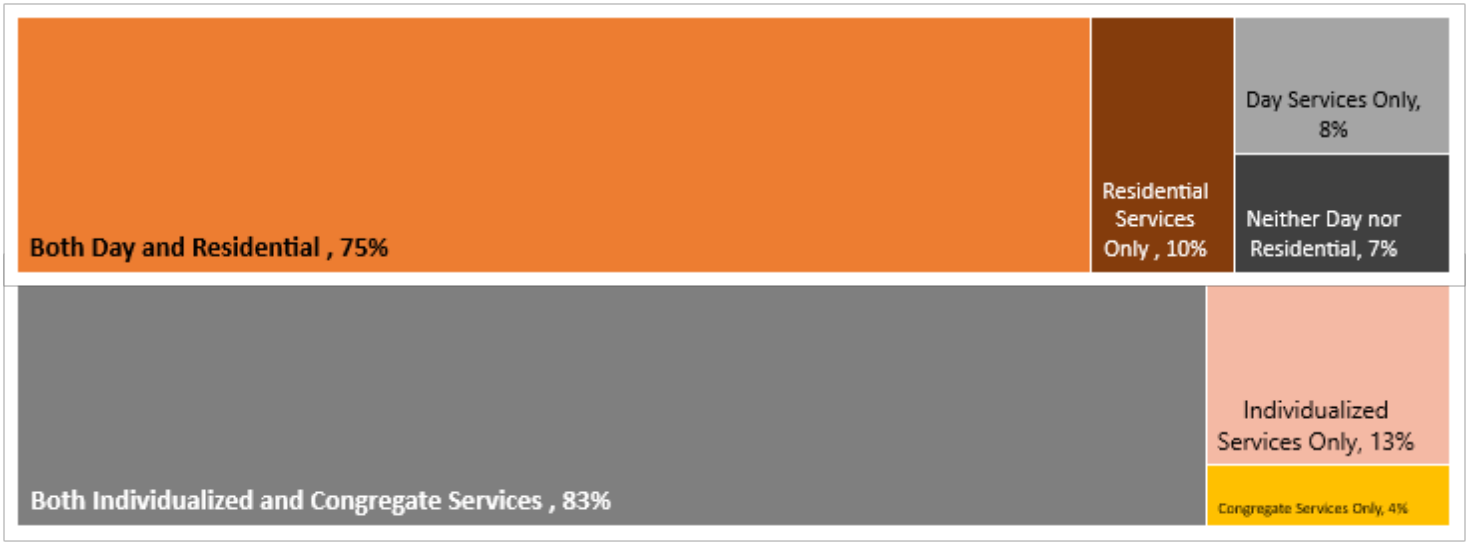
Respondents occupy various levels of positions at their agencies; many hold leadership and management/ supervisory positions (35% and 27% respectively). A substantial proportion of respondents are also Direct Support Professionals (19%). There was a large range of titles reported, including Regional Executive Director, Nurse, Quality Enhancement Specialist, Program Manager, Habilitative Specialist, and Direct Support Specialist, to name a few.

Respondents' agencies represent various sizes and types of services. More than half of respondents (56%) work at agencies that support less than 300 people, 93% support less than 3,000. Most respondents described their agency as a private not-for-profit (70%).

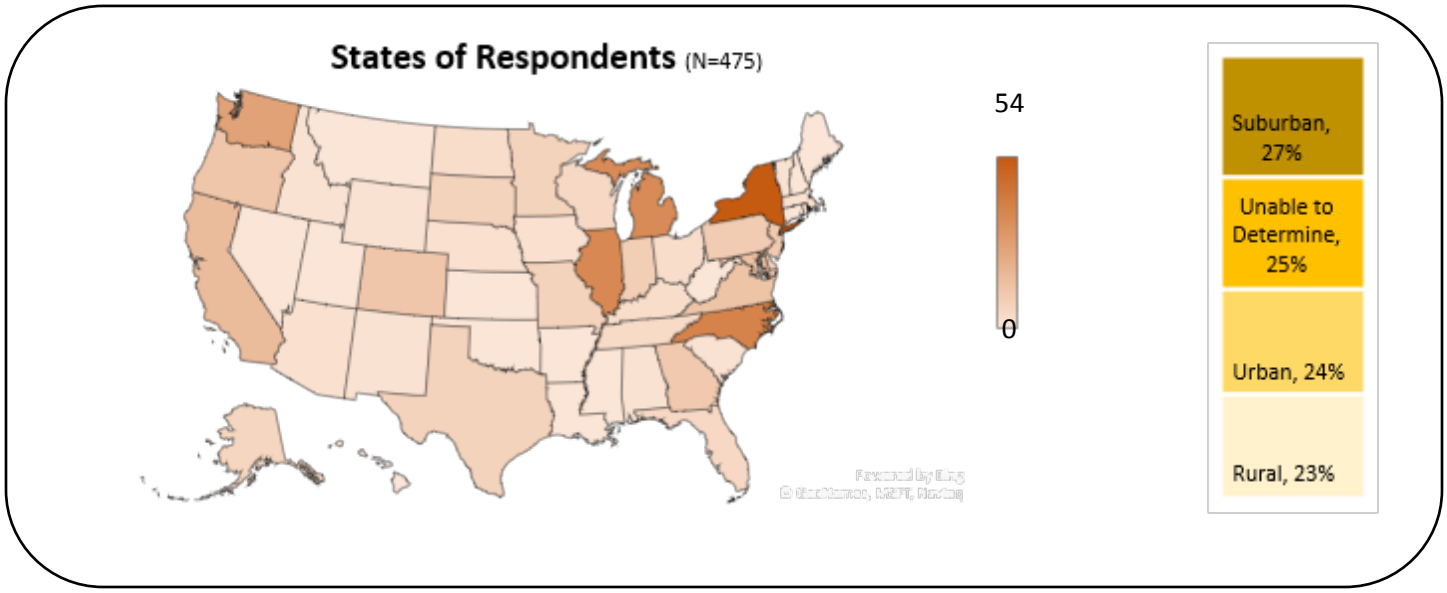




Nearly 75% of respondents work at agencies that provided both day services (i.e., center-based day programs, day habilitation, and pre-vocational support) and residential services (i.e., ICF/facilities and group homes). Of the other respondents, 8% work at agencies that provided day services only, 10% at agencies that provided residential services only, and 7% provide neither day nor residential services. Most agencies directly providing services (day and residential) provide both congregate and individualized services (83%); 4% provide only congregate services and 13% provide only individualized services. Because such a large portion of respondents provided services in both individual and congregate settings, and both day and residential settings, no comparisons could be made across these groups about how the type of services of an agency provided related to other factors examined in the survey.



Respondents from 37 states participated in the survey, representing a relatively even regional distribution. Nearly 4% work for agencies that supported people in multiple states.

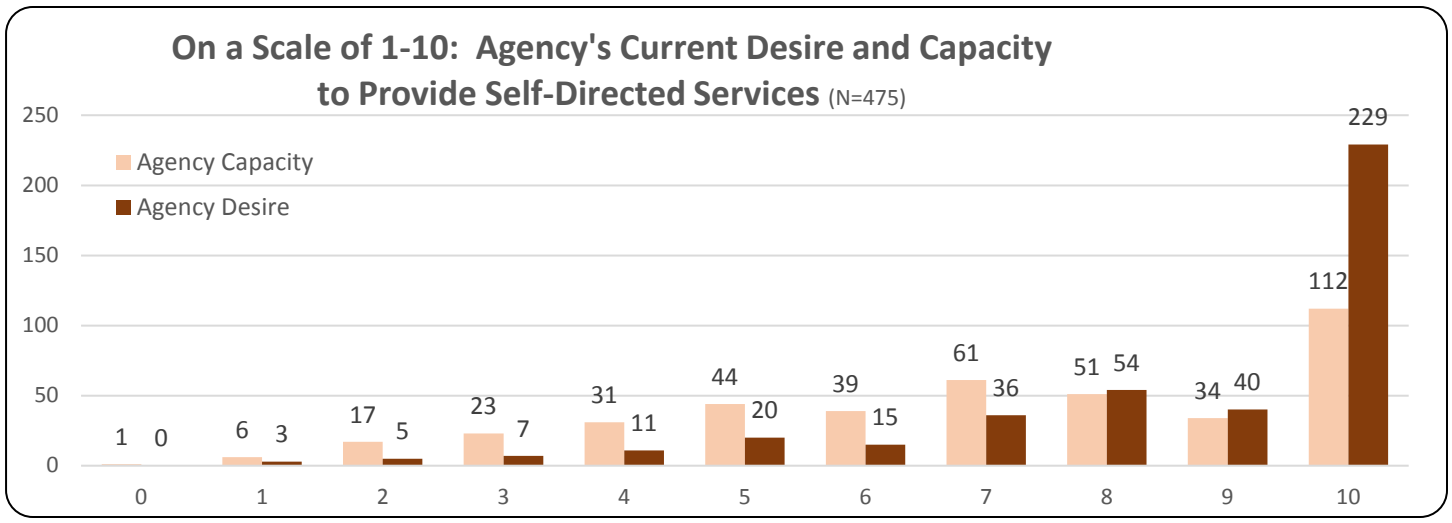


Northeast | 20%	Midwest | 30%	South | 27%	West | 20%
Massachusetts, Vermont, New Jersey, New York, Pennsylvania	Illinois, Indiana, Michigan, Ohio, Wisconsin, Iowa, Minnesota, Missouri, Nebraska, North Dakota, South Dakota	Delaware, Florida, Georgia, Maryland, North Carolina, South Carolina, Virginia, Alabama, Kentucky, Tennessee, Texas	Arizona, Colorado, Idaho, New Mexico, Wyoming, Alaska, California, Oregon, Washington

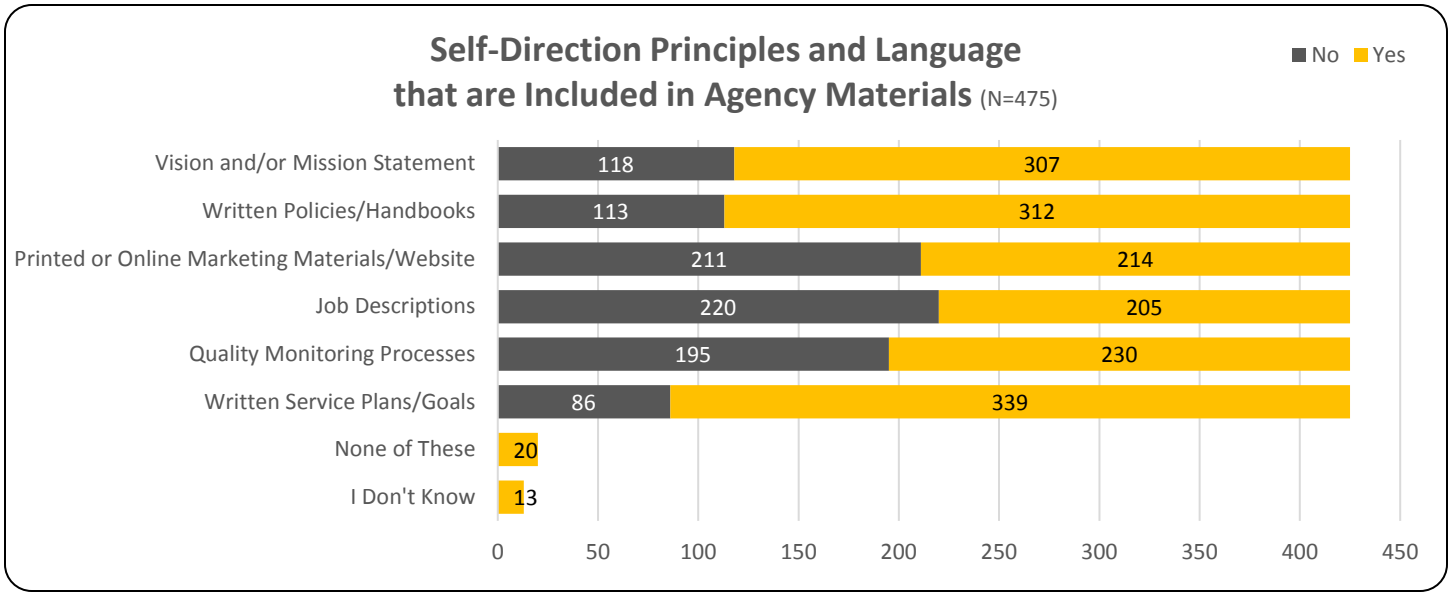
A National Overview of Agency Practices Related to Self-Directed Services

To best understand the origins of the selected barriers and facilitators to self-direction, the survey included questions about agency motivation and capacity for self-directed services, desire to implement self-directed services, and agency practices. There is substantial evidence to support the need for alignment across agency values and practices to ensure implementation of quality individualized services[xxix]. Results from this study show that the same is true for respondents of this survey.

Agency Desire and Capacity to Deliver Self-Directed Services | It is clear that while most agencies are motivated to provide self-directed services, barriers to providing them hinder agencies in actual practice. Nearly 55% of respondents rated their agency's desire to deliver self-directed services at the highest rating (10 out of 10); while only 27% rated current capacity of their agency to provide self-directed services at the same level.

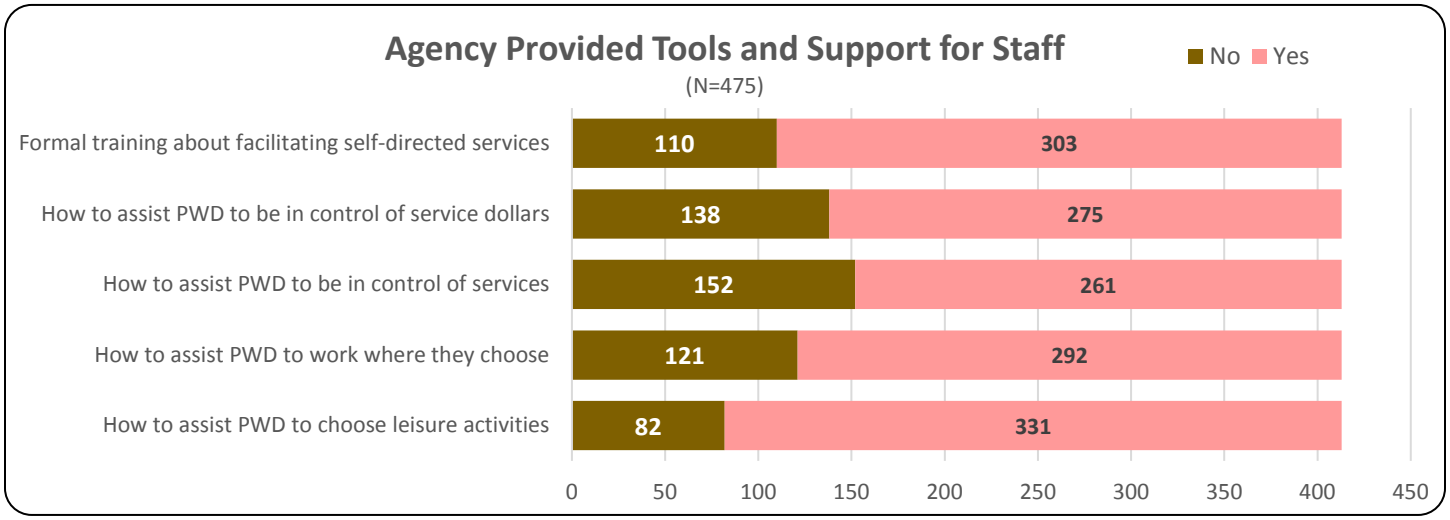


Agency Self-Direction Practices | This study examined how principles and language of self-direction were incorporated into an agency's written materials and practices as researchers have found that this can have a significant impact on agencies' capacity to provide person centered services. Almost all agencies included language and principles of self-direction in their materials (91%). The materials that were most likely to include principles and language regarding self-direction included: Written Service Plans (80%), Written Policies and Handbooks (73%) and Quality Monitoring Processes (54%).

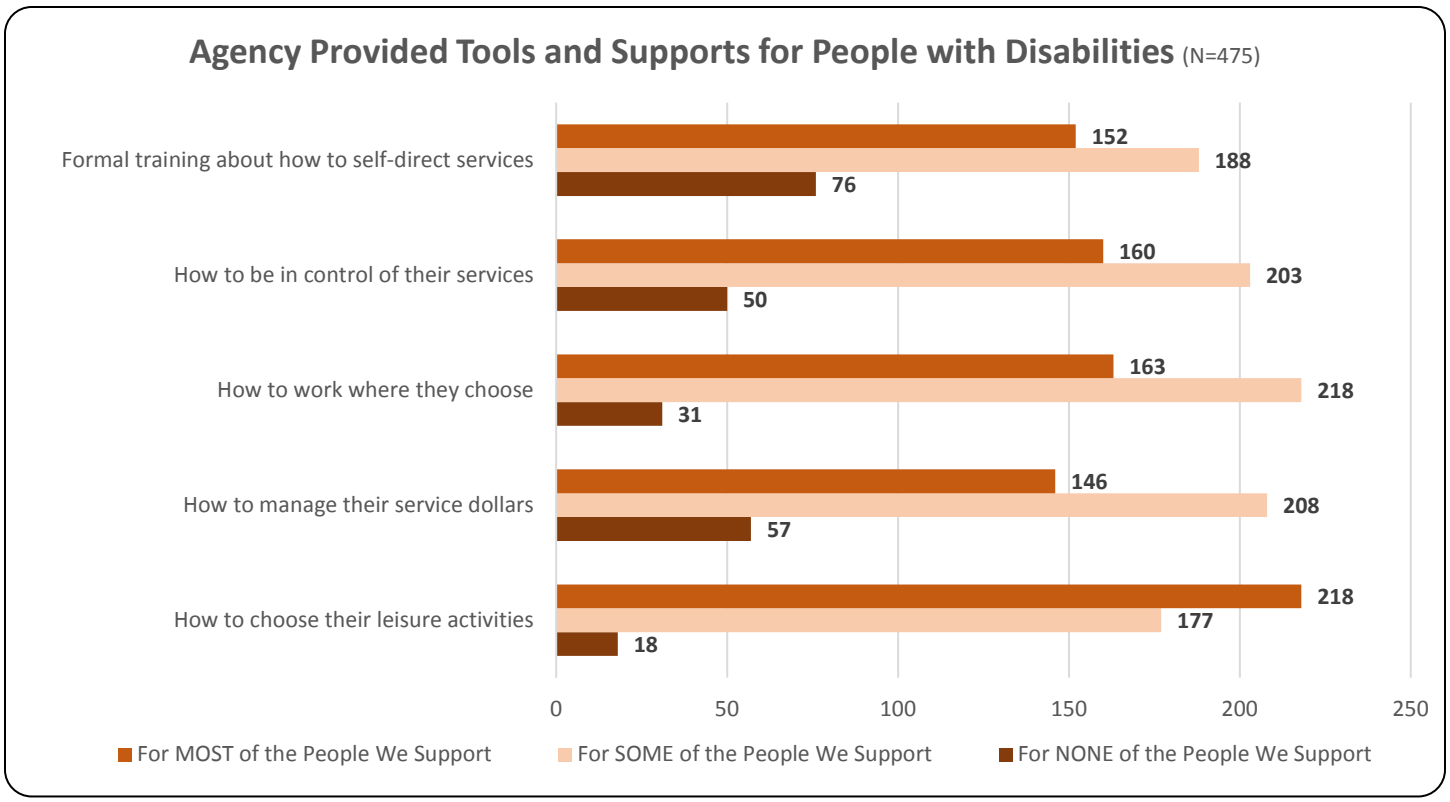


The majority of responders (97%) reported that their agency provides staff support so that they have the training, skills and tools needed to provide self-directed services. The most common support was in the form of: formal training about facilitating self-directed services (73%), as well as tools and support about how to assist people with leisure activities (80%), self-directed employment (71%) and managing their own budgets (67%).

Similarly, 99% of agencies reported that they provide tools and support to all or some people they serve to



assure that people are truly directing their services. The most frequent supports provided to some or all include choosing leisure activities (96%) self-directing employment (90%) and managing personal budgets (90%).

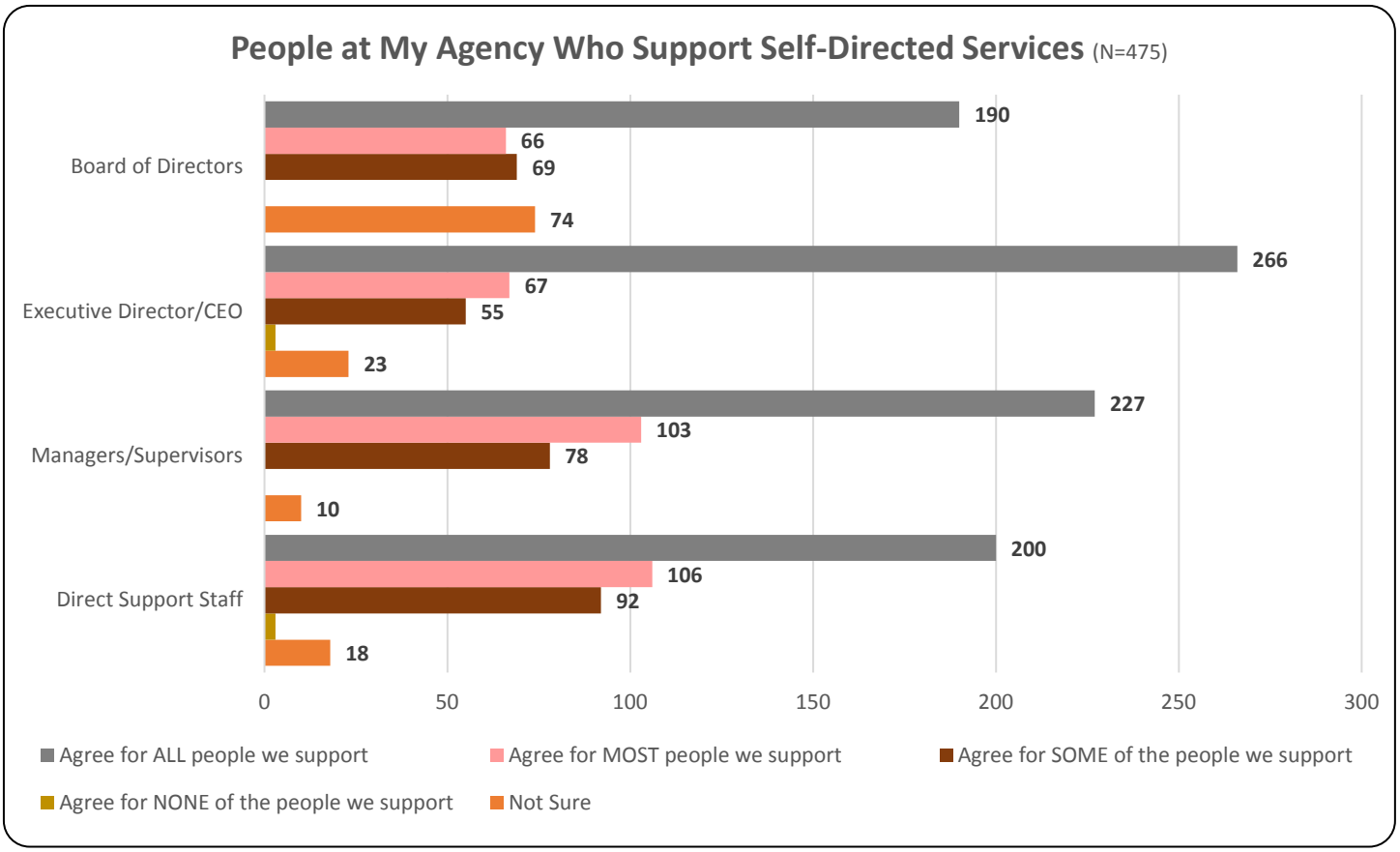


However, agencies failed to provide formal training about how to self-direct to 18% of the people they support and did not provide tools and supports to 14% of them about how to manage their own service dollars and spending money. Further, as the chart above shows, in all categories but leisure activities support, most

respondents shared that they provide support to *some* of the people they serve (instead of *most*) indicating that there are differences in the individualization of services that certain people receive. This may align with the findings that all or most agencies provide both congregate and individualized services.

Attitudes and Beliefs about Self-Direction | The survey explored the attitudes and beliefs about the appropriateness of self-directed services to better understand how professionals at various agency levels viewed them. These questions were designed to explore the alignment of beliefs with self-direction, as researchers have found that the attitudes and beliefs of employees have a significant impact on agency practices[xxx].

First, responders were asked to rank the level of supportiveness towards self-directed services from people at various positions at their agency. Many people indicated strong support for self-direction for *all* across agency stakeholders, the charts and tables below show the distribution.

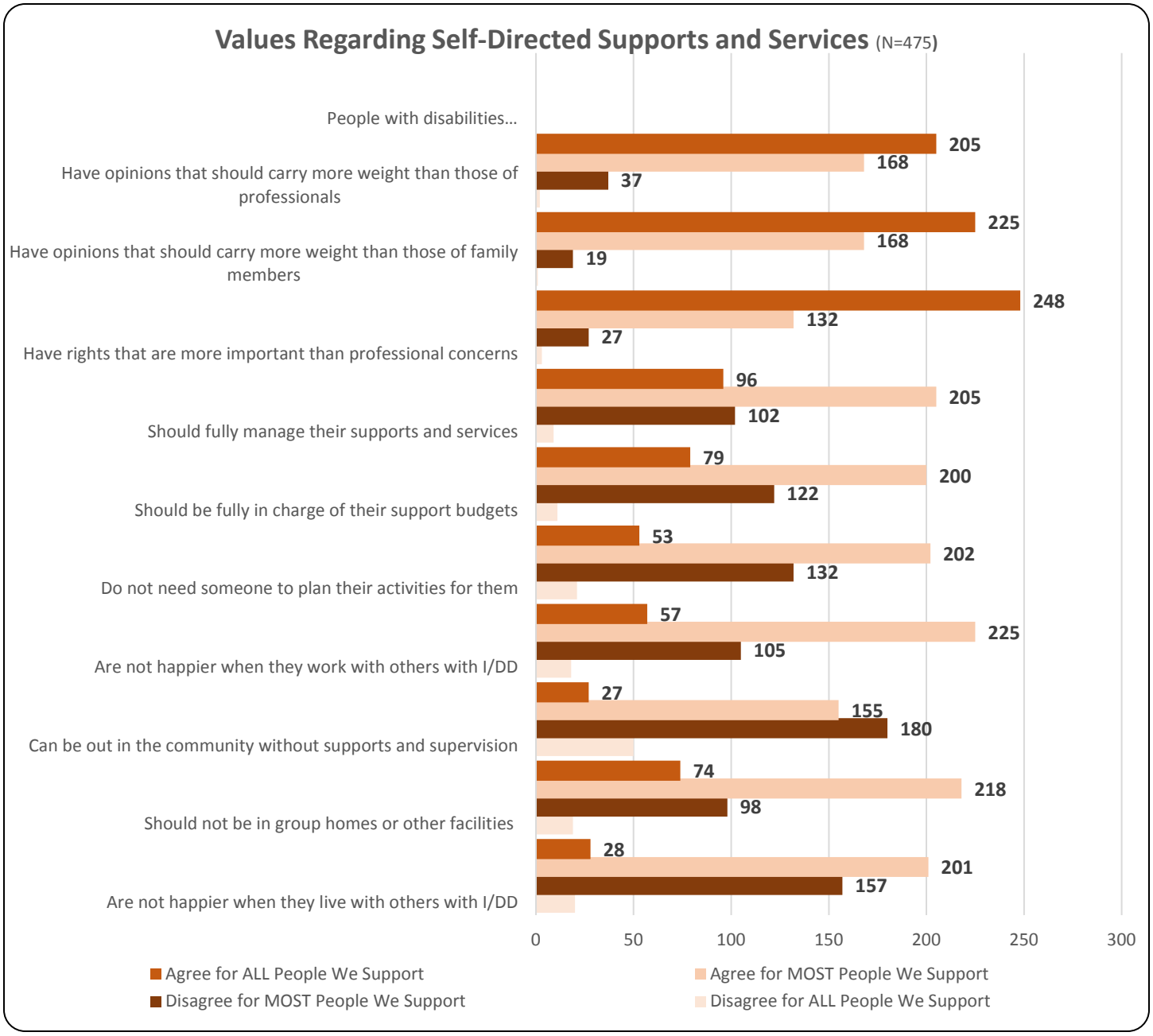


Position	Agree for All People Agency Supports	Agree for Some People Agency Supports
Board of Directors	54%	17%
Executive Director/ CEO	48%	13%
Managers/ Supervisors	54%	19%
Direct Support Professionals	48%	22%

Survey responders were then asked to share their own personal beliefs and attitudes about how people with disabilities are best supported. Questions focused on areas related to self-direction, including autonomy, choice, control and individualization of services. The majority of respondents agree that overall, *all* people with I/DD that they support have rights that are more important that professional concerns (61%), have opinions that

should carry more weight than those of family members (55%), and have opinions that should carry more weight than those of professionals (50%). However, when asked more detailed questions about whether people with disabilities should manage their services and budgets, living situations, activities, and work, respondents were more likely to agree only for *most* people their agencies support.

These differences in responses speak to the adoption of self-directed principles in theory and practice. While many people in the I/DD services field today agree that people should have control over their own services and lives, many agencies struggle to assure that services models and practices align with principles of self-direction for all people they support.



Barriers and Facilitators to Providing Self-Directed Services and Supports

Participants were asked to rank the top three most impactful barriers and facilitators to providing self-directed services out of a list of 10 barriers and facilitators (the same factors were used for each). They included:

- Federal policies, regulations, funding and service definitions ranked as number two
- State policies, regulations, funding and service definitions ranked as number two
- Managed Care Organizations' policies, structures and practices ranked as number two
- Community systems, opportunities and attitudes ranked as number two
- Board of Directors' attitudes, tradition and leadership ranked as number two
- Service Coordination/Case Management attitudes and processes ranked as number two
- Provider agency policies, structures and practices ranked as number two
- Provider agency leadership or staff attitudes, beliefs and skills ranked as number two
- Family attitudes, knowledge and involvement ranked as number two
- People who receive support – their attitudes, ability and opportunity ranked as number two

Because participants worked at agencies that delivered various services, responses were grouped according to service delivery types (i.e., advocacy, case management/support/resource coordination, center-based day programs, community-based day support, day habilitation, family support services, healthcare, ICF/facilities, pre-vocational support, residential/group homes, respite services, shared living/host homes/adult foster care, services in family home, services in individual home, support brokering, sheltered workshops, and supported employment) to investigate if professionals working in diverse domains of service delivery experienced different obstacles and facilitators to providing self-directed services and supports.

Overwhelmingly, *State and federal policies, regulations, funding and service definitions* were ranked top two selections as the "Most Impactful Barriers," with *Family attitudes, knowledge and involvement* sharing the third most popular "Most Impactful Barrier" designation with *Provider agency leadership or staff attitudes, beliefs and skills* (selected third by those providing sheltered workshops) and *Service coordination/case management attitudes and processes* (selected third by those providing shared living/host homes/adult foster care). For the "Most Impactful Facilitator," most respondents selected *People who receive support—their attitudes, ability and opportunity* as their first choice, with the exception of those working in advocacy, healthcare, and shared living/host homes/adult foster care who selected *Provider agency leadership or staff attitudes, beliefs and skills* as their top choice. The tables on the following pages outline the top three barriers and facilitators by services type.

Services	Rank	Most Impactful Barrier	Second Most Impactful Barrier	Third Most Impactful Barrier
Advocacy	1	State policies, regulations, funding and service definitions (32%)	State policies, regulations, funding and service definitions (28%)	Family attitudes, knowledge and involvement (23%)
	2	Federal policies, regulations, funding and service definitions (20%)	Family attitudes, knowledge and involvement (23%)	Community systems, opportunities and attitudes (15%)
	3	Family attitudes, knowledge and involvement (14%)	Federal policies, regulations, funding and service definitions AND Community systems, opportunities and attitudes (13%)	Managed Care Organizations' Policies, structures and practices (10%)
Case Management/ Support/ Resource Coordination	1	State policies, regulations, funding and service definitions (31%)	State policies, regulations, funding and service definitions (28%)	Community systems, opportunities and attitudes (22%)
	2	Federal policies, regulations, funding and service definitions (21%)	Family attitudes, knowledge and involvement (21%)	Family attitudes, knowledge and involvement (21%)
	3	Family attitudes, knowledge and involvement (14%)	Community systems, opportunities and attitudes (12%)	Provider agency leadership or staff attitudes, beliefs and skills (10%)
Center-Based Day Programs	1	State policies, regulations, funding and service definitions (32%)	State policies, regulations, funding and service definitions (24%)	Family attitudes, knowledge and involvement (18%)
	2	Federal policies, regulations, funding and service definitions (19%)	Family attitudes, knowledge and involvement (20%)	Community systems, opportunities and attitudes AND Federal policies, regulations, funding and service definitions (14%)
	3	Family attitudes, knowledge and involvement (16%)	Community systems, opportunities and attitudes (13%)	Provider agency leadership or staff attitudes, beliefs and skills (11%)
Community-Based Day Support	1	State policies, regulations, funding and service definitions (31%)	State policies, regulations, funding and service definitions (26%)	Community systems, opportunities and attitudes (18%)
	2	Federal policies, regulations, funding and service definitions (20%)	Family attitudes, knowledge and involvement (21%)	Family attitudes, knowledge and involvement (17%)
	3	Family attitudes, knowledge and involvement (17%)	Community systems, opportunities and attitudes (13%)	Federal policies, regulations, funding and service definitions (12%)
Day Habilitation	1	State policies, regulations, funding and service definitions (26%)	State policies, regulations, funding and service definitions (31%)	Family attitudes, knowledge and involvement (18%)
	2	Federal policies, regulations, funding and service definitions (26%)	Family attitudes, knowledge and involvement (16%)	Community systems, opportunities and attitudes (14%)
	3	Family attitudes, knowledge and involvement (15%)	Federal policies, regulations, funding and service definitions (10%)	Federal policies, regulations, funding and service definitions (12%)
	1	State policies, regulations, funding and service definitions (35%)	State policies, regulations, funding and service definitions (35%)	Community systems, opportunities and attitudes (20%)

Family Support Services	2	Federal policies, regulations, funding and service definitions (20%)	Family attitudes, knowledge and involvement (19%)	Family attitudes, knowledge and involvement (19%)
	3	Family attitudes, knowledge and involvement (14%)	Federal policies, regulations, funding and service definitions AND Community systems, opportunities and attitudes (12%)	Federal policies, regulations, funding and service definitions (11%)
Healthcare	1	State policies, regulations, funding and service definitions (24%)	State policies, regulations, funding and service definitions (27%)	Community systems, opportunities and attitudes (21%)
	2	Federal policies, regulations, funding and service definitions (21%)	Family attitudes, knowledge and involvement (21%)	Provider agency leadership or staff attitudes, beliefs and skills (16%)
	3	Family attitudes, knowledge and involvement (19%)	Community systems, opportunities and attitudes (11%)	Family attitudes, knowledge and involvement (12%)
ICF/Facilities	1	Federal policies, regulations, funding and service definitions AND State policies, regulations, funding and service definitions (28%)	State policies, regulations, funding and service definitions (26%)	Community systems, opportunities and attitudes AND Provider agency leadership or staff attitudes, beliefs and skills AND Family attitudes, knowledge and involvement (17%)
	2	Provider agency leadership or staff attitudes, beliefs and skills (13%)	Family attitudes, knowledge and involvement (17%)	People who receive support--their attitudes, ability and opportunity (15%)
	3	Family attitudes, knowledge and involvement (11%)	Federal policies, regulations, funding and service definitions AND Community systems, opportunities and attitudes (11%)	Federal policies, regulations, funding and service definitions AND Provider agency leadership or staff attitudes, beliefs and skills (10%)
Pre-Vocational Support	1	State policies, regulations, funding and service definitions (33%)	State policies, regulations, funding and service definitions (24%)	Community systems, opportunities and attitudes (19%)
	2	Federal policies, regulations, funding and service definitions (20%)	Community systems, opportunities and attitudes (13%)	Family attitudes, knowledge and involvement (18%)
	3	Family attitudes, knowledge and involvement (17%)	Federal policies, regulations, funding and service definitions (10%)	Provider agency policies, structures and practices AND Federal policies, regulations, funding and service definitions (13%)
Residential/Group Homes	1	State policies, regulations, funding and service definitions (34%)	State policies, regulations, funding and service definitions (26%)	Family attitudes, knowledge and involvement (21%)
	2	Federal policies, regulations, funding and service definitions (21%)	Family attitudes, knowledge and involvement (17%)	Community systems, opportunities and attitudes (17%)
	3	Family attitudes, knowledge and involvement (16%)	Community systems, opportunities and attitudes (11%)	Federal policies, regulations, funding and service definitions (12%)

Respite Services	1	State policies, regulations, funding and service definitions (33%)	State policies, regulations, funding and service definitions (23%)	Community systems, opportunities and attitudes AND Family attitudes, knowledge and involvement (18%)
	2	Federal policies, regulations, funding and service definitions (20%)	Family attitudes, knowledge and involvement (19%)	Federal policies, regulations, funding and service definitions (12%)
	3	Family attitudes, knowledge and involvement (17%)	Community systems, opportunities and attitudes (14%)	Provider agency policies, structures and practices (11%)
Shared Living/Host Homes/ Adult Foster Care	1	State policies, regulations, funding and service definitions (35%)	Family attitudes, knowledge and involvement (22%)	Community systems, opportunities and attitudes AND Family attitudes, knowledge and involvement (18%)
	2	Federal policies, regulations, funding and service definitions (20%)	State policies, regulations, funding and service definitions (21%)	Federal policies, regulations, funding and service definitions AND State policies, regulations, funding and service definitions AND Provider agency policies, structures and practices (10%)
	3	Service Coordination/Case Management attitudes and processes AND Family attitudes, knowledge and involvement (10%)	Federal policies, regulations, funding and service definitions (14%)	Managed Care Organizations' Policies, structures and practices (9%)
Services in Family Home	1	State policies, regulations, funding and service definitions (32%)	State policies, regulations, funding and service definitions (25%)	Family attitudes, knowledge and involvement (21%)
	2	Federal policies, regulations, funding and service definitions (19%)	Family attitudes, knowledge and involvement (18%)	Community systems, opportunities and attitudes (20%)
	3	Family attitudes, knowledge and involvement (18%)	Community systems, opportunities and attitudes (13%)	Federal policies, regulations, funding and service definitions (12%)
Services in Individual Home	1	State policies, regulations, funding and service definitions (34%)	State policies, regulations, funding and service definitions (24%)	Family attitudes, knowledge and involvement (21%)
	2	Federal policies, regulations, funding and service definitions (20%)	Family attitudes, knowledge and involvement (21%)	Community systems, opportunities and attitudes (19%)
	3	Family attitudes, knowledge and involvement (16%)	Community systems, opportunities and attitudes (13%)	Federal policies, regulations, funding and service definitions (11%)
Support Brokering	1	State policies, regulations, funding and service definitions (30%)	State policies, regulations, funding and service definitions (30%)	Family attitudes, knowledge and involvement (22%)
	2	Federal policies, regulations, funding and service definitions (18%)	Family attitudes, knowledge and involvement (21%)	Federal policies, regulations, funding and service definitions AND

				Community systems, opportunities and attitudes (15%)
	3	Family attitudes, knowledge and involvement (16%)	Community systems, opportunities and attitudes (11%)	State policies, regulations, funding and service definitions (12%)
Sheltered Workshops	1	State policies, regulations, funding and service definitions (28%)	State policies, regulations, funding and service definitions AND Family attitudes, knowledge and involvement (21%)	Community systems, opportunities and attitudes (22%)
	2	Federal policies, regulations, funding and service definitions (16%)	Community systems, opportunities and attitudes (14%)	Family attitudes, knowledge and involvement (18%)
	3	Family attitudes, knowledge and involvement AND Provider agency leadership or staff attitudes, beliefs and skills (12%)	Provider agency leadership or staff attitudes, beliefs and skills (12%)	Provider agency policies, structures and practices (11%)
Supported Employment	1	State policies, regulations, funding and service definitions (33%)	State policies, regulations, funding and service definitions AND Family attitudes, knowledge and involvement (23%)	Family attitudes, knowledge and involvement (19%)
	2	Federal policies, regulations, funding and service definitions (21%)	Community systems, opportunities and attitudes (14%)	Community systems, opportunities and attitudes (18%)
	3	Family attitudes, knowledge and involvement (16%)	Service Coordination/Case Management attitudes and processes (10%)	Federal policies, regulations, funding and service definitions (12%)

Services	Rank	Most Impactful Facilitator	Second Most Impactful Facilitator	Third Most Impactful Facilitator
Advocacy	1	Provider agency leadership or staff attitudes, beliefs and skills (23%)	Provider agency leadership or staff attitudes, beliefs and skills (30%)	Provider agency policies, structures and practices (19%)
	2	People who receive support--their attitudes, ability and opportunity (21%)	People who receive support--their attitudes, ability and opportunity (18%)	Board of Directors' attitudes, tradition and leadership (15%)
	3	State policies, regulations, funding and service definitions (13%)	Provider agency policies, structures and practices (15%)	Community systems, opportunities and attitudes (14%)
Case Management/ Support/ Resource Coordination	1	People who receive support--their attitudes, ability and opportunity (21%)	Provider agency leadership or staff attitudes, beliefs and skills (26%)	Provider agency policies, structures and practices (16%)
	2	Provider agency leadership or staff attitudes, beliefs and skills (23%)	Provider agency policies, structures and practices (14%)	Provider agency leadership or staff attitudes, beliefs and skills (15%)
	3	Provider agency policies, structures and practices AND State policies, regulations, funding and service definitions (13%)	People who receive support--their attitudes, ability and opportunity (13%)	Community systems, opportunities and attitudes AND Service Coordination/Case Management attitudes and processes (13%)
Center-Based Day Programs	1	People who receive support--their attitudes, ability and opportunity (28%)	Provider agency leadership or staff attitudes, beliefs and skills (28%)	Provider agency policies, structures and practices (21%)
	2	Provider agency leadership or staff attitudes, beliefs and skills (18%)	Provider agency policies, structures and practices (18%)	Provider agency leadership or staff attitudes, beliefs and skills (14%)
	3	Provider agency policies, structures and practices (13%)	People who receive support--their attitudes, ability and opportunity (13%)	Community systems, opportunities and attitudes (13%)
Community-Based Day Support	1	People who receive support--their attitudes, ability and opportunity (26%)	Provider agency leadership or staff attitudes, beliefs and skills (28%)	Provider agency policies, structures and practices (19%)
	2	Provider agency leadership or staff attitudes, beliefs and skills (22%)	Provider agency policies, structures and practices (19%)	Provider agency leadership or staff attitudes, beliefs and skills (14%)
	3	State policies, regulations, funding and service definitions (14%)	People who receive support--their attitudes, ability and opportunity (13%)	Board of Directors' attitudes, tradition and leadership AND Family attitudes, knowledge and involvement (11%)
Day Habilitation	1	People who receive support--their attitudes, ability and opportunity (27%)	Provider agency leadership or staff attitudes, beliefs and skills (24%)	Provider agency leadership or staff attitudes, beliefs and skills (18%)
	2	Provider agency leadership or staff attitudes, beliefs and skills (21%)	Provider agency policies, structures and practices (20%)	Community systems, opportunities and attitudes (17%)
	3	State policies, regulations, funding and service definitions AND Provider agency policies, structures and practices (14%)	Family attitudes, knowledge and involvement (16%)	Provider agency policies, structures and practices (16%)
	1	People who receive support--their attitudes, ability and opportunity (25%)	Provider agency leadership or staff attitudes, beliefs and skills (26%)	Provider agency policies, structures and practices (17%)

Family Support Services	2	Provider agency leadership or staff attitudes, beliefs and skills (19%)	Provider agency policies, structures and practices (17%)	Provider agency leadership or staff attitudes, beliefs and skills (16%)
	3	State policies, regulations, funding and service definitions (14%)	People who receive support--their attitudes, ability and opportunity (14%)	Board of Directors' attitudes, tradition and leadership AND Community systems, opportunities and attitudes (13%)
Healthcare	1	Provider agency leadership or staff attitudes, beliefs and skills (19%)	Provider agency leadership or staff attitudes, beliefs and skills (27%)	Community systems, opportunities and attitudes (19%)
	2	People who receive support--their attitudes, ability and opportunity (18%)	Provider agency policies, structures and practices (15%)	Provider agency leadership or staff attitudes, beliefs and skills AND People who receive support--their attitudes, ability and opportunity (15%)
	3	State policies, regulations, funding and service definitions (16%)	Family attitudes, knowledge and involvement (13%)	Provider agency policies, structures and practices (11%)
ICF/Facilities	1	People who receive support--their attitudes, ability and opportunity (22%)	Provider agency policies, structures and practices (20%)	Community systems, opportunities and attitudes (19%)
	2	Provider agency leadership or staff attitudes, beliefs and skills (20%)	Provider agency leadership or staff attitudes, beliefs and skills (18%)	Provider agency leadership or staff attitudes, beliefs and skills (17%)
	3	State policies, regulations, funding and service definitions AND Family attitudes, knowledge and involvement (12%)	Family attitudes, knowledge and involvement AND People who receive support--their attitudes, ability and opportunity (14%)	Service Coordination/Case Management attitudes and processes AND Family attitudes, knowledge and involvement AND People who receive support--their attitudes, ability and opportunity (13%)
Pre-Vocational Support	1	People who receive support--their attitudes, ability and opportunity (28%)	Provider agency leadership or staff attitudes, beliefs and skills (33%)	Provider agency policies, structures and practices (20%)
	2	Provider agency leadership or staff attitudes, beliefs and skills (20%)	Provider agency policies, structures and practices (17%)	Service Coordination/Case Management attitudes and processes (12%)
	3	Provider agency policies, structures and practices (13%)	People who receive support--their attitudes, ability and opportunity (14%)	Board of Directors' attitudes, tradition and leadership AND Provider agency leadership or staff attitudes, beliefs and skills (11%)
Residential/Group Homes	1	People who receive support--their attitudes, ability and opportunity (26%)	Provider agency leadership or staff attitudes, beliefs and skills (27%)	Provider agency policies, structures and practices (20%)
	2	Provider agency leadership or staff attitudes, beliefs and skills (20%)	Provider agency policies, structures and practices (16%)	Community systems, opportunities and attitudes (13%)
	3	Provider agency policies, structures and practices (14%)	Family attitudes, knowledge and involvement AND People who receive	Board of Directors' attitudes, tradition and leadership AND People who

			support--their attitudes, ability and opportunity (13%)	receive support--their attitudes, ability and opportunity (11%)
Respite Services	1	People who receive support--their attitudes, ability and opportunity (28%)	Provider agency leadership or staff attitudes, beliefs and skills (29%)	Provider agency policies, structures and practices (21%)
	2	Provider agency leadership or staff attitudes, beliefs and skills (20%)	Provider agency policies, structures and practices (15%)	Provider agency leadership or staff attitudes, beliefs and skills (13%)
	3	State policies, regulations, funding and service definitions (14%)	People who receive support--their attitudes, ability and opportunity (14%)	Service Coordination/Case Management attitudes and processes AND Family attitudes, knowledge and involvement (11%)
Shared Living/Host Homes/ Adult Foster Care	1	Provider agency leadership or staff attitudes, beliefs and skills (24%)	Provider agency leadership or staff attitudes, beliefs and skills (28%)	Provider agency policies, structures and practices (18%)
	2	People who receive support--their attitudes, ability and opportunity (23%)	Family attitudes, knowledge and involvement (13%)	Community systems, opportunities and attitudes (16%)
	3	State policies, regulations, funding and service definitions (15%)	People who receive support--their attitudes, ability and opportunity (12%)	Service Coordination/Case Management attitudes (15%)
Services in Family Home	1	People who receive support--their attitudes, ability and opportunity (26%)	Provider agency leadership or staff attitudes, beliefs and skills (30%)	Provider agency policies, structures and practices (20%)
	2	Provider agency leadership or staff attitudes, beliefs and skills (20%)	Family attitudes, knowledge and involvement (14%)	Family attitudes, knowledge and involvement (15%)
	3	State policies, regulations, funding and service definitions (16%)	People who receive support--their attitudes, ability and opportunity (13%)	Service Coordination/Case Management attitudes (13%)
Services in Individual Home	1	People who receive support--their attitudes, ability and opportunity (25%)	Provider agency leadership or staff attitudes, beliefs and skills (29%)	Provider agency policies, structures and practices (20%)
	2	Provider agency leadership or staff attitudes, beliefs and skills (22%)	Provider agency policies, structures and practices (15%)	Provider agency leadership or staff attitudes, beliefs and skills AND Community systems, opportunities and attitudes (13%)
	3	Provider agency policies, structures and practices (15%)	People who receive support--their attitudes, ability and opportunity (13%)	Service Coordination/Case Management attitudes (12%)
Support Brokering	1	People who receive support--their attitudes, ability and opportunity (28%)	Provider agency leadership or staff attitudes, beliefs and skills (35%)	Service Coordination/Case Management attitudes AND Provider agency policies, structures and practices (18%)

	2	Provider agency policies, structures and practices (24%)	Family attitudes, knowledge and involvement (20%)	Board of Directors' attitudes, tradition and leadership (13%)
	3	Provider agency leadership or staff attitudes, beliefs and skills (17%)	People who receive support--their attitudes, ability and opportunity (15%)	Provider agency leadership or staff attitudes, beliefs and skills AND Family attitudes, knowledge and involvement (11%)
Sheltered Workshops	1	People who receive support--their attitudes, ability and opportunity (24%)	Provider agency leadership or staff attitudes, beliefs and skills (29%)	Provider agency policies, structures and practices (22%)
	2	Provider agency leadership or staff attitudes, beliefs and skills (20%)	Provider agency policies, structures and practices (17%)	Board of Directors' attitudes, tradition and leadership AND Provider agency leadership or staff attitudes, beliefs and skills (15%)
	3	Provider agency policies, structures and practices (17%)	People who receive support--their attitudes, ability and opportunity (13%)	Community systems, opportunities and attitudes (11%)
Supported Employment	1	People who receive support--their attitudes, ability and opportunity (27%)	Provider agency leadership or staff attitudes, beliefs and skills (29%)	Provider agency policies, structures and practices (18%)
	2	Provider agency leadership or staff attitudes, beliefs and skills (20%)	Provider agency policies, structures and practices (14%)	Provider agency leadership or staff attitudes, beliefs and skills (15%)
	3	Provider agency policies, structures and practices (15%)	People who receive support--their attitudes, ability and opportunity (13%)	Community systems, opportunities and attitudes AND Family attitudes, knowledge and involvement (11%)

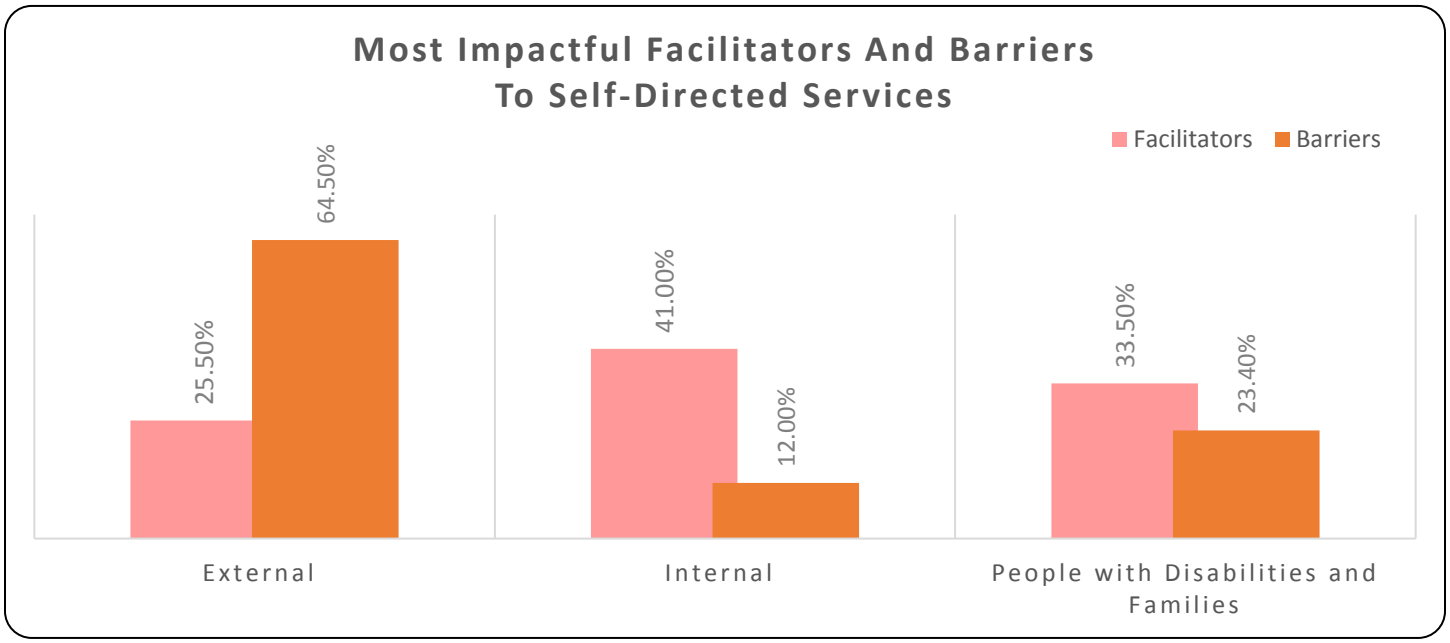
Differences in Agency Practices by Type of Primary Barriers and Facilitators

The data was analyzed to explore trends in agencies by how they categorized the biggest barriers and facilitators to providing self-directed services and supports. Ideally, identified differences in these trends can help stakeholders better understand how to support the implementation of self-directed services in practice.

The data was first split into three categories: external barriers and facilitators, internal barriers and facilitators, and barriers and facilitators related to families and people with disabilities using services.

Interestingly, most agencies identified external barriers as the most impactful indicators that hinder the provision of self-directed services, while they identified internal facilitators and people with disabilities and their families as the most impactful indicators that support the provision of self-directed services. The table below categorizes the barriers and facilitators by category (external, internal and people with disabilities and family members. The frequency for each indicator is also included to show the distribution of responses (first by facilitators, then by barriers).

Each group of barriers and facilitators (external, internal and people with disabilities and family members) were analyzed in the context of how respondents rated: 1) their organization's motivation and capacity to provide self-directed services; 2) their organization's practices that facilitate self-directed services; 3) their personal attitudes and beliefs towards self-directed services; and, 4) the attitudes and beliefs of their coworkers towards self-directed services. The results below outline the significant findings.



External	Internal	People with Disabilities and Family Members
Federal policies, regulations, funding and service definitions | Fac: 4.5% | Bar: 16.7% | State policies, regulations, funding and service definitions | 11.6% | 32.1% | Managed Care Organizations' policies, structures and practices | 1.3% | 4.7% | Community systems, opportunities and attitudes |2.9% | 5.4% | Service Coordination/ Case Management attitudes and processes | 5.2% | 5.7% |	Board of Directors attitudes, tradition, and leadership |Fac: 4.5% | Bar: 1.0% | Provider agency policies, structures and practices | 14.5% | 3.3% | Provider agency leadership or staff attitudes, beliefs and skills | 21.9% | 7.7% |	Family attitudes, knowledge and involvement | Fac: 9.0% | Bar: 16.1% | People who receive services' attitudes, ability and opportunity | 24.5% | 7.4% |

Facilitators | Respondents who reported that internal factors, practices and values were the primary facilitators to providing supported living services were significantly more likely to report that their agency staff and board of directors support the provision of self-directed services. Further, they rank both the motivation and capacity of their agency to provide self-directed services significantly higher than those who rated external factors and people with families and I/DD as the top facilitators.

Barriers | Respondents who shared that external factors as well as families and people with disabilities were the primary barriers to providing self-directed services also reported that their agencies were more likely to implement practices that facilitate self-direction (provide support and tools to agency staff and people using services) and believe more in their agency's capacity to provide self-directed services. However, their personal attitudes and beliefs were significantly less likely to fully align with principles of self-direction, indicating that they felt less sure that *all* people with I/DD should receive fully self-directed services.

Magic Wand: Number One Barrier Respondents Would Address

To better understand what agency professionals would prioritize to enhance their capacity to provide self-directed services, participants were asked,

"If you had a magic wand and could fix ONE factor instantly, which would you fix?"

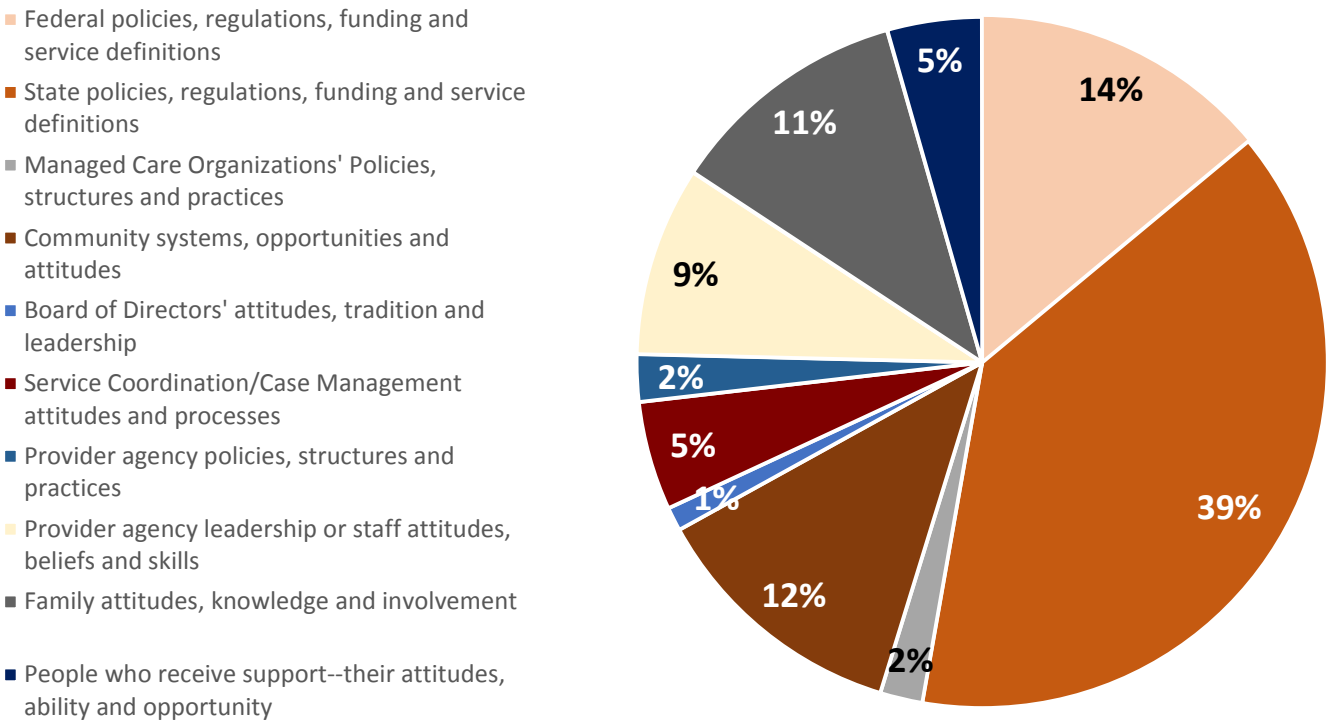
Thirty-nine percent (39%) prioritized "State policies, regulations, funding and service definitions" as the number one factor to fix, followed by "Federal policies, regulations, funding and service definitions," selected by 14% of participants. There was a 25-percentage point difference between the top selected barrier to fix and the second most selected choice, indicating that respondents believe that change at the state level would most improve their capacity to provide self-directed supports. In total, 88% of respondents indicated that, if they had a magic wand, they would fix something external to their agency. These results are consistent with top-ranked choices when respondents were asked to select what they saw as the top three barriers to self-directed service delivery, which were: state policies, regulations, funding and service definitions; federal policies, regulations, funding and service definitions; and family attitudes, knowledge and involvement.

"State policies create an administrative burden and risk: documentation and tracking of service delivery overwhelms providers and the risk of adverse and retrospective audit findings to the ill-defined standards for Medicaid reimbursement is high."

"Regulations and funding prevent us from hiring the best people to support those we serve. If I could hire people at a living wage, they might invest and help us to educate communities, families and even the individuals themselves. Time, money and an honest serious investment in the people we serve would go a long way."

The Top 100 Words from Magic Wand Question Responses

Top Choice of Barrier to Fix with a Magic Wand (N=475)



"The regulatory demands are counter intuitive to allowing people to take risks and self-direct their supports/services. Regulatory demands force agencies to be in a position of power and control versus shifting choice and control to the person choosing services."

"Funding plays a big part in allowing people to do what, how, when they want to do things. It effects how much staff/support hours they have and what activities they can afford to do. If an individual lives in a house with a roommate with one staff member on shift and they plan on going to the park for coffee, and then one person changes their mind at the last minute, the staff are stuck because there isn't the funding to have two staff at the house. Funding also effects how to hire and retain good DSPs. If their wage is just the minimum all that get hired are new people into the work force or young 18-year-old college kids looking for a short-term job not a career."

"Our state has a one size fits all. They state person-centered over and over, but there is none. The definitions and trainings are the same for every provider. They have not really come up with a program that is person-centered in any sense of the word. The service definitions and training are the same for provider agencies and we just have to follow along. We are just not the same. Policies should reflect the agency and the differences."

Explanation of Magic Wand Responses

In addition to selecting the top barrier they would fix using a magic wand out of the given 10 choices, participants were asked to explain why they chose that barrier. The reasoning behind their choices supplied a more detailed picture of factors that respondents viewed as detrimental to providing self-directed services and supports. Their responses were grouped into themes within each category of barrier, as displayed in the thematic map below. Common themes across barriers included: funding, outdated beliefs or processes, and negative attitudes toward self-direction. Respondents also frequently expressed that the reason they chose a certain barrier was that they considered it the source of change, and if that barrier could be eliminated then other processes could function more effectively.

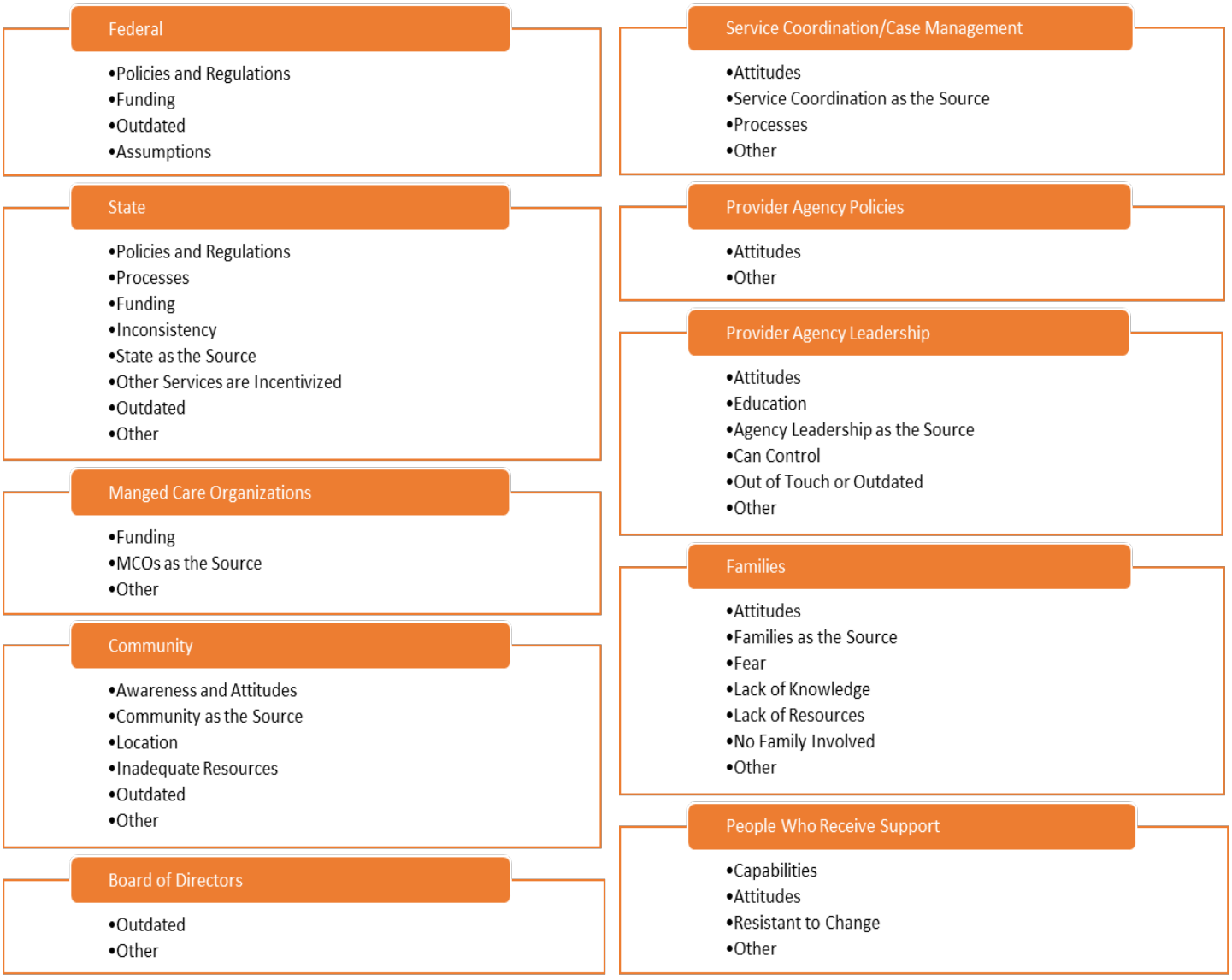
State Policies, Regulations, Funding and Service Definitions | State barriers were selected most, with 39% of respondents choosing to fix state issues with a magic wand over other barriers. Respondents felt that state policies, regulations, and processes are restrictive or outdated when it comes to self-direction. Many people reported that states make it easy or even incentivize going with more restrictive supports for people with I/DD, while others expressed discontent with regulations preventing service providers from hiring competent staff. One respondent said, “Regulations and funding prevent us from hiring the best people to support those we serve. If I could hire people at a living wage, they might invest and help us to educate communities, families and even the individuals themselves. Time, money and an honest, serious investment in the people we serve would go a long way.” Additionally, too many rules, paperwork and inflexibility at the state level, along with a risk adverse approach to services were often blamed for a slow and complicated system that prevents self-directed supports. One respondent reported, “The regulatory demands are counter intuitive to allowing people to take risks and self-direct their supports/services. Regulatory demands force agencies to be in a position of power and control versus shifting choice and control to the person choosing services.”

There were 54 respondents who expanded upon their reasoning for choosing state funding as a main barrier to self-directed services. Respondents explained that without funding for staff working with the people with I/DD and other resources like housing make the system more business-centered than person-centered. As one respondent describes, “Underfunded services are a significant limitation for EVERY aspect of service delivery. Ineffective regulatory standards and duplication of regulatory oversight only compound the impact of strained funding. Moving the needle on things like community attitudes, family attitudes, and navigating the ever-evolving managed care process takes a back seat to maintaining health and safety. Service providers that have every desire to make significant changes to service delivery to be fully customized and self-directed are faced with making decisions that simply keep their doors open instead.”

Federal Policies, Regulations, Funding and Service Definitions | Federal barriers were the second most popular choice selected; 14% of respondents selecting it over others. Explanations within this choice were grouped into three categories: policies and regulations are restrictive or outdated, funding is limited, and assumptions are made by policymakers without knowing enough about the population or the impact of their policies. One respondent expressed frustration with federal regulations by saying, “It seems as though the process of self-direction is very long and complex; it’s almost as if it was built for people NOT to understand.” Another respondent discussed how lack of funding affects people served and their support staff: “Many people are on an extensive wait list due to a lack of funding and those currently receiving funding often do not have enough to cover necessities. Also, provider rates are low when compared to other jobs and do not support a living wage, leading to burnout and a lack of adequate supervision.” Some respondents voiced their concern about the disconnect between policy and implementation of that policy. One respondent explained, “Our Government is creating policies and eliminating funding without truly knowing the impact on our community. There are so many people without services who really, really need it and there are people with services that are at risk of losing it. As a support staff for 35 plus years, I have seen lots of changes. It would be great to see all of the individuals with I/DD funded and supported based on their individual needs, not as a collective group.”

Community Systems, Opportunities and Attitudes | The third most selected thing to fix with a magic wand were community barriers, chosen by 12% of respondents. Many viewed the lack of awareness and negative attitudes within the community as the primary hurdles, while others identified lack of community resources (e.g., housing, employment, transportation) as the main concern. One respondent expressed concern with the way potential employers and others in the community viewed people with I/DD, saying, "If the community better understood this population, so many more doors of opportunity would open for our individuals. Many in the community still view individuals with intellectual disabilities as people who need to be 'watched' and 'taken care of,' not as individuals who can work a job, make their own decisions, and contribute to our community." Another respondent talked about the willingness of community entities to change being a barrier, saying, "As an agency we are able to be creative and innovative in how we support people. As an organization we can influence our community and we do—sometimes the community is just not as willing to be creative or innovative or be open to change." If the community began supporting self-direction, the rest of the barriers could be overcome, said another respondent: "If we can get community systems, opportunities and attitudes aligned with, accepting of and advocating for self-direction, there would be sufficient support and advocacy to impact government, organizations, individuals, families and the community to shaping all systems, policies, practices towards a prevailing framework of self-direction."

Successful Strategies Associated with Agency Capacity to Deliver Self-Directed Services



While many respondents indicated external forces are the most hindering to providing self-directed services, (such as state and federal polices and funding), there are many agencies who experience the same external factors but are able to deliver self-directed services; for instance, in every state, there are agencies who provide only individualized services and supports, even though many other agencies feel that the same would be impossible for them due to state policies and funding regulations. Given that, it is important to conduct an in-depth investigation into internal agency factors (structures, values and practices) to explore strategies that may be associated with its capacity to deliver self-directed services and supports.

Agency Desire and Agency Capacity | There was a strong correlation between respondents' reported ratings of how much their agencies want to provide self-directed services and their ratings of how much their agencies currently have the capacity to provide self-directed services. As ratings of desire to provide self-directed services increased, so did ratings of their capacity to do so. These findings reflect the notion that desire and change are closely linked and if there is a will to implement change, change may be more likely.

Self-Direction Principles and Language in Written Materials and Agency Capacity | Having self-direction principles and language clearly included in agency written materials was positively associated with participants' ratings of their agencies' capacity to provide self-directed services. Employees of agencies that had self-direction principles and language in their written policies and handbooks and in their written services plans and goals were likely to rate their agencies' capacity for self-directed services higher than those without self-directed language in their written materials.

Training and Support to People with Disabilities and Agency Capacity | Providing tools and support to people with disabilities about how to be truly in control of their services was the greatest predictor of a respondent's rating of their agency's capacity to deliver self-directed services. Providing tools and support to people with disabilities about how to manage their own service dollars and spending money and how to choose their leisure activities were also associated with higher ratings of agency capacity for self-directed services.

Training and Support to Staff and Agency Capacity | Providing staff formal training about how to facilitate self-directed services significantly predicted participants' rating of their agency's capacity to provide self-directed services, as did providing staff tools and support to staff about how to assist people with disabilities to manage their own service dollars and spending money, and providing tools and support to staff about how to assist people with disabilities to be truly in control of their services.

Implications for the Field

Findings from the *I/DD Provider Survey* offer deep insights about agencies' capacity to provide self-directed services and supports to adults with intellectual and developmental disabilities across the U.S. Results can be used to provide key stakeholders, such as state and federal policymakers, Managed Care Organizations, researchers, provider agencies, families of people with I/DD and people with intellectual and developmental disabilities themselves, with ideas about how to support, provide and access self-directed services.

State and Federal Policymakers

Important Findings | State and federal policies, regulations, funding and service definitions were consistently identified as the greatest barriers to providing self-directed services and supports (32.1% and 16.7% respectively). Several respondents shared that regulations, incentives and funding structures are currently set up to deter agencies from shifting service models to self-direction; they discussed a misalignment between state and federal policy and principles of self-direction. For instance, respondents identified current state and federal polices as outdated; citing service definitions, processes to obtain services, funding mechanisms, rates and quality demonstration requirements that all favor traditional, congregate services. At the same time, state and federal policies, regulations, funding and service definitions were also most frequently named as the first thing that respondents would fix if they had a "magic wand" (39% and 14% respectively), indicating that states and federal policymakers can play a significant role in supporting a nationwide shift to self-directed services.

Strategies to employ |

- **Incentivize self-directed services and supports** | Some states have encouraged agencies to transition to and provide self-directed services by incentivizing individualized, community-based supports that demonstrate that people supported have choice and control over their services and lives. Several states have considered and employed strategies such as outcomes-based funding, enhanced rates paid for individualized, self-directed services, providing funding for agency transition costs and approving short term increased rates for people using services as they transition from congregate to individualized services (as supports during transition and change may need to be increased).
- **Assess current policies, regulations, funding structures and service definitions to identify areas that may deter agencies from transitioning to and/or providing self-directed services and supports** | Because respondents consistently shared that state and federal policies are a barrier to providing self-directed services, state and federal policymakers can start to identify specific areas that hinder them. For instance, several states continue to pay higher rates to congregate service models such as ICF-IDDs and group home supports than to individualized services, such as self-directed supports, supported living and shared living. This deters agencies from transitioning to self-directed services if they do not feel that they are able to pay for the same level of supports in a community, individualized setting. Further, state and federal government agencies can review written policies and regulations to assure that they are clear, accessible and supportive of self-directed services; these recommendations align with findings from two national studies of state I/DD administrators from the University of Minnesota and the Human Services Research Institute [xxxvii, xxxviixxxvi]. Areas that may benefit agencies include: clarifying service definitions and allowances so that provider agencies and families understand what they can provide and access, assuring that people with I/DD and families are aware of self-directed options and educated about the benefits, and assuring that quality assurance regulations that agencies have to meet are realistic to support people in their own homes and communities.
- **Provide technical assistance and support to agencies who are interested in transitioning to self-directed Services** | Research from the National Leadership Consortium shows that leaders struggle to transform services, not for lack of will, but because they lack the tools, strategies and acumen to change organizational structures, operations and practices [xxxi]. Knowing this, some state Developmental Disabilities Agencies and Developmental Disabilities Councils have funded grants and provided/

supported pilot initiatives to help agencies transition from congregate to individualized services models. Further, research from the University of Minnesota [xxxvii] and Human Services Research Institute[xxxvi] shows that state administrators recognize their own role in providing support. State employees shared that when they ease administrative burdens (e.g. provide easy to use electronic billing platforms, streamline documentation requirements) and assign self-direction specialists who are available to provider agencies to answer questions, address concerns and offer ideas and strategic support, providers are more successful in the implementation of self-directed services.

Managed Care Organizations

Important Findings | Managed Care Organizations have a unique opportunity to support the shift to self-directed services and supports across the United States; 30.6% of participants agreed that Managed Care Organizations are a facilitator to self-directed services. At the same time, 33% agreed that Managed Care Organizations are a barrier to providing self-directed services (although very few, 4.7%, indicated that they are the biggest barrier). A few respondents shared that they felt that the rate structures and regulations upheld by Managed Care Organizations do not align with principles of self-direction. Further, one person said that Managed Care Organizations who are interested in self-direction mandate it without providing the necessary training and supports to facilitate implementation.

Strategies to employ | The recommended strategies for Managed Care Organizations shared by survey responders align with the recommendations for State and Federal policy makers (see above).

Provider Agencies

Important Findings | Because most agencies provide both individualized and congregate services, we can infer that, for many agencies, barriers to providing self-directed services hinder agencies from completely shifting away from group and segregated service models. Interestingly, most respondents identified top barriers that are external to their organization (64.5%) while they identified top facilitators as internal to the organization (41%). Results also showed that the respondents who identified internal (to their agency) facilitators as the primary catalysts to self-directed services were significantly more likely to believe that self-directed services are better for all people and that their agencies were motivated and had the capacity needed to provide self-directed services. At the same time, responders who identified primary barriers as external to their agency were significantly less likely to believe that self-directed services are better for all people.

Recently, from conversations with national leaders in the field of I/DD services have emerged a common theme; leaders who are known for having built, regulated, evaluated and supported the shift towards self-directed services share that most crucial step to agency transformation is making the decision to change, and holding all changes, practices and operations accountable to that decision. A 2012 study from the National Leadership Consortium on Developmental Disabilities supports this idea[xxxi]. National leaders known for having provided ideal person-directed services in the country were interviewed. They consistently shared that they were able to navigate difficult federal and state regulations, political climates, economic instability, etc. if they remained committed and accountable to their decision to provide only individualized services and supports.

Findings may align with results from the National Leadership Consortium study outlined above; when professionals feel that their agency practices and values are accountable to self-directed services, they are more likely to believe that self-directed services are beneficial and possible for all people with intellectual and developmental disabilities. Because, ultimately, they are responsible for assuring the success of self-directed services.

Strategies to Employ |

- **Learn from agencies that have successfully transformed/ fully implemented self-directed services as models |** Although most agencies indicated that state and federal barriers are the primary hindrances to providing self-directed services and supports, there are agencies in each state and across the country who have figured out how to fully implement individualized, self-directed services under the same regulations and funding opportunities and restrictions. Provider agencies can benefit from opportunities to learn from those agencies to gain insight into the practices and operations that facilitate agency capacity to provide self-directed services. Hands on, practical peer learning could help agencies adopt strategies, policies and practices that have demonstrated successful transformation to and implementation of self-directed services and supports. This may also present an opportunity for provider agencies to partner with Managed Care Organizations and state agencies to offer more widespread technical assistance, support and insight for other agencies who are motivated to shift to self-directed services.
- **Embed principles of self-direction in written and unwritten agency policies, practices and training |** When agencies are intentional about embedding principles of self-direction in their agency policies, documents, practices, and development opportunities for employees and people using services (including training, supervision and support), results from this study clearly show that they are more confident in their capacity to provide self-directed services and supports. Agencies can review their internal written and unwritten organizational mission, vision policies, practices, trainings and norms to assess where and how principles of self-direction are currently embedded and where they can be strengthened. Previous research focused on quality services support findings from this study in that organizational structure, policies, training and supervision were found to be highly related to the quality of services and outcomes[xxxii]. For instance, one study focusing on behavioral supports found that organizations that focused on providing quality and sufficient training and supportive supervision had fewer placement breakdowns than other organizations[xxxiii].
- **Adopt leadership, management and operational philosophies that align with principles of self-direction |** Findings from research in and out of the I/DD sector consistently demonstrate that employee engagement, a factor that is highly influenced by organizational culture, leadership styles, training, management philosophy and supervision practices, is a key catalyst to transformation and change [xxxiv]. For instance, Gallup[xxxv], one of the leading organizational analytic and measurement companies in the U.S., found that organizational culture and employee engagement are highly correlated to organizational performance, productivity and quality. Interviews with Direct Support Professionals in the I/DD sector have demonstrated that some of the key factors to providing individualized services and supports are related to how DSPs are trained, supervised and supported. When they are supported to be creative and flexible and have the information and resources they need, they are more engaged and better able to provide self-directed services that adapt to the wants, needs and interests of the people they support. Further, when they feel that the agency and supervisors are available to answer questions, provide ideas and help them with issues (rather than punish them for making mistakes) they feel that they are better able to provide quality services. Providers that are trying to transition to self-directed services should assess their management and leadership philosophies to assure that employees have the flexibility and support they need to remain engaged and successful in their roles.
- **Focus on the beliefs and attitudes of agency employees |** Related to the above recommendation, provider agencies may also benefit from an examination of their organizational culture and the beliefs of employees as they relate to/ align with the principles of self-directed services and supports. Results from the survey show that most respondents believe that tenants of self-directed services (including choice of home, right to decision making, autonomy to plan their services and schedules, etc.) are only appropriate for *some*, or *most* people with I/DD, rather than *all* people. Further, the results show that responders believe that others in their organization (including the board of directors, executives and direct support professionals) think similarly; most indicated that others in their organization support self-directed services for *some* or *most* of the people that their agency supports. Successful implementation of self-

directed services requires buy in from agency employees to make it happen. A study from the UK, referenced earlier in this report[xxvii], found that changing service definitions and locations was not sufficient to providing self-directed services; employees needed to understand and adopt philosophies of choice, control and autonomy in order to change how services were actually provided. Provider agencies that are working to transition to self-directed services may better succeed if they fundamentally shift their organizational beliefs and attitudes to align with principles of self-direction.

People with Disabilities and their Families

Important Findings **|** Many survey respondents agreed that people with disabilities and their family members are both essential facilitators and barriers to providing self-directed services and supports (33.5% and 23.4% shared that they are the top facilitator and barrier respectively). Although, fewer shared that if given a magic wand they would first change families attitudes and beliefs (11%), and people with disabilities attitudes, beliefs and abilities (5%) in order to provide self-directed services. It is clear that agencies believe that people with disabilities and family members play an influential role in whether and how self-directed services are provided, thus, they can have an influential role in promoting the widespread shift towards self-direction.

Strategies to Employ **|**

- **Learn from people with disabilities and families who have successfully transitioned to self-directed services |** People with all types and scope of disability are directing their services and thriving in their chosen homes and communities. Learning from their success may help other people with disabilities and family members who are unsure of whether and how to use these services, as they can help people gain insight and strategies related to: who to ask for services; which services are truly self-directing; how to advocate for self-directed services; how to manage self-directed services; how to assure that people are safe while living fulfilling and experience rich lives; how to hire quality direct support staff, and more. This may present an opportunity for provider agencies, Managed Care Organizations and states to leverage the voices and experiences of people with disabilities and family members who are using self-directed services to teach other people with disabilities and their families and engage in peer learning. Findings from state level research in self-directed services found that peer mentors and experienced family members are an essential component of the successful provision of self-directed supports.
- **Leverage your power to influence change toward self-direction |** Advancement in the disabilities field has been historically spearheaded by people with I/DD and their families advocating for rights and services. This trend should continue today through education and advocacy for advanced opportunities in the community. People with disabilities and their families have power to choose services that will suit their needs and foster the best quality of life for the person with I/DD and they can leverage that power to request self-directed services.

Sampling Limitations and Implications for Researchers | Although the *I/DD Provider Survey* yielded statistically powerful sample size, sampling methods did impact the representativeness of the results. First, because the purposive and snowball sampling methodology was employed, respondents were not selected to intentionally provide a representative sample. Further, because 34% of the respondents received the survey through the National Leadership Consortium and its partnering organizations (who were selected as partners, in part, because they share similar values of individualization and inclusion), the sample may be biased towards organizations who have already committed to person-directed services in philosophy and practice. Now that the survey has national recognition, further studies may consider recruiting nationally representative samples to participate.

The *I/DD Provider Survey* offers the perspective of agencies that are directly providing services and supports to people with I/DD. Because similar studies have been conducted with state administrators and

policymakers[xxxvi, xxxvii], there is an opportunity to compare the results between studies and analyze the similarities and differences across groups. Both provider agencies and state administrators may benefit from understanding the experiences and perspectives of the other.

Conclusion

Although there is a considerable desire to provide services and supports that are designed and led by people with intellectual and developmental disabilities, the *I/DD Service Provider Survey on Self-Directed Services and Supports* shows that there is a varying degree of agencies' capacity to provide self-directed services across the U.S.

Ultimately, the movement to convert agencies supporting people with intellectual and developmental disabilities from congregate settings to individualized, self-directed models may require additional supports for successful transformation. Findings from this survey do provide concrete ideas and strategies to enhance self-directed services, including supporting state agencies to provide regulatory and financial incentives (or at least not deterrents) to transitioning to self-directed models, and additional support and incentivization from Managed Care Organizations to continue to facilitate self-direction. Further, agencies may benefit from direct support and technical assistance to better incorporate principles and practices aligned with self-direction in their everyday operations, training and services. These findings provide an important benchmark in the intellectual and developmental disabilities field's understanding of how to continue the shift toward self-directed services and supports.

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