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

EXECUTIVE SUMMARY

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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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].

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 (HCBS) Medicaid waivers, which are becoming more widely utilized.

With 87% of adults with disabilities living with a family caregiver, alone, or with a roommate [ii], more personalized supports that are integrated into people's chosen home and community is needed. HCBS Medicaid waivers with self-direction options allow states to provide non-institutional services, as long as they remain cost-neutral[iii]. 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[iv]. 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].

HCBS self-direction options transfers control of supports that were previously decided and managed by professionals from state and provider agencies to the people with disabilities who choose them. 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. 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[v, vi]. Further, researchers consistently find that the more individualized services are, the better quality of life outcomes people with I/DD experience[vii].

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."

While the evidence in favor of self-direction is strong, information about how to best implement these services is lacking. The 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[viii]. Better understanding of how service agencies are navigating this shift will assist in the transition and ensure appropriate service delivery.

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.

The survey included questions about barriers and facilitators to self-direction, agency practices of self-direction, and individual values about self-direction. Respondents 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.

Survey Respondents

Data from 475 respondents met the minimum criteria for the 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) and were included in the analysis for this project[1].

Respondents from 37 states participated in the survey, representing a relatively even regional distribution. 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%). 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).

Survey Results

Agency Desire and Capacity to Deliver Self-Directed Services / 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. Desire and capacity of agencies to deliver self-directed services were strongly correlated; as desire increased, so did ratings of capacity. These findings imply that if there is a will to implement change, change may be more likely. 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.

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%). 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 more likely to rate their agencies' capacity for self-directed services higher than those without self-directed language in their written materials. Providing staff formal training about how to facilitate self-directed

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[1] Although the *I/DD Provider Survey* yielded statistically powerful sample size, sampling methods may impact the representativeness of the results. Purposive and snowball sampling methodology was employed, therefore respondents were not selected to intentionally provide a representative sample. Further, because 34% of respondents received the survey through the National Leadership Consortium and its partnering, the sample may be biased towards organizations who have already committed to person-directed services in philosophy and practice.

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.

Values Related to Self-Directed Services | When responding to questions 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.

Barriers and Facilitators to Self-Directed Services | Overall, the top three identified barriers to providing self-directed services and supports were: state policies, regulations, funding and service definitions (32%); federal policies, regulations, funding and service definitions (17%); and family attitudes, knowledge and involvement (16%). The top three identified facilitators to providing self-directed services and supports were: People who receive support — their attitudes, ability and opportunity (25%); provider agency leadership or staff attitudes, beliefs and skills (22%); and provider agency policies, structures and practices (15%). Most respondents identified barriers that were external to their agencies as the most impactful indicators that hinder the provision of self-directed services (65%), while they identified internal facilitators (41%) and people with disabilities and their families (34%) as the most impactful indicators that support the provision of self-directed services. 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.

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.

Prioritizing Solutions to Self-Directed Services | Participants were asked, "If you had a magic wand and could fix one factor instantly, which would you fix?" Their top three responses were: state policies, regulations, funding and service definitions (39%); federal policies, regulations, funding and service definitions (14%); and community systems, opportunities and attitudes (12%). Responses as to why they would fix the factor they chose were grouped into themes within each category of barrier. 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.

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 and Managed Care Organizations | State and federal policymakers and Managed Care Organizations should work to: incentivize self-directed services and supports; 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; provide technical assistance and support to agencies who are interested in transitioning to offer self-directed services.

Provider Agencies | Provider agencies should work to: learn from agencies that have successfully transformed/fully implemented self-directed services as models; embed principles of self-direction in written and unwritten agency policies, practices and training; adopt leadership, management and operational philosophies that align with principles of self-direction; and work to align the beliefs and attitudes of agency employees with principles of self-direction.

People with I/DD and Their Families | People with I/DD and their families should work to: learn from people with disabilities and families who have successfully transitioned to self-directed services; leverage their power and influence to make self-direction a reality.

While 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. 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 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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