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NATIONAL LEADERSHIP CONSORTIUM
ON DEVELOPMENTAL DISABILITIES

LEADING OUR VALUES

What It Takes to Provide Individualized and Inclusive Services

Project funded in part by a grant from the May and Stanely Smith Charitable Trust

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The National Leadership Consortium

Leadership, Values and Vision: Transforming Lives and Organizations

The National Leadership Consortium was founded in 2006 to develop current and future generations of disability sector leaders to have the knowledge, skills, and values needed to transform services and systems to be responsive to the needs, wants, and rights of people with disabilities. Our mission is to provide quality training, technical assistance, and support aimed at the development of values-based leadership in disability sector leaders. The National Leadership Consortium is focused on promoting the rights of people with disabilities to direct their services and lives and to fully belong in their chosen communities. One way the National Leadership Consortium works to meet this mission is through a nationally recognized, intensive leadership development program, the Leadership Institute. These in-person or virtual trainings focus on knowledge, skills, and supports leaders need to transform systems and organizations in the disability service sector.

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Plain Language Summary

The National Leadership Consortium on Developmental Disabilities, funded in part by the May and Stanley Smith Charitable Trust, conducted a study to find common organizational qualities and practices that help service providers begin and keep offering individualized, inclusive services for adults with disabilities who receive direct support.

This study had four parts. In Phase 1 (April-June 2014), the research team created surveys and interview questions, with help from people with IDD and experts, to learn about organizations that offer individualized, inclusive services. In Phase 2 (July-September 2024), a survey was sent to professionals in service organizations across the country to gather information about their work, leadership, and other factors that affect these services. In Phase 3 (October-December 2024), 15 leaders from these organizations were interviewed to get more in-depth views. In Phase 4 (January-March 2025), the research team analyzed the data from the surveys and interviews, creating charts and themes to summarize the results. They wrote a report with findings from the study and recommendations for people working in the disability field.

The study found that to make sure people with disabilities get the support they need, different groups need to take action:

Leaders in the government can help by giving money for inclusive services, offering rewards, and closing old institutions. States should make clear rules and check that organizations are following the best practices to support inclusion.

Leaders in service organizations should work with employees, families, and others to get their support for change and listen to their concerns. It's also important to have people with disabilities in leadership roles and to work together as a team with provider organizations. Training and keeping strong workers is important for long-lasting change. Service organizations can work together, share ideas, and get help from state agencies. Fundraising and working with local businesses can help get money for needed services and resources. To make sure everything is going well, organizations should check often to see if they are truly including people with disabilities.

Advocacy groups play an important role in teaching lawmakers about what people with disabilities need. Sometimes, laws and policies can make it harder to offer inclusive services. Experts can share helpful information with lawmakers about why inclusive services are important. Leaders should look at these rules and see how they can help make change happen.

Introduction

Federal policy and funding to support individualized and inclusive Home and Community Based Services have become more common over the past decade, and research has shown these services promote better quality of life outcomes for people with disabilities. However, many organizations continue to offer congregate services that allow little choice and control to people with intellectual and/or developmental disabilities (IDD) receiving services. Service provider leaders would benefit from additional guidance on how to transition to the current the best practices of person-centered, inclusive, community-based supports.

This research project, led by the National Leadership Consortium on Developmental Disabilities and funded in part by the May and Stanley Smith Charitable Trust, aimed to identify common leadership and organizational characteristics and processes that promote the transition to and maintaining of individualized, inclusive services for adults with disabilities receiving direct support services.

For the purposes of this project, "**individualized, inclusive services**" include: "supports for employment and volunteer work in the community where people make a fair wage, services in one's own and chosen home, one-on-one services offered solely in the community or out of a facility, and self directed supports." "**Individualized**" services means that services are provided solely or primarily to one person at a time, meaning someone has support to choose where and how to spend their time, and their opportunities are not limited by the support needs of others who use services. "**Inclusive**" services means that services are provided solely or primarily in one's chosen community (in places that aren't specialized for people with disabilities, that include people with and without disabilities).

This research sought to answer the following questions:

1. Why do organizations continue to offer congregate, noncommunity-based services?
2. Why do organizations begin to offer inclusive, community-based services?
3. Which internal and external factors help facilitate the transition to inclusive, community-based services?
4. What organizational processes of direct service providers promote inclusive, community-based services?
5. What are the characteristics of organizations that deliver inclusive, community-based services?
6. What are the characteristics and leadership practices of leaders at organizations that deliver inclusive, community-based services?

Project Summary

This mixed methods study followed an explanatory sequential design with four main phases:

Phase 1: Instrument Development [April-June 2014]

The research team of the National Leadership Consortium, in consultation with key informants (people with IDD and experts in the field), developed survey and interview instruments in the Spring of 2024 to use during Phase 2 of the study. Questions in the instruments were aligned with the research questions of the project and aimed to gain a deeper understanding of the characteristics and practices of provider organizations that offer individualized, inclusive services and supports, as well as their experience transitioning to provide these services, and the barriers and facilitators to offering these services.

Phase 2: National Survey [July-September 2024]

A web-based survey collected data from professionals across the country working at service provider organizations that offered at least some individualized, inclusive services during the summer of 2024. The survey consisted of about 50 multiple-choice and ranking questions related to participant demographics, organizational demographics, organizational processes, service practices and how they relate to best practices in the field, factors that help or hurt individual and inclusive services, leadership characteristics, and leadership practices. Respondents identifying as holding “executive” or “director” level positions were given additional questions related to organizational demographic information that may not be known by frontline professionals, for example, they were asked to identify funding sources and the number of the organization’s part-time employees. Survey participants were incentivized with the opportunity to enter a drawing to win one of two $50 Amazon eGift cards for completing the survey.

Phase 3: Executive Interviews [October-December 2024]

In-depth interviews with 15 executive leaders across the country were conducted in the fall and winter of 2024 via Zoom (see Appendix A for the interview schedule). Interviews lasted 1-2 hours and were audio recorded and transcribed to ensure accuracy. Interview participants each received a $20 Amazon eGift Card for completing the interview.

Phase 4: Data Analysis and Report Development [January-March 2025]

Data was analyzed and a report and plain language summary were developed in early 2025.

Descriptive and logistic regression analyses were used to analyze survey data and produce total or mean scores and odds ratios. Results of the survey were organized into charts and figures.

Thematic Analysis was used to code the interview data and identify themes. To analyze interviews, the research team reviewed transcripts and audio recordings then generated initial codes of interesting features of the data, before reviewing and refining codes during a second round of analysis. Codes were then collated into potential themes and the concepts from the data were further refined by the research team. Final themes and related content were organized into thematic maps.

Participants

Study participants were recruited during the summer and fall of 2024 to respond to the national web-based survey and take part in individual executive interviews. Participants were recruited by direct email invitation, listservs of the National Leadership Consortium and its national partners, and through various social media outlets of the National Leadership Consortium and its partners to professionals working at organizations that provide some individualized, inclusive services to adults with IDD. Participants who were contacted directly were invited to share information about the study and how to participate in the survey and interviews widely, to encourage a diverse and well-rounded sample.

Survey Participants

Responses from 134 people from the national web-based survey were used in this study. Survey respondents worked at organizations that provided at least some individualized, inclusive direct services to adults with disabilities and worked at the executive level, director level, manager level, or frontline level.

About one-third of participants held executive roles (34.3%), one-third were managers (35.7%) and one-third were directors (3.6%) and frontline professionals (26.4%) (see Table 1). In addition to their main professional roles, participants were also advocates or activists (35.9%), parents, guardians, or family members (31.1%), board members of another disability organization (25.2%), volunteers of another disability organization (14.6%), or had disabilities themselves (4.9%). Most participants were White (77.9%), with the remainder being Black or African American (13.0%), Hispanic or LatinX/Latine (3.8%), Native Hawaiian or Other Pacific Islander (1 participant, 0.8%), and 4.6% chose not to identify their race/ethnicity. Most respondents were female (78.4%), and half of the participants (60.2%) were aged 45-54 years old (33.6%) and 35-44 years old (26.6%). Experience in the disability field and time at current organizations varied widely among survey participants. Almost half of the participants (47.6%) had 20 or more years of experience in the disability field, with 11.2% of those participants having more than 40 years of experience in the field. Of the participants with less experience, 15.7% had 15-19 years of experience, 9.7% had 10-14 years, 14.2% had 5-9 years, and 12.7% of participants had less than 5 years of experience in the disability field. More than half of participants (56.7%) have spent less than 10 years at their organizations, about one-third have spent 10-24 years at their organizations (30.6%) and the remaining 12.7% have been at their organizations for more than 24 years.

Table 1: Survey Participant Demographics (N=134)

Variable	n	%
Age		

Under 25	3	2.29%
26-34	19	14.50%
35-44	27	26.61%
45-54	44	33.59%
55-65	26	19.85%
Above 65	12	9.16%
Race/Ethnicity		
American Indian or Alaska Native	0	0%
Asian	0	0%
Black or African American	17	12.98%
Hispanic or LatinX/Latine	5	3.82%
Native Hawaiian or Other Pacific Islander	1	0.76%
White	102	77.86%
I Prefer Not to Answer	6	4.59%
Gender		
Male	27	20.15%
Female	105	78.36%
Non-Binary/Third Gender	0	0%
Identity Not Listed	1	0.75%
I Prefer Not to Answer	1	0.75%
Years at Current Organization		
Less Than 5 Years	49	36.57%
5 to 9 years	27	20.15%
10 to 14 years	11	8.21%
15 to 19 years	14	10.45%
20 to 24 years	16	11.94%
25 to 29 years	4	2.99%
More Than 30 years	13	9.70%
Years Worked in the Disabilities Field		
Less Than 5 Years	17	12.69%
5 to 9 years	19	14.18%
10 to 14 years	13	9.70%
15 to 19 years	21	15.67%
20 to 24 years	15	11.19%
25 to 29 years	14	10.45%
30 to 34 years	13	9.70%
35 to 39 years	7	5.22%
More Than 40 years	15	11.19%
Position		
Executive Level	48	34.29%
Director Level	5	3.57%
Manager Level	50	35.71%

Frontline Level	37	26.43%
Other Roles		
Board Member of Another Dis Org	26	25.24%
Parent/Guardian/Family Member	32	31.07%
Advocate or Activist	37	35.92%
Person with a Disability	5	4.85%
Volunteer of Another Dis Org	15	14.56%

Executive Interview Participants

Fifteen (15) executives who worked at organizations providing at least some individualized, inclusive direct services to adults with disabilities and who had knowledge about the history, structure, and operations of their organizations were interviewed. Interview participants held many titles, including: Executive Director (3), Chief Executive Officer (3), Chief Operating Officer (1), Chief Programs Officer (1), Chief Services Officer (1), Director of Innovation and Expansion (1), Quality Coordinator (1), Community Connection Coordinator (1), Employment Specialist (1), Resource Developer (1), and Case Resource Manager (1). Participants worked in 13 states, including Alaska, Arkansas, California, Florida, Illinois, Maryland, Missouri, New Jersey, Ohio, Pennsylvania, Rhode Island, South Dakota, and Washington.

Survey Participant Organizational Demographics

Survey participants were asked questions about the organizations they worked for when responding to the survey. Participants represented a wide range of organizations from across the United States and Canada, in different service areas, of different sizes, and with various experience providing individualized, inclusive services.

About one-third of participants worked in organizations in the South (31.5%), one-third (33.8%) worked in the Northeast (17.7%) and Midwest (16.2%), and the remaining third of participants were from the West (21.5%) and Canada (13.1%) (see Table 2). Most participants (60.5%) provided services in mixed urban, suburban, and rural settings. More than one-third of participants (36.6%) worked in organizations that had more than 200 employees, and almost half (45.5%) worked at organizations that supported more than 200 people with disabilities.

Table 2: Survey Participant Organizational Demographics (N=134)

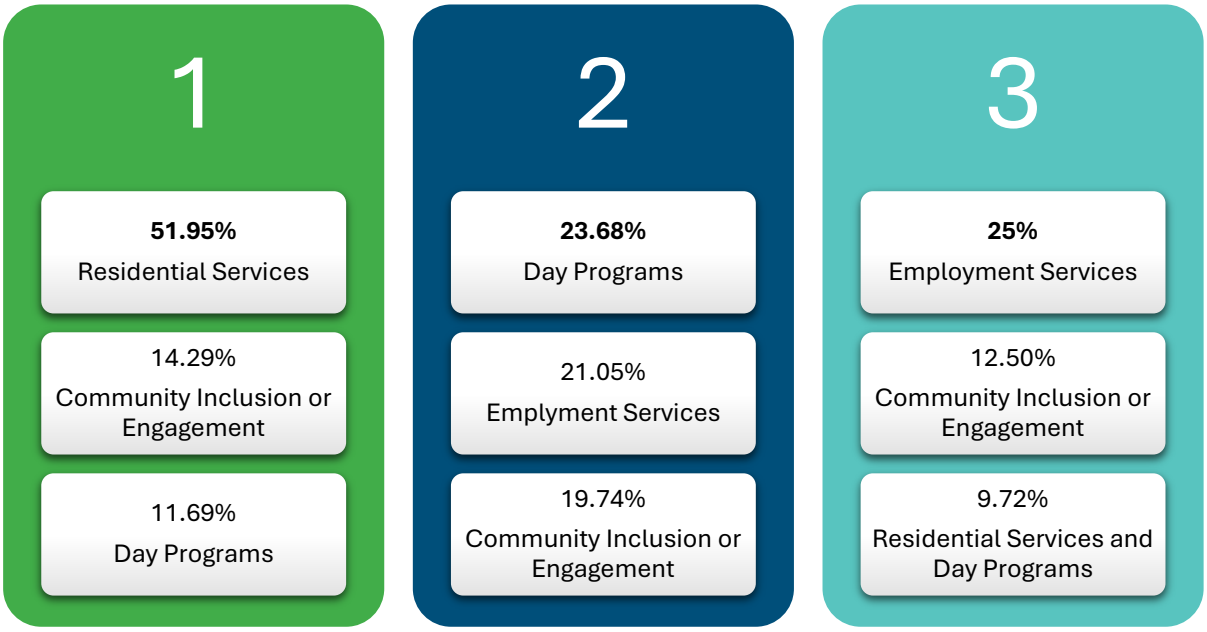
Variable	n	%
Region		
Northeast	23	17.69
Midwest	21	16.15
South	41	31.54

West	28	21.54
Canada	17	13.08
Service Area Type		
Urban	17	12.69%
Suburban	23	17.16%
Rural	13	9.70%
Mixed	81	60.45%
Number of Employees		
1-25	14	10.45%
26-50	17	12.69%
51-75	8	5.97%
76-100	10	7.46%
101-125	7	5.22%
126-150	6	4.48%
151-175	3	2.24%
175-200	6	4.48%
201-500	29	21.64%
500-1,000	20	14.93%
More Than 1,000	5	3.73%
I Don’t Know	9	6.72%
Number of Parttime Employees		
1-10%	15	31.25%
11-20%	7	14.58%
21-30%	6	12.50%
31-40%	10	20.83%
41-50%	3	6.25%
51-60%	5	10.42%
61-70%	0	0%
71-80%	0	0%
81-90%	1	2.08%
91-100%	0	0% e
Number of People with Disabilities Supported		
1-25	15	11.36%
26-50	12	9.09%
51-75	6	4.55%
76-100	7	5.30%
101-125	8	6.06%
126-150	6	4.55%
151-175	1	0.76%
176-200	1	0.76%
More Than 200	60	45.45%
I Don’t Know	16	12.12%
Year Started Delivery of Services		

2015-2024	8	10.39%
2005-2014	11	14.29%
1995-2004	3	3.90%
1985-1994	12	15.58%
1975-1984	13	16.88%
1965-1974	16	20.78%
1955-1964	9	11.69%
Before 1955	5	6.49%
Offering of Ind, Inclusive Services		
Early on in the process	4	5.19%
Still building these services	20	25.97%
Well established but still offer congregate	22	28.57%
Only offer individualized, inclusive services	31	40.26%

We asked survey respondents to select the top services they provided at their organizations. The top services offered were residential services (14.3%), the second most popular services offered were day programs (23.7%), and the third most popular services were employment services (25%) (see Figure 1).

Figure 1 Top Three Services Offered at Survey Participants' Organizations



We asked survey respondents to rate their organizations based on the six principles of the Organizational Priorities and Practices Inventory (OPPI), a tool developed by the National Leadership Consortium to measure effective practices for disability service sector agencies based on best practices in the disability field (see Appendix B). The six principles of the OPPI

are: 1) Autonomy, decision making, and control for people with intellectual and developmental disabilities; 2) Community living, employment, and engagement; 3) Stakeholder input to organizational management and governance; 4) Staff participation, value, impact, and support; 5) Leadership strength and skill development; and 6) Diversity, equity, and inclusion. Overall, participants rated their organizations highly, with average scores of organizational alignment with organizational best practices between 8.03 and 8.87 out of 10 (see Figure 2). Average ratings for *Community living, employment, and engagement* (with the guiding principle of: People with disabilities are better off when they live in and are engaged in their communities. All people with disabilities should be supported to live, work, and become meaningful members of their communities.) were the highest at 8.87 out of 10, and the lowest for *Stakeholder input into organizational management and governance* (with the guiding principle of: All governing and management practices are informed by people with disabilities and their families and should reflect principles of person-centeredness and self-determination.) at 8.03 out of 10.

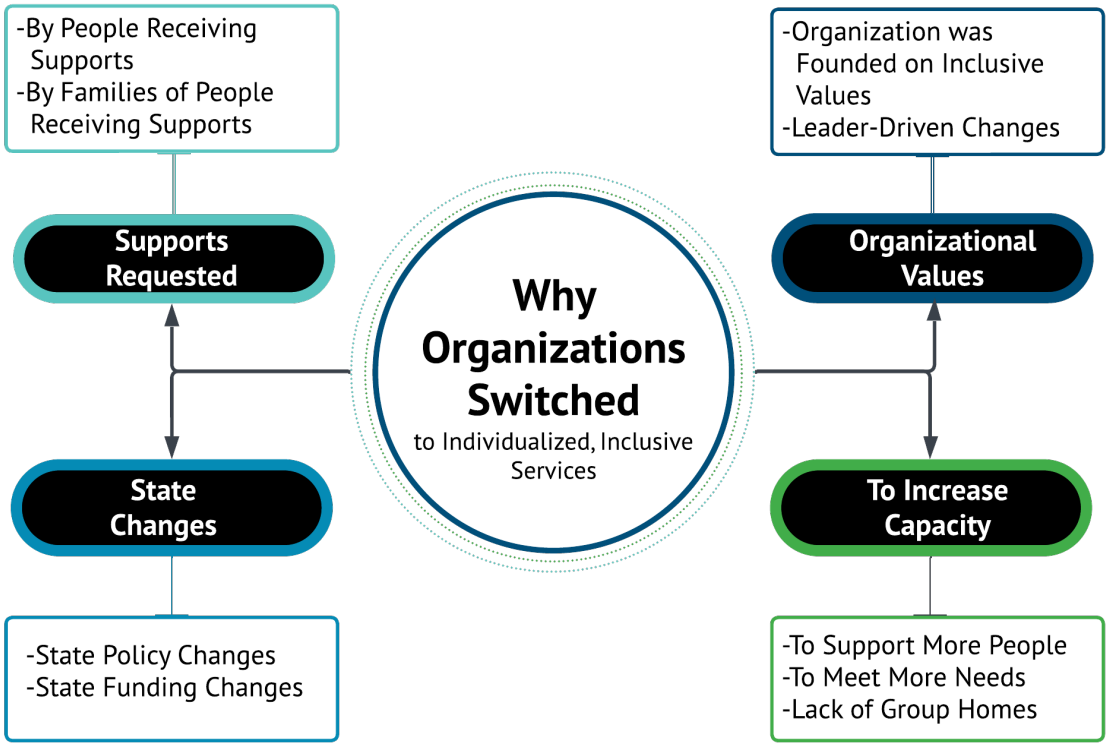
Figure 2 Average Organizational Priorities and Practices Ratings of Participant Agencies

Transformation Toward Individualized, Inclusive Services

Why Organizations Switched to Individualized, Inclusive Services

Interview participants were asked what prompted their organizations to switch and start delivering individualized, inclusive services. Interviewees discussed several causes ranging from structural to adaptive reasons and four main themes emerged. According to participants, the switch to individualized inclusive services was led by organizational values, supports requested, state-based changes, and to increase capacity (see Figure 3).

Figure 3 Why Organizations Switched to Individualized, Inclusive Services



Organizational Values

Participants talked about the role of organizational values in driving the switch toward more individualized and inclusive services. Factors such as the foundation of the organization within an inclusive framework of values seemed to have played a critical role. For example, a leader shared that the organization prioritized following values framed in choice, empowerment, and decision making as a way to pursue and maintain the switch.

"...one of the most important aspects for us is just a firm, documented categorization of priorities and a commitment to really going through the decision tree and the decision making process based on those priorities for us. We want to begin and end with the empowerment of

the people that we support and the opportunities for them to choose the lives that they want to live…"

Other organizational values mentioned by leaders were the organizational capacity to clearly differentiate between potentially profitable non-inclusive services and truly inclusive services, by following a stoic process of innovation and creativity.

"So, if you're living in a group home, but it's in the community, really, it's okay to say that it's more cost effective, but it's not individualized and inclusive supports. There's the same level of confinement; there's the same loss of control. For us, it's the mechanisms that we really try to use internally to maintain that focus — you have to be innovative and creative."

Other leaders shared how they started their organizations after being part of values movements such as the Self-Determination Movement. The interviewees talked about their first-hand experience with the benefits of inclusive and individualized services. They mentioned how they work alongside people with disabilities, their family members, and local and national leaders, paving their way to funding an organization that they would follow this path.

"Our participation in that project was like we never looked back. The lessons learned are that people are really able to make the best decisions for themselves and learn from people themselves. When we talk about person centered planning, when people truly are at the center of all considerations, there's a big difference in how both big decisions that are made about them and the tiny decisions that can have a profound impact on a person. So once we knew and could kind of really speak with credibility on the differences between provider managed and self-directed services, we knew that we could never return to trying to justify why it was okay to just house people together based on a medical diagnosis and to be making those big and small decisions for people, as opposed to what we learned was giving people the information, the resources and the technical assistance that they may need at any given time to make their own decisions. So that was really the basis of why we started."

Another driver of other organizational changes leading to inclusive services was leaders with an emancipatory vision for people with disabilities. Several participants described how they lead the switch within their organizations by following an inclusive and individualized service model.

"This isn't about me, and it should never be about any single leader, but it was certainly me coming in and lighting the place on fire, and not for nothing, but understanding and embracing at a governance level the need to really sort of shift the way we think about and deliver the supports that we deliver. So that was a strategic planning process, which was a massive catalyst for us."

Also, participants shared that some leaders started the switch after criticism of the available programs at their organizations. Leaders' ideas on questioning and inquiring about the impact

of existing programs initiated a process of revamping them to make initiatives more inclusive and participatory for people with disabilities.

"Rhode Island has been under a consent decree since 2014. The previous executive director and the leadership team recognized it as an area that could be done differently, and they started building it in 2017. Up to that point, the historical day program was more setting-based. But they weren't doing any work on it, about how do we move people into the community."

Support Requests

Support requests were another factor in transitioning to more individualized and inclusive services. The families of people receiving support played a significant role in driving these organizational changes by communicating their wants and requests for more inclusive programs.

"Well, we were doing it before the regulation change, and it was so holistic and awesome. It was almost like a person-directed system that was set up in the state. So, what prompted us to do it? [The organization] was established by parents in our community that wanted more for their children when they left high school. So, it really started out as a vocational program."

Parents with children with disabilities played an active role in the transition to more community-based services. Some participants described parents' requests for inclusive educational programs that would lead to new progressive initiatives.

"We were founded in 1988 as a Family Support Program by a group of five moms who all had kids with disabilities, and all hated the options that they saw for their kids. Focus was heavy on education, because their kids weren't even really welcomed at school at that time. Any education options for them were institution-based and really segregated, really isolated. So, they originally applied for a state grant and used that initially to go to progressive provider structures and get some conceptualization about what was possible. And so we did that, and we were really successful with just the community building aspect of that, and supporting families to support one another, and it worked out really well."

According to interviewees, some of the initiatives started by parents determined the organization's future and guaranteed their definitive transition to inclusive services.

"So, we were one of Arkansas's first licensed, first providing Medicaid waiver providers to provide supported living services. So, from day one, that's how we've always supported people from the beginning, and how we kind of continue to scrap and fight to be able to maintain that ability to support people that way today."

Participants mentioned that people with disabilities also demanded a switch to inclusive services. There seemed to be a push toward self-directed services from people with disabilities,

which initiated a request for services change from organizations. This initial push and request moved organizations to an eventual transition to inclusive services.

"That was prompted by lots of people saying some things have to be different. Those people are people we met through just our connections, service provider work, and typically people through an organization called People First. And there was the demand and push for something different. The push was that self-directed services started then in Maryland, and then professionally for me, my moves have always been to a more pure place where people are in charge of their services. It really did all happen at once."

State-Based Changes

Changes in state policies also lead to a gradual transition to community-based and individualized services. Policy change provided the legal infrastructure for organizations to guarantee such a service model change. Organizations felt supported and validated by states to proceed with providing more inclusive services.

"The rules had changed so that we could provide support in more independent settings, and so that people could spend time at home alone. A lot of it would have to do with the rules changing."

Another participant specifically highlights California's policy-driven initiative to move away from a strict medical model towards more personalized and inclusive supports, making state policy a significant catalyst for organizational change.

"Historically, in California, there have been individualized planning processes like the Individual Family Service Plan (IFSP) for younger children, which transitions into the Individualized Education Program (IEP), and eventually into the Individual Program Plan (IPP). Initially, these plans were heavily focused on medical care supports. However, there has been a recent drive from the state level in California to make these services more individualized and inclusive, leading to revisions in these planning documents."

This indicates how policy changes at the state level, like in the case of revisions to existing individualized service planning documents, have directly influenced organizational shifts toward providing more inclusive and individualized services.

Shifts in state funding mechanisms also directly influenced organizational approaches to delivering individualized, inclusive services. A participant discussed how individual state grants allowed organizations in their state to deliver highly personalized support. However, changes in Medicaid funding regulations significantly impacted service delivery models, compelling organizations to adopt a medical model aligned with Medicaid reimbursement guidelines.

"We started very early in Alaska, before Medicaid allowed billing for supports in home and community-based settings. Initially, in 1995, Alaska provided individual grants directly to agencies to deliver individualized services. A person came with $40,000, and the agency provided individualized services specifically for them. However, around 1997, regulations changed, forcing us to transition from the state-funded individual grant model to the Medicaid medical funding model."

Increase Capacity

Another decisive factor driving the switch was the aim of increasing the service capacity to support more people to meet more needs. A leader mentioned that with the intent of supporting more people and effectively meeting their diverse needs, organizations increased their capacity, which was a decisive factor driving the switch. The positive outcomes observed reinforced the decision, highlighting the value of individualized and inclusive services for meeting increasing demand and diverse needs.

"We were growing, and we felt shifting to individualized services was a way to support more people. A significant driver was that we served many individuals with severe behavioral needs. Initially, we moved individuals into their own bedrooms rather than shared spaces, then transitioned them into apartments. At first, we placed two people per apartment, but eventually each person had their own individual apartment. Throughout these transitions, we consistently saw a decrease in challenging behaviors. So that was another big reason, too."

Another participant discussed how increasing capacity allowed their organization to support a broader range of people, particularly those previously underserved or completely unsupported. This organization developed a transitional program of support options for people who do not qualify for state funding but who still face significant challenges. This is an example of how the organization expanded its reach and improved outcomes as part of the switch towards individualized and inclusive supports.

"Everything we do is very much individual-centric. It ensures that we are meeting the support needs of that individual and meeting their needs. We pretty consistently are looking at what needs are being met, what needs are being missed, and how can we help fill those gaps? So that's where the transitional program for people who don't get state funding came from. We see a lot of people who have a disability, but are independent enough, the state is not funding them, and those are the people who end up in jail a lot because people don't understand why they're making the decisions that they're making. So we developed that program. We launched this transitional program about a year ago, providing young adults with weekly group sessions, similar to group therapy but more focused on shared experiences, as well as weekly one-on-one life coaching, whether in job skills or independent living skills, depending on their immediate needs."

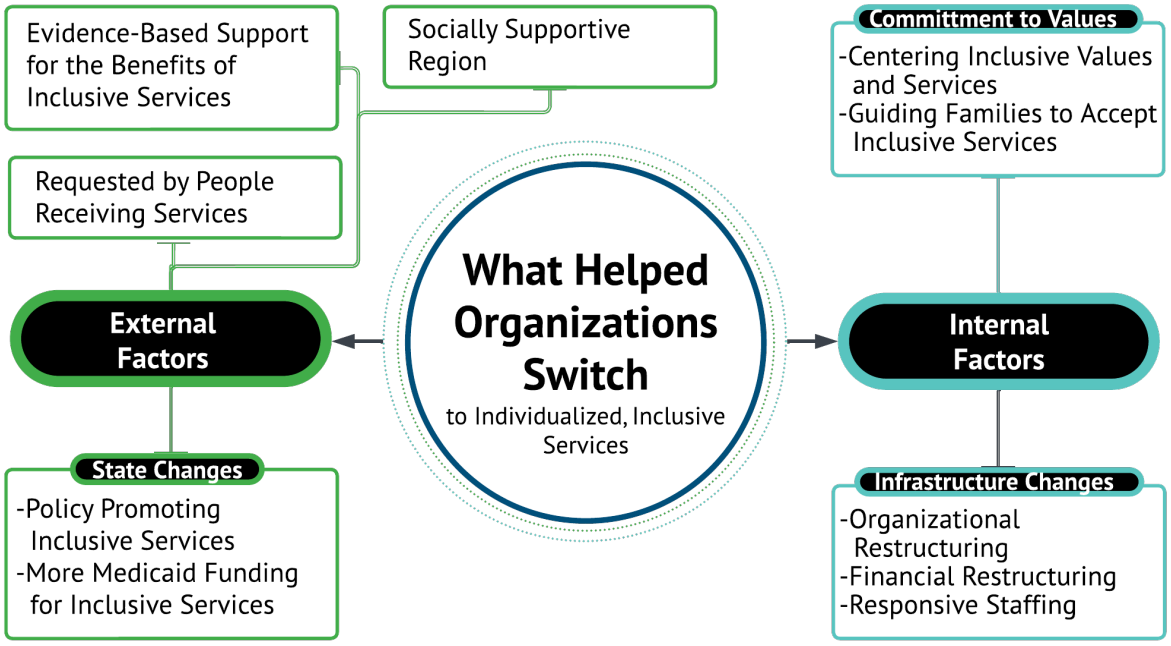
One of the interviewees talked about how the scarcity of residential services acted as a catalyst to diversify service offerings, leading a switch to more individualized, inclusive services. This participant described how insufficient residential capacity prompted their organization to expand and strengthen the provision of community-based supports.

“I think it's just that the desire for services outpaced the beds in our homes, so people wanted our services, but all we could really offer was community support. That's also really great, because a lot of these folks will work during the day and then have the opportunity to do something that they want to do in the community, in the evening or on the weekend, get a break from siblings or parents, and just kind of have that time to adventure out, do something that's fun for them.”

What Helped Organizations to Make the Switch

Interview participants provided insights into what factors helped organizations to switch their services to Individualized, inclusive services. According to interviewees, there was a combination of external and internal factors. Some external factors included changes in state policies and funding, regional-specific support, direct services requests, and the rise of evidence-based support. On the other hand, participants mentioned internal factors such as Infrastructure changes and commitment to values (see Figure 4).

Figure 4 What Helped Organizations to Switch to Individualized, Inclusive Services



External Factors

Among the external factors, the state changes are related to specific changes in policies promoting inclusive services and more Medicaid funding for inclusive services. Participants mention the critical role Medicaid waiver funding plays as an external factor enabling organizations to deliver individualized, inclusive services sustainably. For organizations, policies like Medicaid waiver funding are a financial resource that serves a critical factor stabilizing and improving service quality. In this regard, more supportive state changes strengthen relationships between staff and service recipients and provide emotional reassurance for families while ensuring Individualized and inclusive services.

"Having the Medicaid waiver funding available is essential — it would be extremely challenging to rely solely on private donations or grants. Without the waiver, providing inclusive supports would require significant fundraising. Medicaid waiver funding enables us to consistently deliver individualized, inclusive services and adequately compensate staff, leading to greater staff retention. This stability means staff build deeper relationships and provide more meaningful and

personalized care. As a result, individuals receiving services experience more meaningful growth and improved quality of care. Additionally, knowing that the funding and supports are stable provides families comfort, as they trust the consistency and quality of the services their loved ones will receive."

"I think that the drive of HCBS has really had everyone looking at things in a different lens and promoting the individual services and inclusive services."

According to another participant, state policy and funding structure changes also incentivized the shift toward more individualized, inclusive services in their organization. The participant discussed how Maryland's policy change to financially favor smaller, individualized supports over congregate care created a practical incentive for organizations to adapt and align with these priorities, thereby facilitating more effective and personalized service delivery.

"Another significant factor was Maryland's policy shift around 2021 or 2022, which fundamentally changed how the state funded support services. Maryland inverted its funding approach, making smaller, individualized supports more financially viable by funding them at a higher per capita rate compared to congregate care."

The active role of people receiving services in requesting an organizational switch was another fundamental factor facilitating the transition. One of the interviewees described how community demand and the inherent appeal of inclusive services served as a driving force behind organizations shifting to inclusive service delivery models. There seemed to be a high demand and positive perception of individualized, community-integrated support, leading organizations to change practices to meet the needs of people and their families.

"We really ramped up from the beginning, we had just more folks interested in desiring our supports, and could live with us. Some of that is because our model of inclusion is desirable, and there's a real want and need for folks with IDD to be in community with and without other people with and without intellectual disabilities. The idea that someone's loved one could become part of a community, still maintaining their family, but growing with others is something that folks are drawn to. I think the need being evident that folks in the community want our supports or want to become part of this community. I think that was the first kind of way that the ball got rolling."

Finally, a participant talked about the external factor of geographic localization. In particular, they discussed how regional cultural and philosophical environments can significantly influence organizational decisions to adopt individualized and inclusive support. This interviewee provided the example of the District of Columbia, Maryland, and Virginia region's broader social and cultural values, with particularly progressive perspectives on autonomy and inclusion. These socio-environmental factors contributed substantially to their organization's shift toward

person-centered practices, recognizing the inherent diversity and unique needs of people with IDD.

"The DMV as a region of the planet is just a little bit more socially progressive. I think that the environment, the geographic region, and the space within which we were birthed in the first place and still continue to sort of reside both give us a better shot at staying person focused, staying outcomes oriented and staying individualized."

Internal Factors

As part of the internal factors included in infrastructure change, participants talked about financial restructuring the organization as a critical factor in materializing the switch to inclusive individualized services. For example, one interviewee discussed the mindset shift of their organization towards ideas like strategic human investment.

"Putting our money where our mouth is. So structuring the way we think about supports, where we invest dollars, how we invest dollars, introducing the concept of strategic human investment. Because the mindset historically has been to invest in things. And so we introduce the possibility of investing in humans, which is sort of an interesting way of thinking about it…"

This participant also mentioned how financial infrastructure changes related to the organizational restructuring led to impactful ontological changes. The participant talked about the chain effect of these kinds of changes, which led to improved inclusive services.

"Then really putting the dollars where individualized supports, can be, in fact, catalyzed and fueled with resources, and that went to everything from policy and procedure and how we think about creating a policy framework that forces an individualization in the way we think about the work that we do, and introducing new language like 'customization of supports.'"

Another participant talked about the critical role of staff in supporting these infrastructure changes. The interviewee described the impact of responsive staffing in completing and ensuring the transition to individualized services.

"The biggest thing is staffing, since so much of it takes place on evenings and weekends, which are already some of the harder times to staff. And at the end of the day at our group homes, we need to be available 24/7, and a lot of our staff is shared between both, and so if you start guaranteeing services, you really need that infrastructure of staffing and hiring…"

Some participants talked about the role of leadership in organizational infrastructure change that helped their organizations to switch to individualized and Inclusive services. One participant talked about the influence of leadership in materializing the switch. This person discussed how leadership change brought new ideas and perspectives that supported the organization's movement towards inclusive services. Another interviewee talked about the

impact of leadership decisions in making the switch happen and talked about how restructuring organizational leadership can streamline the implementation processes.

"Our entire administrative team came from New York State, which is farther ahead than Florida in terms of where services are provided. So, coming with an understanding and knowledge of the transition that New York state made in their services, I think, really helped bring that to our organization. He came down in 2017 and brought a lot of people with him. So there's definitely more of a that individualized approach mindset that came with that, that we've been able to bring into and adapt."

"So instead of a traditional kind of top-down organization, she built a leadership team of an executive director, myself, but then 10 directorship positions underneath, and in that, she inspired and continued to help them grow in terms of Person-Centered philosophies. And in doing so, not only if you were the Director of Community Supports day program, if you were a Director of Residential you still applied that basic understanding of, what can I do for a person that's based on what their needs are, rather than looking at people groups, but looking at them as individuals."

Another relevant factor in helping the switch happen was the organization's commitment to values by working to shift values in others. An interviewee discussed how impactful the efforts were in guiding families to accept inclusive services. This person highlighted how, on some occasions, families are the ones hindering the switch to inclusive services.

"It took a while for families to believe that too, and still, even now … Somebody we just looked at in the last year, we would take him out of our state institution and have him live in an apartment complex where we knew he would be very well supported. We were pretty confident that he would be fine here in an apartment. There was enough staff support, because some of our apartments have a lot of staff support, and his family said, 'No, he can't live in an apartment.' And so families really believe that's not a possibility. A common misconception, they just can't see beyond group, homes, and other entities."

Other participants talked about organizations' commitment to values as a driving force to make the change happen, from their conviction to their decision to make the changes that are needed. This person talked about the transformative capacity of organizations to break with legacy ideologies like the commitment to financial efficiency and disrupt the status quo by proposing progressive perspectives.

"Will just sort of amassing and then touching and embracing the will to do it. The old generation of the board looks at its balance sheet and sees $17 million worth of bricks and sticks and says, 'Well, that's the way we must be. There's this sort of inertia. That's the way we've always done it.' And so, we had to blow that kind of up a little bit."

Facilitators to Individualized, Inclusive Supports

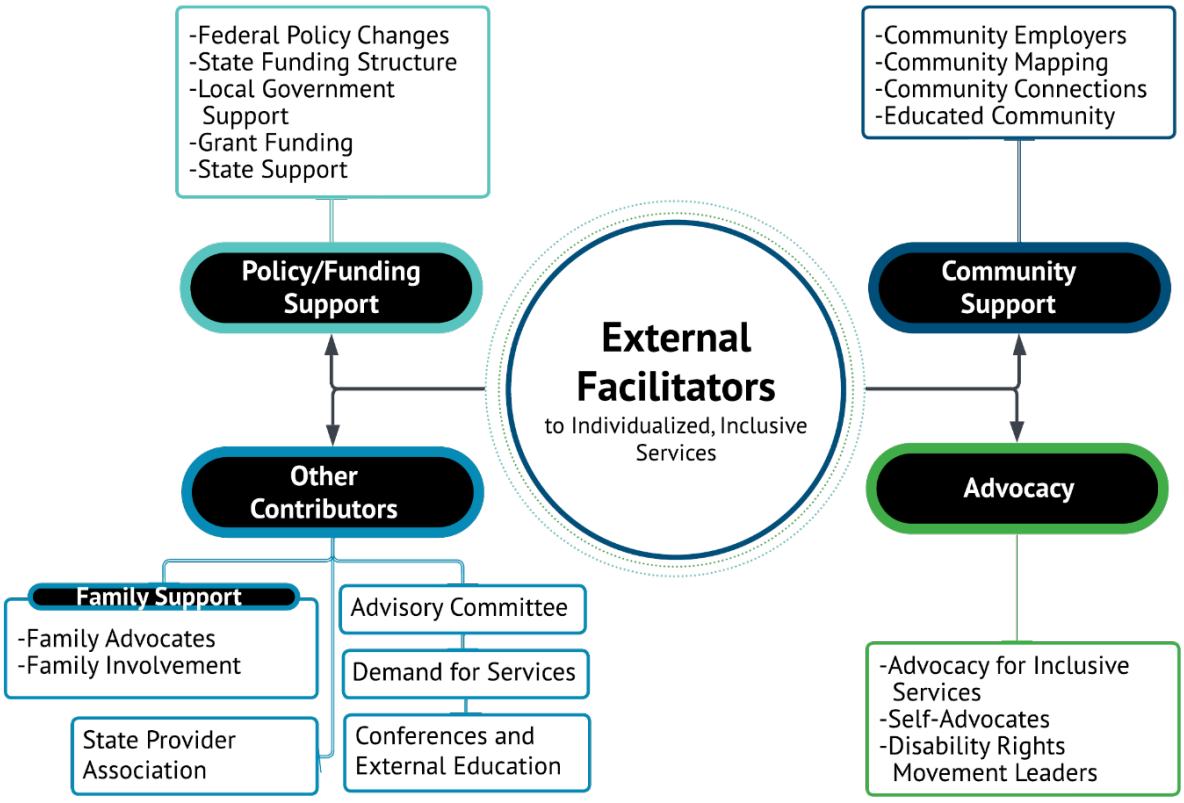
External Facilitators

We asked interview participants what external factors, or things outside of their organizations, helped them deliver individualized, inclusive services. Factors they discussed related to four main themes: policy and funding support, community support, advocacy, and other outside contributors (see Figure 5).

Related to policy and funding support, many participants talked about how federal policy changes played a role in shifting some state funding structures and focusing more toward supporting people with IDD in the community.

"You can tell the states where there's values-based leadership, and you can tell the states where they say, 'Yeah, no, we don't think so,' right? Which is why it's so important to preserve CMS, because I'm old enough to remember when states were in control of Medicaid, and it wasn't pretty. At least with the federal protections, if people have the waiver funding, they have rights within that system to not have to live in an institution or a nursing home or a facility."

Figure 5 External Facilitators to Individualized, Inclusive Services



Some participants also spoke about the value of grant funding and additional local county support for programs that encouraged individual services in the community that were not financially supported by state or federal funding, such as environmental modifications to a

home, paying for security deposits to get established in a home, and mental or behavioral health support.

Regarding community support, interview participants noted some key facilitators of individualized, inclusive services as: employers who recognized the value of employing people with disabilities; community mapping or connections, where providers knew and had relationships with many businesses and organizations to enable people with disabilities to connect with other people who had shared interests; and a surrounding community that is educated about disabilities so they welcomed people with disabilities.

"We try to understand not only a person and what they want and need, but also where they're living, or where are we providing that service. Because for some people, we're providing community participation services, which means we're picking them up at home, or we're meeting them somewhere in their neighborhood, and then our work is helping them be in and of their community. So, I see a key training and skill development for the direct supporters as, 'Do you understand community mapping? Do you understand and know the places, know the people that are in and of this community, so that you can best help that person based upon what we know they like?' And how do we set it up so that people, namely the direct support professional, is putting the best foot forward, literally, in a way that then positions that person with a disability to be welcomed into that space, to be included in that space."

Participants spoke about the importance of their organization consciously being involved in the community and building relationships with organizations over time.

"We definitely have a welcoming community. For a lot of years, we've been doing things in the community. We've been looking for opportunities to be involved. So now the chamber [of commerce] calls us and says, 'Hey, we got this going on. You want to join with us?' And we have a lot of relationships like that with the schools. They really depend on us for some for some things. I bet it's been close to 15 years that we've done pumpkin carving every year with the middle school. So, we'll get 67 pumpkins, 60 or 70 pumpkins and invite some of the middle school classes and some people we support to carve pumpkins. That's really been cool. … Another thing that that we do in our partnership with the middle school is we have a Lead for Life program where people with disabilities go and teach kids about disabilities and about inclusion. It's a three-day curriculum where we go into the sixth grade PE class, teach a little bit about disabilities, and people we support are being the teachers, and then we're playing games in the PE class, so they get to interact together, and so they build relationships in that. It's really cool to see the relationships they build in those three days, and how they develop even from between day one and day three. And we've been doing that for about 15 years, I would say, and we have really seen a lot of who we call our 'Lead for Life kids' come and they become our employees. And so that's been a really nice circle. … We have a lot of community partners who want to be involved. We've built a lot of them over the years."

Interview participants also credited past disability rights movement leaders, current self-advocates, and overall advocacy for more inclusive services as a facilitator to their offering more inclusive services.

"We have a very good local self advocacy group. … I find that I rely on them quite a bit to make sure that we are always staying true to the to the voices of people with disabilities."

"I think the Disability Justice Movement, and the leaders in that movement, who continue to push for not just, 'Yeah, we have rights,' but 'We have a right to exercise those rights, and we have a right to be seen and to be treated with equity and respect.' So I think first and foremost, there's that there's the driving change from those with the actual lived experience."

Participants also named other facilitators beyond their organization that helped make delivering individualized, inclusive support easier. Family advocacy and involvement, as well as families and people with disabilities asking for more inclusive services, help these services be more prevalent and successful.

"I think that this younger generation of families are continuing to stand on the shoulders of the families that came before. They're sending their kids to typical neighborhood schools. They expect for their children to be included in classrooms with typical children, and so these kids are graduating, and for those fortunate enough to get services, they're not going to be sent off to a group home. We have families who want to be involved in those decisions. We see more and more people opting to use self direction. We're meeting people younger and younger, and so I think also with that continuing to introduce ourselves to the school professionals and to work with family networks to make sure that we're reaching people younger and reaching families an earlier time, so that we can really better inform them and give them the tools that they need to advocate for their family members before they graduate."

Outside entities, such as state provider associations and advisory committees of an organization, were also named as being helpful to facilitating individualized, inclusive services. Advisory committees supported by the organization, complete with community members and people with disabilities, were said to be helpful in making decisions and understanding the impact of those decisions. State provider associations were said to be helpful with training and network building to improve services.

"We have an amazing statewide provider association that is just doing dynamic things, bringing people together, and training on person directed services and what that would look like. So that's super positive."

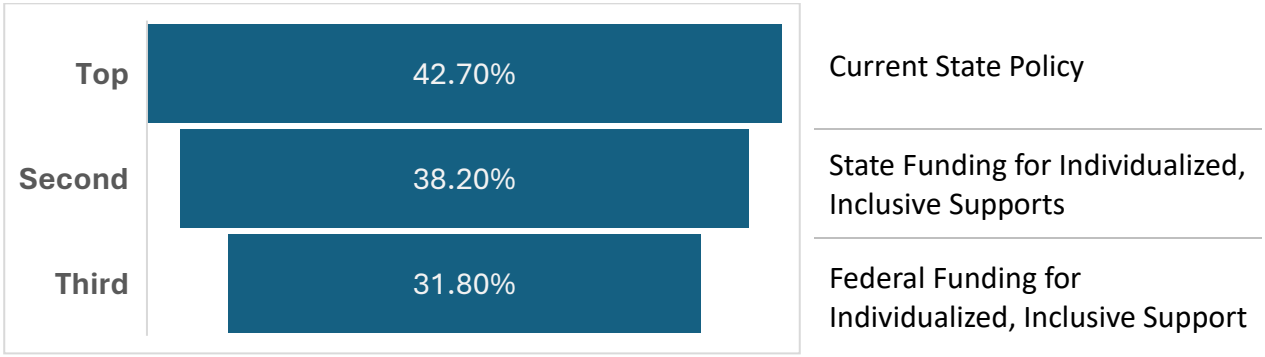
Participants also attributed participation in outside training and conferences, even those not in the disability field, to helping deliver better services.

"Members of the leadership team that I oversee are always looking for new resources, and so they're the ones who are more likely, along with myself, to find best practices that really make us think, 'Wow, that's something we want to look into.' Four of them just attended the Reinventing Quality Conference in Baltimore and one came back and said, 'I've got a really great idea for that DSP Council of bringing together DSPs,' which was innovative. So I think that we try to always keep apprised as to what's out there, constantly reading, constantly attending things and picking the best that we find."

"We access a lot of different training platforms. The conferences that we attend, and we attend conferences that are not human service related a lot, and our commitment is that we go, we listen, and then we come back and figure out how we apply that. The principle is: these problems really aren't unique to us. Somebody else in another industry has this problem and has probably found some effective ways of dealing with it. We just don't see it as a solution for us, because it's in the construction industry. But that doesn't mean it's not applicable."

Survey participants were also asked, *"In your opinion, what are the **TOP 3** external, community, systemic, or societal factors that **HELP** your organization to provide individualized, inclusive services and supports:"* and given 16 options to select and an *"Other"* write-in response option. Their responses mirrored the role of policy and funding supports identified in the interviews, with the largest number of participants (42.7%) selecting "*current state policy*," the second most popular choice selected was "*state funding for individualized, inclusive supports*" (38.2%), and "*federal funding for individualized, inclusive supports*" (31.8%) was the third most popular external factor selected (see Figure 6). "*Other*" write-in responses for facilitators that help provide individualized inclusive services included: "none," "I don't know," available funding for transportation services, making it an organizational priority and part of the mission statement, the state agency recognizing and providing incentives to agencies for inclusive services, and collaboration with other like-minded, person-centered, inclusive organizations.

Figure 6 Top Three External Facilitators to Individualized, Inclusive Services



Organizational Facilitators

The policies and practices of organizations can greatly impact the types and quality of services they provide. We asked interview and survey participants to identify organizational facilitators for their delivery of individualized, inclusive services. Interviews were dense with key facilitators within an organization that were categorized into four main themes: funding factors, employee factors, leadership factors, and operational factors (see Figure 7).

Funding Factors

Most practices mentioned by interviewees related to funding factors were categorized by organizational practices, practices related to employees, and practices related to people with disabilities that they supported (see Figure 8). Practices such as keeping overhead low and realigning services to funding that is available helped organizations make the most of existing funding. But executives also mentioned using funding to intentionally help advance individualized, inclusive services by creating specialized positions, like a Community Connection Specialist, and investing in research to track community inclusion efforts.

"We have specialized direct support professional positions. So, while we have the standard, historical direct support professional, we also have a position called the direct support professional community connection specialist, and their job entirely is to assist people in building natural inclusion in the community, so they eventually no longer need to apply and have paid support. So whether that means, in some cases, transportation or just connecting with an organization, they build those connections, then they fade back."

Funding was also used to support employees, which helps keep employees educated, engaged, and stay at the organization. Interviewees mentioned offering equity raises, implementing programs to support staff to reach their personal goals, making public funding work so they could offer better pay to employees, and paying staff to participate in activities with the people they support.

"When managed care came online, we really started trying to learn about what are the possibilities, what can look differently, what are the ways that we can really structure? We've done a lot of realignment internally but being able to access consultation billing that we can utilize, and trainers and supports for support teams and add to that."

"We raise money so that our staff, when taking our core members on outings can also fully participate. So if we take someone to Starbucks and they get a drink with their money, our agency will pay for us to also get something. When you're with somebody, they don't want to be the only one drinking that drink, and you're just like drinking nothing, or they don't want us to have to pay for it ourselves, just like being able to fully do things together. Sometimes we get to go on trips together, or go to Six Flags, and that's all taken care of by our agency for staff. It just really allows everybody to be fully participating in what you're doing without it being a burden for anyone. You're just able to fully be present and have a good time."

Figure 7 Organizational Facilitators to Individualized, Inclusive Services

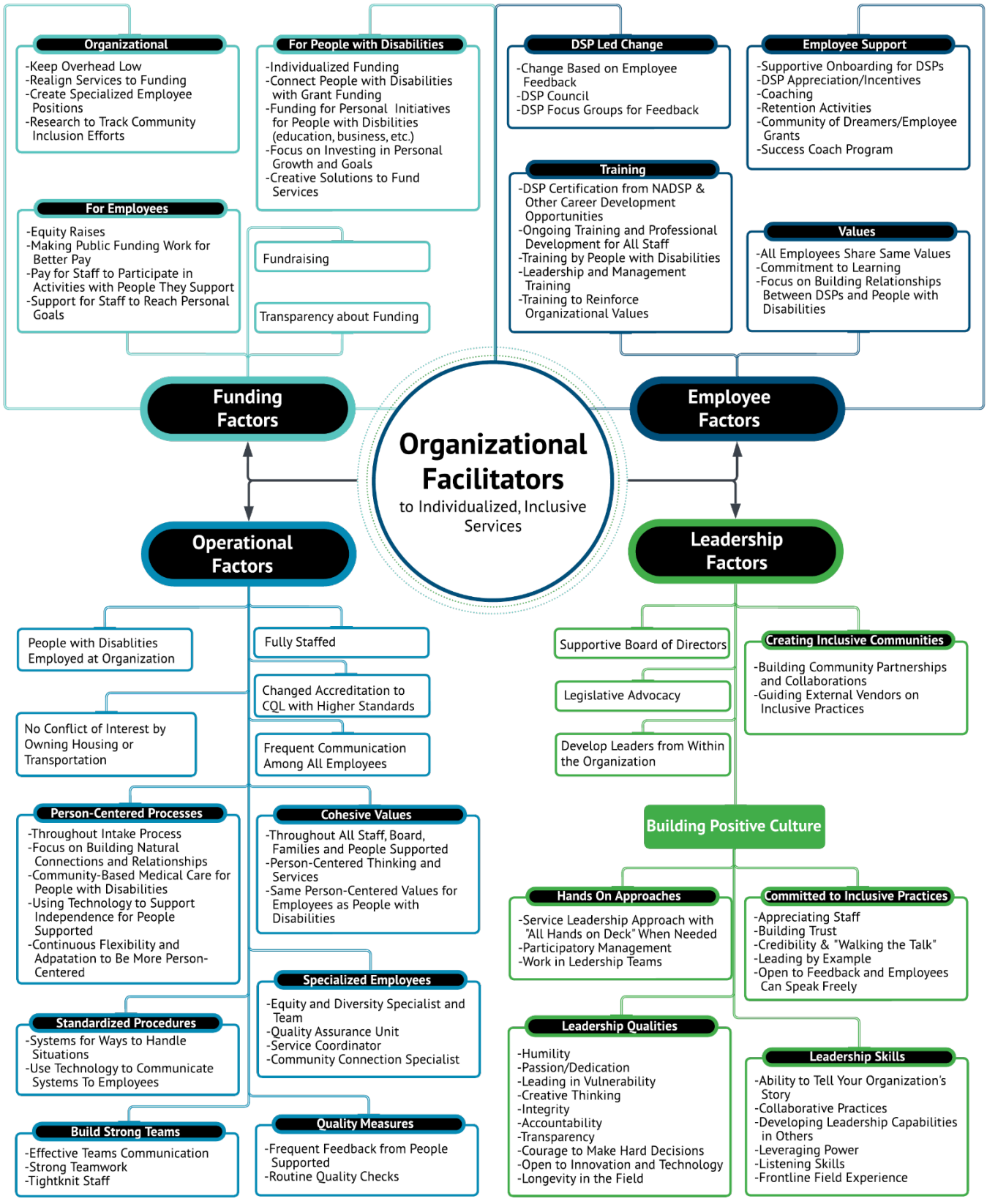
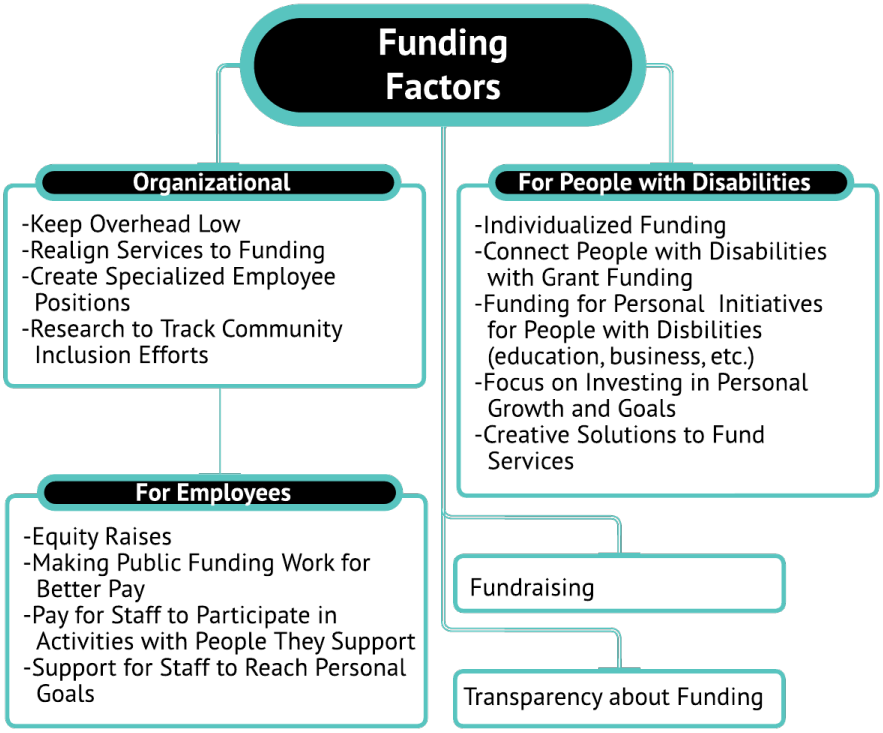


Figure 8 Funding Factors That Facilitate Individualized, Inclusive Services



Funding as it relates to people with disabilities also contributed to organizations being able to deliver individualized, inclusive services. Executives interviewed said that having individualized funding for each person and finding creative solutions to fund services, such as fundraising and helping the people they support apply for small grant funding for housing or other services, was helpful to providing inclusive services. Additionally, some organizations provided funding for personal initiatives of the people they support, such as furthering their education or supporting their new business.

"One of the smaller grants we tap into is through the Alaska Mental Health Trust, they offer many grants, up to $2,500 per person, and that allows individuals and in their beneficiary base, and this could be elders, disabilities, children with disabilities, to tap in and get a burst of money to support them in their home environment. This could be for environmental modifications, so that's really helpful. The other funding source we tap into, and this is a different group, but if they go through our behavioral health program for supported employment, they can tap into some money, which helps them establish a home. Oftentimes, the most expensive thing to have individualized supports is getting first and last month's rent and your deposit. So if you run through that, so if you're looking for employment and you're working with our behavioral health clinician, you can tap into that, and you can get set up and stable with an apartment, which is huge, considering how expensive everything is right now. So when I'm talking about individual supports, I'm really looking for that with that whole continuum of people."

Many executives mentioned fundraising as a means to supplement public funding and support additional programs and initiatives needed to push individualized, inclusive services forward.

"We have a major fundraising event every May. It's a walk that we have, and all that money is dedicated to special projects that people will help people become more part of the community. It doesn't pay for any salaries. It's purely there when someone says they want to do something. For example, we had a gentleman who wanted to start a cornhole event for a local Knights of Columbus. Last year, he organized it with money from this project. He had the second one last night. So, it's really dedicated to being able to say, we have this money set aside for just this and people who have used it for all kinds of really interesting experiences. Some people have put together a series of lending libraries. They've gone throughout a town and just built them, and they that's a way to connect people. Someone else has started what's called a doggy cafe, where they put bowls and treats out for the people walking by, and that gives them a chance to talk with them, get to know their neighbors. So, I would say that's one area we've really dedicated our fundraising efforts. The money that comes from fundraising towards those actual people be able to get those experiences, employment classes, art classes, all kinds of experiences that would be harder to obtain because the funding is so limited."

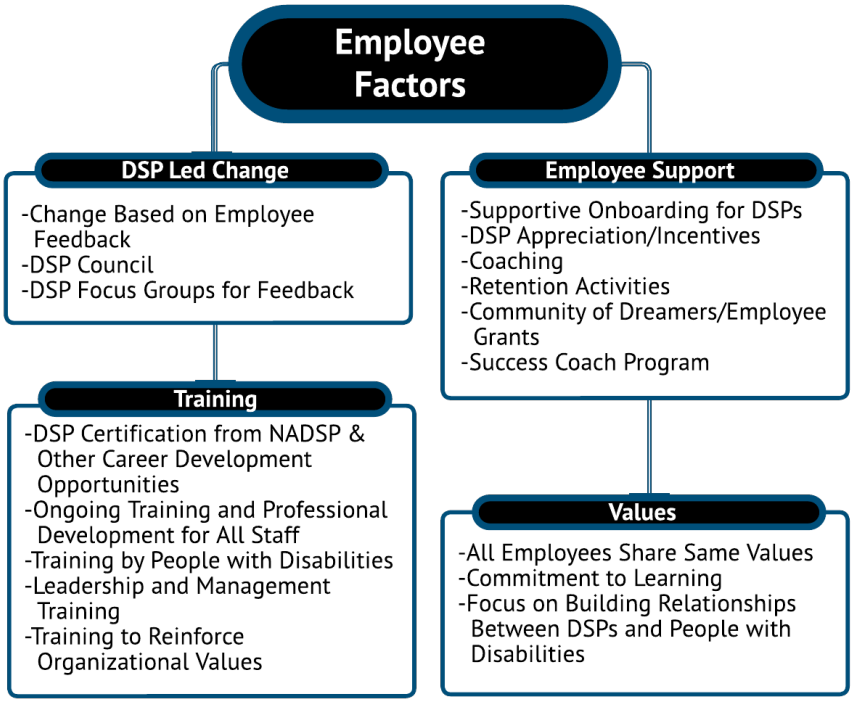
Employee Factors

Executives in interviews discussed how employee factors were integral to supporting individualized, inclusive services. Organizations invested in employees in many ways so they were prepared, confident in their ability to deliver quality services, and felt valued and supported by the organization, including: supportive onboarding for DSPs, coaching, retention activities like DSP appreciation and incentives, special programs like employee grants and a Success Coach program, and special staff dedicated to helping frontline employees problem solve (see Figure 9).

"We invest in the whole person — we don't just invest in the person at work. We invest in them in their entire life. Like, we don't ask people to carry two phones and have two calendars. We say your life is your life, and we all work way more than we should. So we have a lot of grace for people having autonomy in their schedule, so that they can still take care of their families and their personal lives, but do their work as well. We have a program, it's called Community of Dreamers and basically, it's a seminar on dreaming. It's offered to people we serve, to their families, and to all of our employees. We have a scholarship that people can apply for — it's not a huge one, but they can apply for it and declare a dream. And it doesn't have to be work related. It could be, 'I want to buy a house.' 'I want to I want to retire.' Even if it ends up taking them away from the organization, we'll give them a coach, somebody that can mentor them through that and be a champion for them. And then they can even apply for a scholarship towards that."

"That's what our Success Coach does, in addition to making recommendations to the organization about progressive thinking, they say, 'Let's make sure we follow through with DSP appreciation and give incentives.'"

Figure 9 Employee Factors That Facilitate Individualized, Inclusive Services



"We're using a realistic job preview that was put together about 10 years ago … The realistic job preview has allowed people to screen clearly what the job entails, and therefore self-select out if they feel it's not for them. We've recognized in our studies that the biggest turnover we have was in the first six months, and so we were hoping a job preview would save some of that. The second thing is we do structured behavioral interviewing. So instead of asking what often is open ended, or yes/no questions for people, it truly is focusing in on how a person will respond to situations. So, we give them a scenario, they respond, and again, the hope is that they truly will match with a situation that we're looking for. Well, mostly we're looking to a true situation that they're going to encounter in a setting that they're potentially being an applicant for. … And then we do in play check ins, and that is a period where we check in on people within one month, three months, and then six months, and we're following them along and hearing about their experience so we can help walk them through the first six months, which has been identified as a challenging period for people."

A key way that organizations supported their employees was to provide appropriate and ongoing training opportunities. Training mentioned by interviewees ranged from DSP certification from NADSP and other career development opportunities like leadership and management training, to training led by people with disabilities receiving services and training centered around organizational values.

"The most important thing that we do? DSP training—Direct Support Professionals are the key to good supports."

"Training has been provided to the service coordinators and all the employees within the organization on implicit bias, HCBS, and self-determination."

"I have a participant that came to me about 14 months ago, and she said, 'I want a job.' And I said, 'What do you want to do?' She says, 'I need to train.' And she has a cognitive disability, which is different, because we're used to people with physical disabilities leading. She said, 'I need to train these DSPs.' And I said, 'Okay, let's do that.' And she said, 'I want to get paid for it.' I said, 'What do you want your job title to be?' So, we created a job description, and her and I do this in tandem training of our journey of getting to this person-directed spot. She tells them exactly what she needs from them and it is the most genuine training that we do for our new folks. It's only an hour and like 15 minutes, but it really sets the philosophy tone. Having her speak as an equal on the leadership team to our new hires has been the most powerful. We presented it at a state level as well to encourage other providers to put people with disabilities, and not just physical disabilities, but cognitive disabilities too, on boards, in leadership positions, and in training positions, and in hiring and firing decisions."

"We have a training model for every position. We call it a 'passport' – so we've got an established checklist of all of the things that information that people need based on the position. If you work directly with an individual, then that's a whole other passport, because it's, it's about the person. And then there is benchmarking. So, at 30 days, you should be able to do these things independently, and these things with help. And we have the whole first year of employment benchmarked in that way. And then every position has a Leadership and Development expectation, that even our direct support staff do. So we've invested a lot into the concept of our job is to raise up leaders and we can't grow as an organization if we don't do that. So we've got a decently developed training system and that is kind of a pillar of how we're able to serve the amount of people that we do well. Not just serve them, but serve them well."

Many leaders we interviewed mentioned training about values and the importance of making sure frontline employees shared the values of the organization related to inclusion, self-direction, and building relationships.

"If you want people to care for others, you must care for your people. And so I think that's our philosophy here. We changed our mission statement to say 'empowering people to live a life they choose and love.' And we used 'people' as in all people, not just people with disabilities, but everyone needs to feel that way."

"We don't really treat employees any differently than we're training the people we support. At least, that's what we strive to do."

"Training, professional development, training, training, training, professional development. It's the introduction of a new language. It's the introduction of new concepts. It is shifting us away from 'caregiving' to 'support,' and defining those terms. Here's what caregiving means, here's why that ain't us. Here's what support means, here's why that is us. And really training about whose opinion matters here? Because it turns out, it ain't ours!"

"Our organization was founded with the idea that people with intellectual disabilities and people without intellectual disabilities have a lot that we can share with each other. Isolation is toxic for everybody, and so at the heart of that is being in community together. We are able to share the gifts that we can both all bring to each other's lives, and so I think we take a lot of time to train our staff and kind of stress that goal that at the end of the day, our core members are at the center. They are most essential community members, and also you matter! And then this should be mutually beneficial. I think that a lot of it starts with that training and the way that we even just welcome our staff. We have a lot of little celebrations and traditions of like, as soon as someone's new, they get a welcome sign. We celebrate the anniversaries of when everyone has joined the community. It's really small, but I think having kind of cultivated an organizational culture of celebration and welcoming. It translates beyond just our residents and then I think sets that expectation of this is how we treat people here which I think is really, really valuable."

"We have people that have been here for 32 years providing direct supports, and that has nothing to do with any magic sauce that we're doing as an agency. What it has to do with is that the culture of this agency is one that allows all of us to be in community and relationship with each other. And so what happens is that our DSPs form these human relationships with the folks that they support, and they grow to love them and care about them, and become really invested in them. And so, when we when we talk conversations about staff turnover and retention and development and things like that, you know, I try to always acknowledge that the people that stay here, stay here not because of anything that we've done right as an employer, but because of the relationships that they have with the people we support."

Organizations supporting inclusive services also reinforce values of person-centeredness by turning to employees to help make improvements. Interviewees mentioned involving all employees by developing a DSP council, forming DSP focus groups, and setting up systematic ways to receive feedback at their organizations.

"We just put together a DSP Council. They will become an essential part of our strategic planning and a lot of agency decision making going forward, as well as the creative aspects. I expect to be able to rely on them when it comes to, 'Hey, we really want to innovate some of these community inclusiveness. What do you guys think? What can you do?' We want to give them the opportunity to go off and do some really interesting projects."

"We make sure that we're looking at our policies and procedures and one of the things we did was, with the help of the Council on Quality and Leadership, we now have a grievance procedure for people that we support, as well as the staff. … That has led to a lot of changes using that process that affects the employees and the people we support."

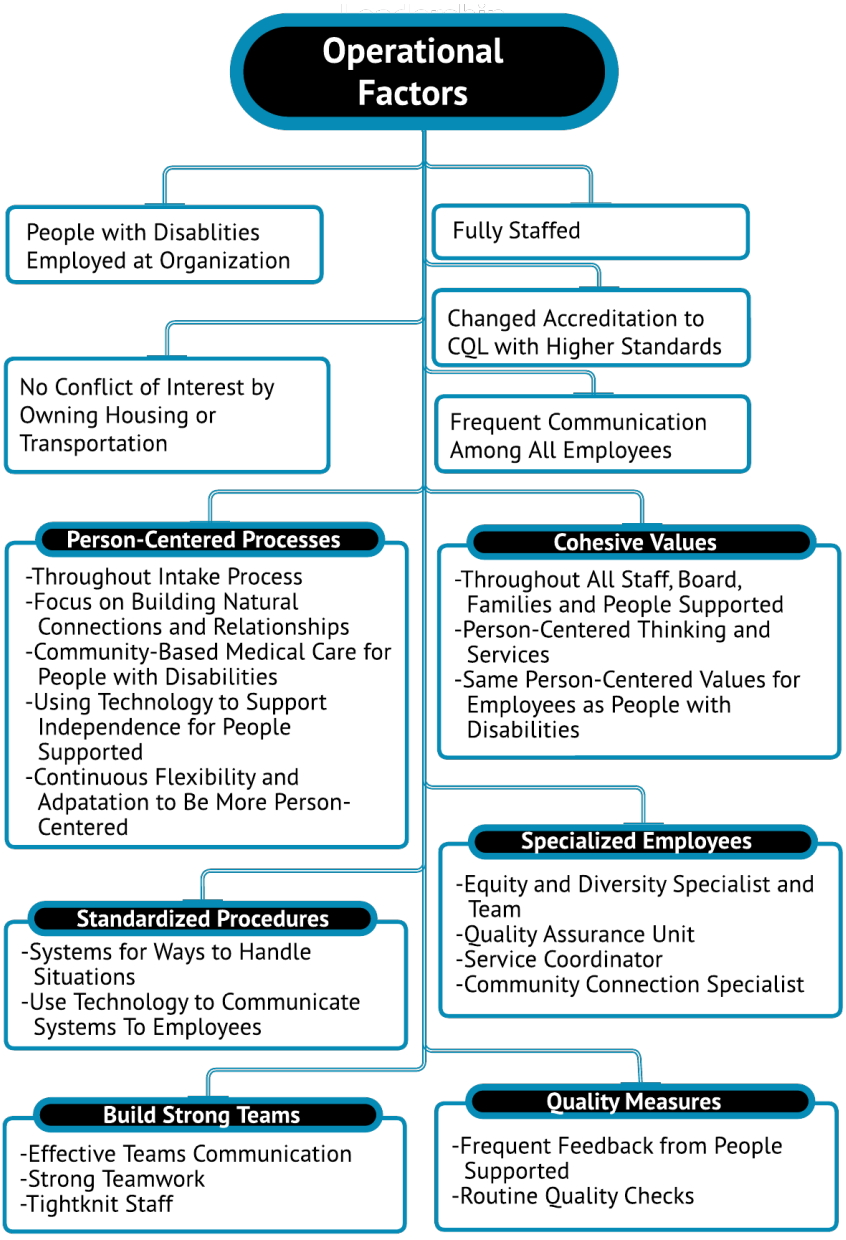
Operational Factors

Interview participants emphasized the influence of operational factors in delivering individualized, inclusive services. Specifically, factors were grouped into six main themes: having cohesive values, person-centered processes, having standardized procedures, developing

specialized employees, building strong teams, and having quality measures in place (see Figure 10). Participants also said that having people with disabilities employed at their organizations, being fully staffed, changing to accreditation with higher standards, encouraging frequent communication among all employees, and having no conflict of interest by owning housing or transportation helped promote individualized, inclusive services.

Leaders of organizations in this study emphasized keeping the same core organizational values of person-centeredness consistently centered with everyone working at the organization and with the people with IDD they support.

Figure 10 Operational Factors That Facilitate Individualized, Inclusive Services



"There's no pressure anywhere to do something that is not in line with [our values]. … So, everyone from an employee to a contractor [has the same values]. We don't want our bookkeeper thinking we should be doing something different. So literally, everyone understands what we do and supports it to a degree that nothing else would happen here."

"Could it be something as simple as actually speaking to real humans and asking and then taking their answers seriously to the following question, 'How do you want to live?' Because it gets to the places and spaces where I want to reside. It gets to careers. … The question really is, 'What brings you joy? What do you love to do?' We don't use 'jobs' anymore. We don't use 'employment' anymore. … We actually talk with people about careers, because it opens the conversation to the possibility of all sorts of stuff. So, let's say I want to work for the fire department. Well, right down here at Montgomery College in my backyard, there is a certificate program for folks who want to become a firefighter or an EMT or a whatever. And so rather than just thinking about a job, we think about a career. That sort of thing is just a mind shift, but it really all starts with opening ourselves to the possibility that if we ask the right question and invite the person to bust ass through the door, they'll answer us. And then it's our job to get to get to work, to support that human achieving that dream, that quality of their life."

Participants stressed the values of person-centeredness starting from the intake process and continuing in the way services are delivered, using technology to support independence, and being flexible in their supports.

"Anyone who comes in has a pretty intensive intake process that includes a lot of documentation, functional assessments on the individual that either they do or they do with their family and then an interview tour process, where they come and look and we meet with them and really get to know them as an individual, and then set up a very detailed plan that fits their specific needs. So, I think that process and insisting that people come and meet us one-on-one, so that we can make sure that we are getting the right support is important. Before, we were insisting we can go on what their people, maybe their family or a support coordinator or someone, would be saying, 'Hey, this is the service that this person needs.' And then we'd meet them and we'd be like, 'We don't actually think that that's the right fit for that individual. They need a different service.' So now we were very insistent that our staff must meet them to get to know them a little bit before we decide which service is the right fit."

"Ohio is a technology first state, so we have a lot of access if we know how to use it and how to get to it. We have a pill minder support where it can help people be more independent on taking their medications, and with less need for staffing, where the nurse would set up this machine and it helps the person take their medications. So we've been piloting that. We try to have communication devices for anyone who is nonverbal, and we seek out grants to take care of that. We currently have a grant right now we have three communication devices for three young men with autism who need help with communication. So that's where technology comes in. Also, just after the pandemic, how do you connect people with their community? Sometimes we had to think alternatively about that. And so all of our homes have technology in them —laptops with cameras so that they can participate in video calls, video meetings, zoom, it is more

personable and helps them stay connected to things that they appreciate in the community if for some reason, they can't leave their home."

A few executives interviewed also talked about the importance of having people with disabilities employed at their organizations in meaningful ways.

"The most important thing, particularly from a leadership level, is the firm commitment to the accountability of error and change that's necessary. Um, you cannot define and operate a structure of operation and business, stay anchored to that and consistent with that, and also meet the demands of the lives that evolve and unfold within your organization. … One of the things that I say a lot to people, is that in the work that we do, the goal is not to be right — the goal is to make it right. As a director, an officer, a leader, a manager, a coordinator, even a DSP, if we go into these situations in which we're being asked to support people through all realms of life and we approach those situations thinking that we're doing the right thing and what we've done is right, but the situation still isn't right, that the person's life still doesn't look like what they wanted to look like. There's still conflict, there's still a concern. If we respond to that with just the basic defense of me being right, even if I am right, then we make the situation worse. The situation is not right until it's right. And that's not ours to define. It's the folks that we support, it's theirs to define if that really is individualized and inclusive supports. It's difficult to really be able to navigate that."

Executives who were interviewed also talked about how technology helped them communicate with staff and streamline systematic ways of handling things.

"I think [during the pandemic] we really started to lean more on technologies use, updating our software so that it is more AI driven where it can do more for us so we can do our jobs better, to work smarter, not harder. So, we have a newer software program and, of course, that creates more learning curves and additional needs for training, but ultimately, it can help us in our system practices by being able to generate reports, being able to look at things in one system versus paper all over the place."

One organization even went so far as to develop its own software company to create technology that better met its needs.

"We actually started a software company because we started moving to digital, there wasn't a software from our experience that could tailor things to the complexity of our specific service. We have hours that are funded by lots of different places. So we started that software company so that we had a digital management system, so that things were readily accessible, because we had problems like one employee had all the knowledge, or even the paperwork, the plan, and then turnover, and then we lose that, and we start again, which impacts the person's services negatively. So, we have a lot of systems that are connected to this software. We've got systems for staff training, where the information is available on the go for them if they need it. So, if somebody ends up in the hospital, their person centered plan is even available to the nurses, things like that. So, there are a lot of systems connected to that for documentation, the way we capture daily notes. Now we kind of have a system for everything."

Organizations created specialized positions that are helpful to supporting individualized, inclusive supports, like an Equity and Diversity Specialist and team, a Quality Assurance Unit, a Service Coordinator, and a Community Connection Specialist.

"We have an Equity and Diversity specialist team that's been being developed and they've applied for grant money as well to encourage new types of services and supports."

Participants also noted the positive impact of having people with disabilities as employees at their organizations.

"One of the things that that we're most proud of is that we have people who receive services as an essential part of our organization. So, for example, three people are part of our orientation process. They lead a class, and they get paid as trainers. We have other people who are receiving services who take part in the screening and the interviewing process of new employees on site. We have meetings regularly that where we're saying, 'Okay, here's a strategic discussion,' and we include the people receiving the services in that conversation. There are other outlets for them to share information. Sometimes it's through their families. We include a lot of families and friends and support circles in that. And then lastly, I'd probably say that we, and this is not as uncommon, but we have members that we provide support to who are on our board and also on our Human Rights Committee. So I would say that whenever someone talks about elevating voices of people with disabilities, we try to demonstrate it. And where are the facet the agencies in right sounds good."

"One of the reasons why we struggle so much with leadership of the most impacted is that our approach to that is really an approach of tokenization, where it's like, 'Sure, we want to have a board member who is a person with a disability, but we can't find anybody.' You serve people with disabilities. What the hell do you mean you can't find anybody? What you're telling me is that you're not willing to modify, adapt your process of governance in a way that's actually inclusive of people. You're not willing to recognize and value their lived experiences receiving the services that you provide. You're looking for them to kind of come to this assimilated world of nonsense that has nothing to do with the services you provide. The most connected and pure thing that exists in the services we provide is the person who experiences the services we provide."

Interviewees also talked about how working to increase quality measures like routine quality checks and frequent feedback from the people they support have helped facilitate individualized, inclusive services.

"We continuously spend time talking to folks we support, asking 'Is this working for you?' My board is antsy with me because they want to hurry up and get to metrics. And I keep saying, 'Yeah, but we got to talk to people every day.' Every organization on the planet does satisfaction surveying, and I just want to throw up in my shoe because I'm super satisfied today and tomorrow something pisses me off, and so now I'm not satisfied. That feels super normal to me and super typical to me. And really at the end of the day, am I concerned whether or not I have sucked up enough to you today to make you tick the satisfied box, or is the conversation really

about what you as a human being with all sorts of dreams and aspirations have achieved today?"

"I think there are small ways, like every year folks have their annual ISP meetings, which is a great time to make sure their person-centered plan [is appropriate]. So, at the start of the year, really taking the time to be intentional about talking about likes, dislikes, vision for a good life. We try not to just tick boxes, but to really spend time on whatever that person might be able to articulate that they want. But I would say it's like a lot smaller in terms of, 'Is this person really living their life the way that they've shared that they want to?' I think it just takes a whole team of people at each of our homes and for each of our family support people to be routinely checking in and seeing like, 'Oh, is this different than normal for them?' Like, really knowing our people super well and saying, 'Oh, in the past, this is what you'd like, have you changed?' or 'Are you not able to access what you need for what you've said before is good for you?' So I do think it's hard to tangibly measure, but it's knowing our folks really, really well and saying, 'Oh, your behaviors changed,' or 'You stopped wanting to go to day program. What can we change about the environment? Or do you want to stop going?' That was something we had to deal with recently, and it's like, 'Oh, you just want to go in your wheelchair now. We can make that happen. You don't want to have to walk there anymore.' It's not as easy as, 'How many meta errors did we have this month?'

Organizations also increased quality by changing their accrediting organizations.

"Who you choose to be accredited with also matters. We switched from being CARF accredited to the Council on Quality and Leadership, because it's more happiness driven. Are you happy in your life driven versus how many times did you brush your teeth last week? Why would you brush your teeth if you don't have anyone who enjoys your smile?"

Participants recognized the importance of building strong teams to promote quality supports for the people with disabilities that they provide services for through effective team communication and strong teamwork. A few interviewees talked about how having close-knit employees also helped create strong teams and facilitate inclusive supports.

"When we do good things and we accomplish them, it's because we really have been able to connect people and empower participation and get buy in and involvement. And when we run straight into the wall, it's because usually I have had a three o'clock in the morning great idea with a really detailed vision that I absolutely know is a solution to something somewhere and it's going to make all the difference. And so I just come and say, 'This is what we're going to do,' and people can't see that vision, and it just overwhelms them, and it paralyzes them, and it usually makes it worse."

"We are a tight knit, smaller nonprofit … I've worked for many other organizations that are bigger, and I think that our executive director does the good job of keeping it tight knit and keeping the same people on. I mean, I feel like we're like a family, and I don't think you see that a lot, especially as the organizations get bigger and bigger. And I think our retention rate is

really high because of that, and I think overall that is going to make a big impact on you providing great services for the individuals that come to you."

Frequent communication throughout all staff was also noted as helpful in working toward inclusive services.

"I get emails telling me about every agency wide thing. Emails telling me we're having this training on self-determination and how people can support this and to please invite vendors and invite families. There are in-person meetings and trainings. It's an organization-wide strategy to get everybody within the same level of knowledge and awareness."

Finally, in terms of operational strategies to support individualized, inclusive services, a few participants discussed how their decisions to not own property or vehicles kept them true to their values of inclusion and avoided having a conflict between organizational values and financial benefits.

"We don't own any facilities — no buildings, no homes, no apartments, nothing. And I think we made that decision early on, and we never wavered from it. And so, our focus is exclusively on the person we're not worried about having a rental payment, or an open bed. I think that is central to providing, authentic, individualized, personalized supports, because as a landlord or an owner having a lease, you can't help but be worried about that, because that's money, right? It's resources and it's time, right? Similarly, we don't own a vehicle. We don't have a fleet of vehicles that we have to worry, 'Oh, now we've got 20 vehicles that aren't being used.' When I consult with other organizations, there's this tension between their day and residential where the day part of their organization is like, 'Well, we need transportation.' And I'm like, 'All right, but don't you have all these vehicles literally sitting in driveways of the group homes?' 'Oh, but we can't use them.' That, to me, is just crazy. It just doesn't make any sense. So you're advocating for more funding for vehicles, but meanwhile, you have vehicles that are sitting all day anyway. So, I think the decision is really so fundamental. I call it probably the most strategic decision that we ever made, and we don't even talk about anymore. Like, in the beginning, we used to have someone we contract and they'd be like, 'Well, you need to open a group home. And we're like, 'No, we're not.' And we would literally argue about the fact that we could support the person in leasing their own apartment, which then helps the person build credit, then so many things flow from just renting or owning a home, as many of us know. So, this decision eliminates that potential for conflict of interest."

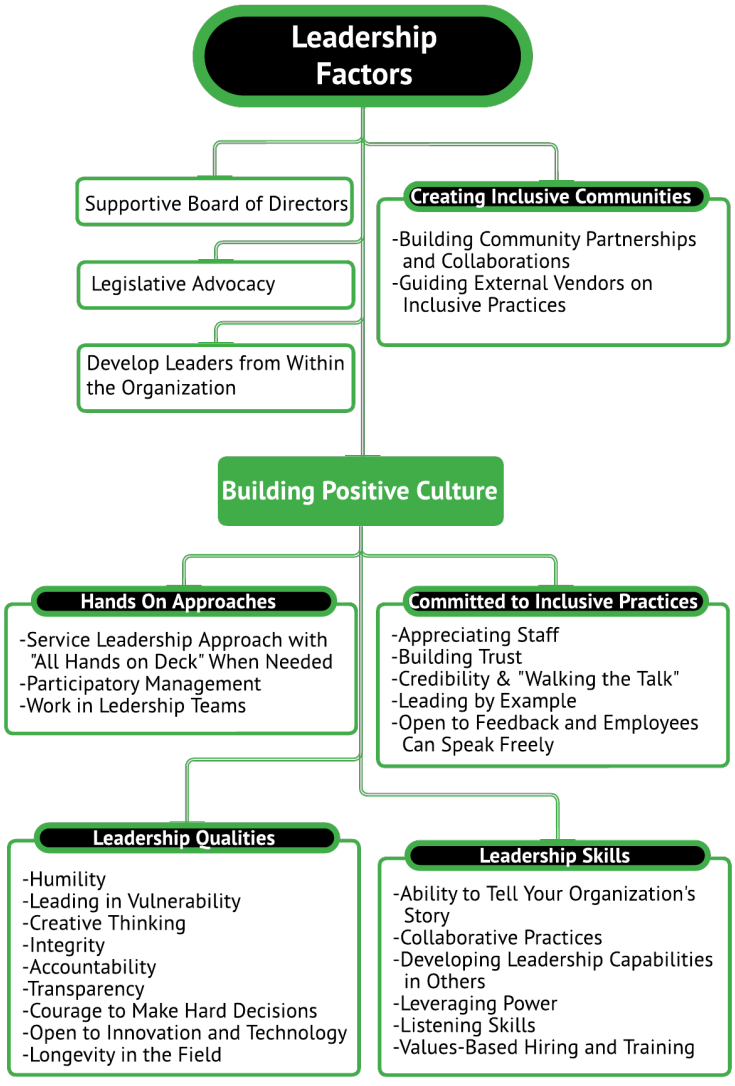
Leadership Factors

Many leadership factors that facilitate individualized, inclusive services were discussed by participants in the interviews. Most leadership factors related to building a positive culture at the organization, including leadership being committed to inclusive practices, hands-on approaches by leadership, and various leadership qualities and skills that contribute to a positive organizational culture and well-functioning organization (see Figure 11). Leaders' role in creating inclusive communities, legislative advocacy, and developing leaders from within the organization were also mentioned, along with having a supportive board of directors.

Executive leaders we interviewed talked about the impact of hands-on leadership styles and how everyone at their organizations is encouraged to take active, participatory approaches to the work, whether that's filling in for frontline staff or contributing to organizational policy.

"We're offering 24/7 supports, and so that's holidays and weekends, and when people call out sick there's a lot of scrambling to figure out what we need to do. I think we tend to have leaders who are just so committed to our homes and our folks and are willing to sacrifice their own time. It's not a burden to need to pitch in. It's like, 'Well, I care about our folks in the community, and so sure I can pull this shift.' Or like, 'Yeah, I'll come and do an overnight tonight.' Our executive director has done some and her husband has gotten trained and been a temporary overnight. So, that kind of commitment to ensuring that we have high quality services, and also a willingness to fill those gaps like at every level of the agency. I think there's only one or two people who work in our office who aren't trained in direct support, so everyone kind of pitches in when needed."

Figure 11 Leadership Factors That Facilitate Individualized, Inclusive Services



“I have a more collaborative approach to leadership. I don't think that I'm ‘helping.’”

“We do a lot of teaming together, which means as a leader of a department, you don't get to fly solo and create your own mini universe based on what you think. We collaborate and communicate and we hold strong to the philosophy that we've developed. And sometimes that is very hard to hold to that, but really it is this collective effort around a leadership philosophy, and it's different. The model here is so different. We have a Service Leadership philosophy, which means we're not going to ask any of our direct support professionals to do anything we won't do, and we hold their schedules as consistent as possible, which means we're not going to ask them to do wicked overtime if something goes wonky because someone quits. I mean, we make a decision and, in this team, we cover it. So, I think we all have to be totally invested in that type of leadership philosophy. It's not a delegation leadership.”

“I would say we practice participatory management. I don't know that we ever arrive fully at that, but we certainly strive to make the organization one that's inclusive. One of the most important principles we operate by is there's nothing about you without you. And that goes for people supported, but it also goes for people who are doing the supporting. … Policies are developed typically in work groups that include people who could be affected by said policy, and then there's a review process where everyone in the organization has an opportunity to review it. … I would say that practice builds the credibility so that when we talk about people with disabilities really being in charge and in control, we couldn't do that while feeling like we were oppressing staff by not paying them well and not helping them to really build work schedules that worked for them in their own lives.”

“[Leaders should] actually be involved. And I'd say our leadership team is, for example, going out to programs to meet people, to see people where they're at, getting to know names and people, rather than just a program. You can attend parent meetings for support, parent support group meetings seeking feedback from vendors, and improve response time. If they're hearing back from the Leadership, that's important because people want to be heard and if there's changes that need to be made then they can look to see how those changes can be made.”

Interviewees said that leaders being committed to inclusive practices not only with the people with disabilities receiving services, but also with their employees, was very important to advancing best practices. By appreciating staff, building trust, “walking the walk,” leading by example, and having open lines of communication with their employees, leaders can contribute to a positive culture.

“Appreciating your employees as a leader, and then that trickles down into the services you provide. If your employees are happy and healthy, I think that that is going to play a big role into providing great services.”

“Basically, we just speak our mind, with grace and being civil. But we basically have an open-door policy. I feel that it's a very flat organization, with minimal hierarchical leadership. So, in

terms of being a leader, it's important to set the tone of where we are going, and also trying to be open to feedback and walking the talk."

"I think that probably the feedback that I've gotten the most is just leading by example. … I think that that's probably my best attribute in the leadership arena, is just the examples that I set — walking the talk. I'm also a support broker, so I do work that everyone does. We all do the work that the organization does."

"I think it's about credibility, which I define as doing what you say you will do. And I think that we really try to subscribe to the notion of people care less about what you say and more about what you do."

Participants shared many leadership qualities that they thought were important to cultivating a positive culture that would support individualized, inclusive services, including creative thinking and being open to innovation. For example, when some people receiving services at one organization were asking for some more community support time, their leadership used a little creative "outside of the box" thinking: *"We're getting creative with the existing service codes, using some existing support codes to create some of the individualized supports in different manner than we had been."* Another participant also thought it was important for leaders to get more creative with technology and innovation: *"Leadership that is open to innovative practices is important. I would say technology is starting to become important in our organization to help people with their supports to live the life that they want to live."*

Participants also thought it was important for leaders to be vulnerable and passionate and have grace, humility, integrity, accountability, transparency, courage to make hard decisions, and longevity in the field.

"We have kind of a cultural expectation that we lead in vulnerability, and that if a mistake is made, that you share that mistake. … So if I look back and I go, 'You know, I missed this with this employee, like I should have held them accountable sooner,' or even, 'I fumbled my budget and miscalculated, and now I'm having to change things.' We have an expectation that, as a leader, you share that with your team. I'm on the executive management team, so we have a time set aside in our meetings monthly for us to say, 'I made a mess, and this is what I'm taking from it,' and the process of sharing that with other people keeps us vulnerable and allows us to have grace for others, but then we're hoping that we learn right from each other's experiences and don't repeat those mistakes. … It's not an easy thing, but I do think it has made a huge difference in terms of our level of leadership."

"Passion is key to me…and dedication. I think the people with passion are always going to succeed, because they're going to go above and beyond. I feel like the best people that work with individuals with disabilities know all of it, or know pieces of all of it, because it's all a puzzle, and you have to kind of do that."

"Well, credibility is at the top of the list for me. We got to do what we say we're going to do. And I think if we're asking any employee to do something as leaders, we ought to be willing to do it

ourselves. I think that there is a need to be flexible. And I guess along with that would be a certain humbleness, like, if you get it wrong, say you got it wrong, and then the flexibility to be able to say, 'Well, we're not going to keep doing things wrong,' or 'We're not going to keep doing things that we shouldn't be doing.' I think that leaders in this space have a responsibility to move towards individualized approaches and practices, because I think we know better. We know better, and we need to be doing better."

"[Leaders need] an understanding of making sure that services are about each individual and not about fitting their thought of what is best for that individual, but really listening to them about what their needs are. Also, having flexibility, transparency, and an understanding of how to fiscally make this type of program work and work around some of the fiscal barriers that might exist. There's a lot of people who talk about, 'We can't do that, because that's not how the state really wants to fund things.' And then you really just got to kind of figure out another way and say, 'Well, if this is a need, our job is to fill that need. So we've got to try to try to figure out a different way now.'"

Participants also described many leadership skills that help facilitate individualized, inclusive supports, such as the ability to tell your organization's story, collaborative practices, developing leadership capabilities in others, leveraging power, listening skills, being steady but flexible, and being mission-minded.

"I think good leaders are not the people who work their whole careers to amass power. I think you're on the brink of an opportunity to be a good leader at that point. But unfortunately, that's the aim for a lot of folks. Like, 'I need the credentials,' 'I need the experience,' 'I need the influence.' I think good leaders get to that place and then really recognize that the value of amassing all these things is to be able to leverage and give it away. Learning how to earn a seat that you then let somebody else sit in and learning how to facilitate the value and the brilliance in the ideas and the contributions of people that otherwise would not have the opportunity to contribute them. And that's really counter to corporate business structure and culture. … That's not how we're taught to lead and develop ourselves and the people around us. And, I think it's really rare. I think that good leadership is not 'good.' Leadership is really about getting to that place where you recognize that that no matter what you know, what you do, what you've accomplished, if it doesn't directly empower and include the people that are most impacted by what you're doing, then it's probably working against them."

"There can be really tough decisions to make. We recently needed for someone to switch homes. It was the right decision, but I think you have to be willing to make hard choices and have difficult conversations with the interests of our core members, those with IDD, at the center. I've seen other communities like ours have to close homes due to a lack of staffing or funding, but just kind of having a commitment that once we start, we're not going to stop [is important]. We really hope that those who start receiving our services do for the rest of their life, or until maybe they have a more significant need than we can support. But I would say also, having a vision for the future is huge. The new home we're building is supposed to be for those who are aging, because that's something we're experiencing a lot of in our community, and so being able to

perceive the future needs of the community and begin planning for those is something I've been really impressed by in our agency just saying, Okay, well, we have this commitment to our folks, and like, the only way to really ensure we can do that is to make a pretty big change. And so I really hope that our new home really does meet that need. I think we are learning that things can come really quickly, and then also you can have a really slow decline, and it's hard to predict how an individual will age and change over time. But yeah, just that commitment to meeting and centering the needs of those who we serve."

"We're really committed to those who work here and promoting from within and just really trying to develop the leadership skills in folks who have been around for a long time."

"We cultivate DSPs from within. … We use self-determination for employees as well as for the people we support that you can tell they're ready to grow and they just need a little extra support. So, watching them be on state associations is very powerful. So the one employee I have that's a participant that trains she's on our Peer Power Association at a state level, everyone has to be on an association. And I like that, because then we get to see a larger system. That's one thing I do, and then they're all cultivated up. I don't have anyone training a DSP that hasn't been a DSP."

"I think it's looking at the big picture. I think that it is keeping your mission in focus — because it's really easy to get off track — and so making sure that what we're doing stays mission driven when we take on different opportunities. Does it fit our mission? Keeping the mission the most important thing. And you just gotta have thick skin and tenacity and just got to ride the wave of the good times and the bad times and know that the bad times don't stay; it'll turn around again. You can't be reactive. You've got to be at firm, steady; you can't be explosive. You just gotta keep riding the wave and trust that you're going to come out on top at one point and you're going to get a breath."

Other participants also said that frontline field experience is critical to being a good leader.

"You have to have worked as a DSP. I don't think you can be a leader in this agency unless you've worked as a DSP. And if you haven't worked as a DSP, and you come on, I make them work as a DSP for 90 days before they can even move up the leadership chain. Because there's just no way you can lead unless you've done this work. It's so unique that I can't even give you a manual on how to lead and do it. You have to understand what we ask our DSPs to do. We ask them to solve big problems with very little support in the middle of the night, and when you don't pick up your phone, it's a bugger. So I want them to feel some of those pain points that their DSPs feel, so they'll be a better leader for them."

Many interviewees mentioned how important it was for leadership to help create inclusive communities by building community partnerships and collaborations, like with potential employers, and by educating vendors about what individualized, inclusive services should be.

"We are radical in our approach and commitment and loud about it. One of the things that we do that a lot of our colleagues these days won't do, is that we recognize and support every

person's right to be involved included in the life of the community, and we really can't do that, we can't carry out our mission, if we don't exist in welcoming communities. And so, we see our responsibility as an organization to not just provide supports to a person with a disability, but to really be a collaborative, positive partner within our community. We see our work as community building every bit as much as it is providing direct supports to someone so we get involved in a lot of human centered collaborations and partnerships."

"Working with vendors of the regional center, trying to explain to them, tricks, tools, tips, how to create inclusive supports [is important]. And a lot of times it still isn't clicking for them operationally, how they can make that happen. So, I have requested assistance from managers and supervisors. We've been getting on Zoom dialogs to just kind of talk through some of the new regulation changes in California around social recreation. The vendor community wants to create little isolated programs and take them out on a group outings and we explain to them, well, ideally, in the best case scenario, you would be able to provide one-to-one staff to these individuals if they need it, and temporary training."

Participants also pointed to having a supportive board as a facilitator of inclusive services.

"We don't ever expect a board member, nor have they ever said, 'Should you open a workshop? Should you have a group home? Should you do these things for financial security or to serve more people?' That has never come up. It's a very safe place to talk about the type of organization that we are without worrying that that would ever be the case, and I think that's enormous."

Finally, interviewed executive leaders saw developing leaders from within and legislative advocacy as the responsibility of leaders at an organization working toward inclusive services.

"Leaders in our organization who tend to be successful, we call them 'home grown organically.' They're typically people who have either worked in youth services, or their family members have youth services, or they've worked in a direct service capacity, and then from there have shown an interest and a willingness to participate in development opportunities."

While advocacy for better programs and funding is important, leaders also talked about advocacy for human rights.

"We do a lot of legislative advocacy, not just about disability services, but really about human rights, trans rights … If there is something that falls within our conceptualization of the world and we see it as an issue that affects human beings, particularly marginalized human beings, we leverage our power as an organization for those purposes in an attempt to create better communities. And that is something that also, you know, probably not the way that we support our employees or communicate with our employees, or encourage our employees, but for many of our employees, our willingness to really stand up for people in a state that is discouraging of that, that is a sense of pride for a lot of folks who have a relationship with the organization."

"This is the drum that I beat all day, every day, in every conversation, at every level. The reason it is like this is because we fundamentally devalue and dehumanize people with disabilities. Like every aspect of it, every absolute, awful aspect of it is that and until we address that, there is no remedy. There's no remedy in creative funding patterns. There's no remedy if you do not recognize that the person that is receiving these services is a whole ass human being with all of the value and all of the hang ups and limitations that come in that human package. Until we get to that place, there is no remedy or solution in creative funding business models. We have to exercise the demon, and that is our own oppressive, ableist biased systems that we all are conditioned into and operate within that disallow us from seeing the people we support as whole human beings."

Read more about leadership characteristics and skills that survey participants thought facilitated individualized, inclusive services in the Leadership Characteristics section of this report (see page 60).

Top Organizational Facilitators to Individualized, Inclusive Services

Survey respondents also named funding, employee, leadership, and operational factors as top facilitators of individualized, inclusive supports. Survey participants were asked, *"In your opinion, what are the **TOP 3** internal or organizational factors that **HELP** your organization to provide individualized, inclusive services and supports:"* and given 13 options to select and an *"Other"* write-in response option. The largest number of participants (35.4%) selected "*current service models*" and "*organizational practices*" (see Figure 12). The second most popular choice selected was "*how we embrace person-directed practices and approaches*" (32.7%), while "*investment in staff retention and recruitment*" and "*organizational philosophy embraces values of inclusion*" (30.9%) tied with being the third most popular internal factor selected.

Figure 12 Top Three Organizational Facilitators to Individualized, Inclusive Services

Importance and Supportiveness of Organizational and Person-Related Factors

To gauge the impact of specific organizational and person-related factors on individualized, inclusive services, survey participants were posed the question, "*How important are the following to your organization's delivery of successful individualized and inclusive services?*" and asked to rate the given categories on a 4-point scale from "*Not Important*" to "*Very Important*." The top-rated organizational factors highlighted the importance of leadership, with "*Management*" (3.8 out of 4) and "*Executive Leadership*" (3.8 out of 4) being rated the highest (see Figure 13). Participants rated "*Self-Advocates*" as the most important person-related factor at an organization that influences individualized, inclusive supports, emphasizing the important role of advocacy in promoting services that match best practices (see Figure 14). The board of directors was rated as the least important factor to impact individualized, inclusive services.

Figure 13 Importance of Organizational Factors to Delivering Individualized, Inclusive Services

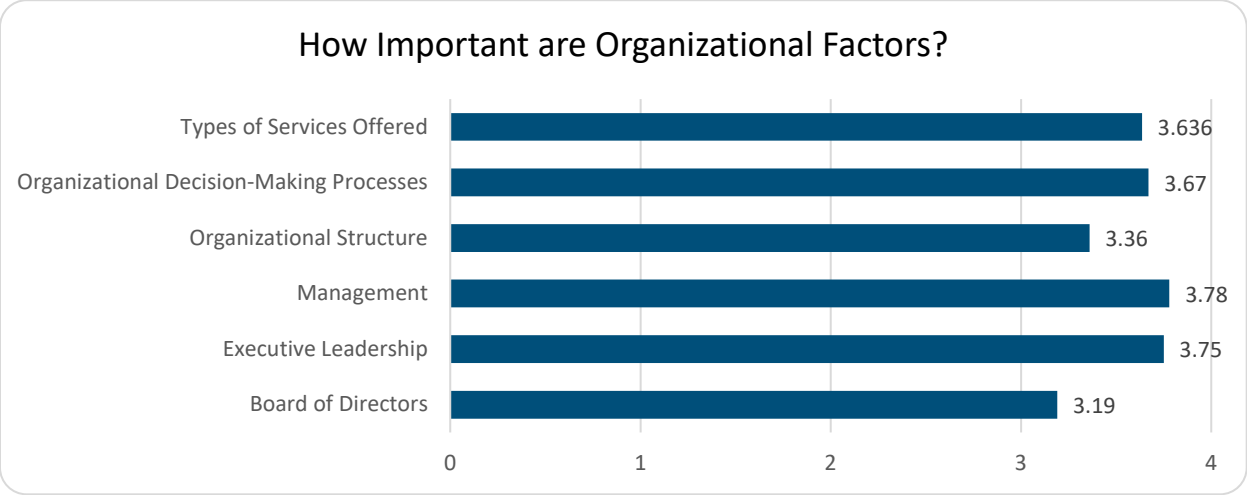
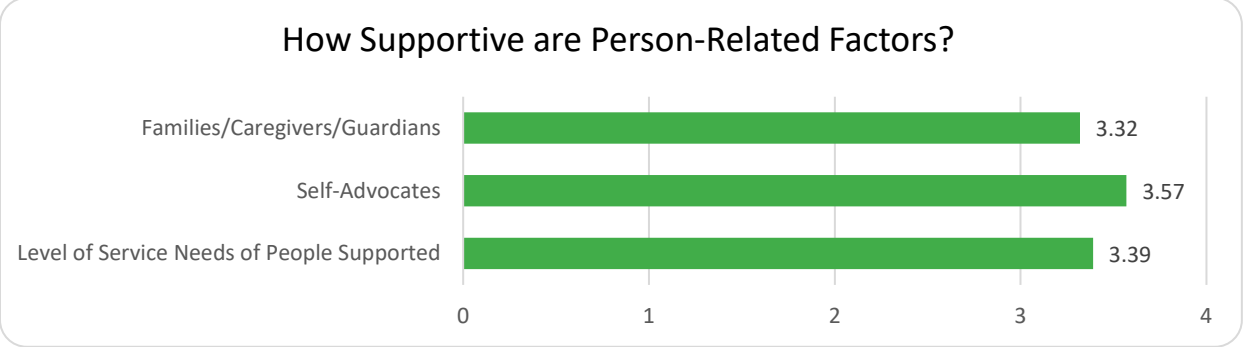


Figure 14 Importance of Person-Related Factors to Delivering Individualized, Inclusive Services



To investigate how supportive specific organizational and person-related factors are of individualized, inclusive services, survey participants were posed the question, "*How supportive are the following to your organization's delivery of successful individualized and inclusive services?*" and asked to rate the given categories on a 4-point scale from "*Very Unsupportive*" to "*Very Supportive*." While all factors were rated relatively high (between 3.4 and 4 on a 4-point scale), "*Executive Leadership*" (3.7 out of 4) was rated as the most supportive, with "*Types of Services Offered*" (3.6 out of 4) a close second (see Figure 15). The most supportive person-related factor for delivering individualized, inclusive supports was "Self-Advocates" (3.6 out of 4) (see Figure 16).

Figure 15 Supportiveness of Organizational Factors to Delivering Individualized, Inclusive Services

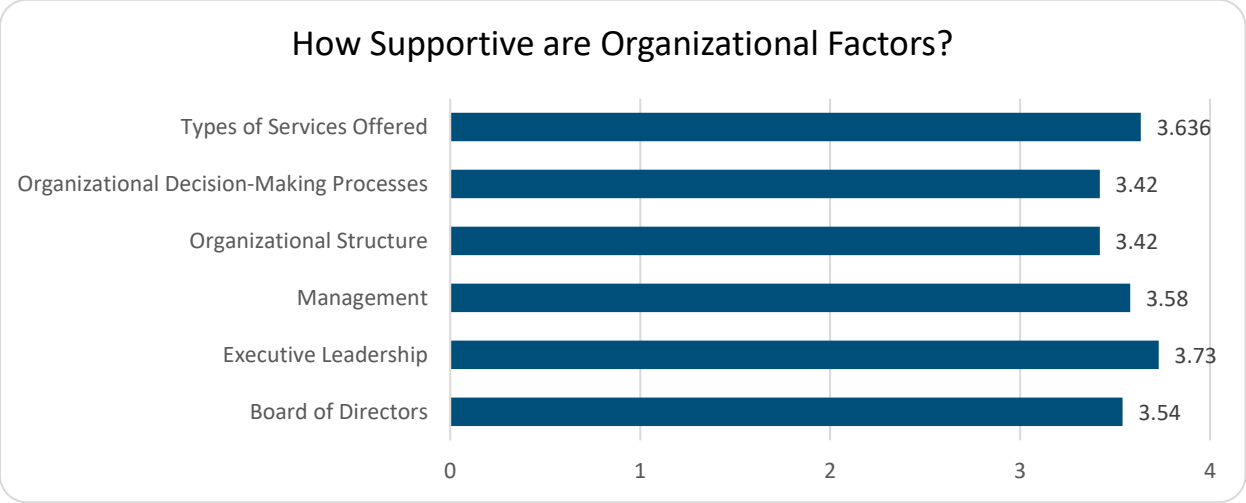
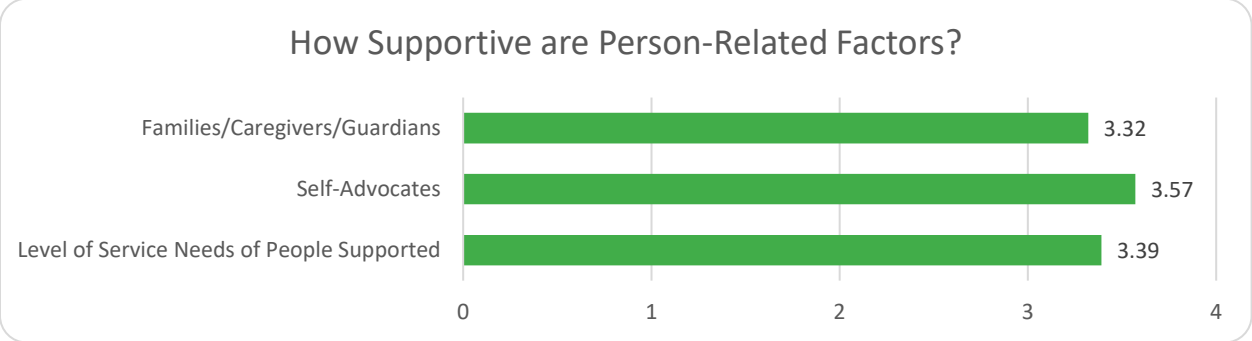


Figure 16 Supportiveness of Person-Centered Factors to Delivering Individualized, Inclusive Services



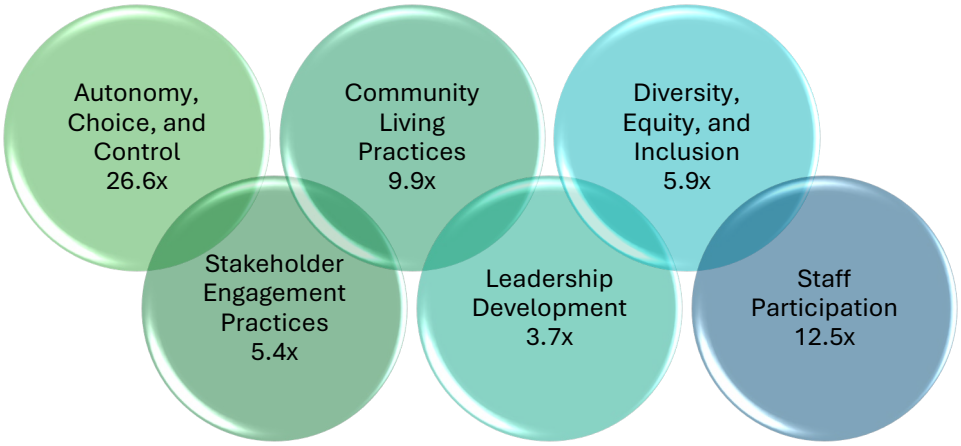
Organizational Best Practices

Survey participants were asked to identify the percentage of people with disabilities supported at their organization who received both individual and inclusive services. Then, responses from people who said their organization delivered individualized, inclusive services to more than 70%

of the people supported were compared with responses from people who said their organization delivered those services to less than 70% of the people they support. Responses from these two groups related to the best practices reflected in the OPPI (see OPPI description on page 10) were analyzed, and significant differences were found.

Results from ordered logistic regressions show that organizations that provide mostly individualized, inclusive services (more than 70%) are much more likely (26.6 times) to provide services that promote autonomy, choice, and control for people with disabilities than organizations that do not provide as many inclusive services (see Figure 17). Additionally, organizations that provide more than 70% of inclusive supports are 5.4 times more likely to have more stakeholder engagement practices, 9.9 times more likely to support community living practices, 3.7 times more likely to have more leadership development, 5.9 times more likely to encourage diversity, equity, and inclusion practices, and 12.5 times more likely to promote staff participation compared to organizations that provide less inclusive services.

Figure 17 Likelihood of Respondents from Organizations Providing Individualized, Inclusive Supports to More than 70% of People with Disabilities Rating Best Practices Higher at Their Organizations



Unique Organizational Practices

Participants were asked if their organizations were doing anything that other organizations would consider "unique" to help advance individualized, inclusive supports. These practices are not necessarily "best practices" but show innovation and a willingness to think creatively about changes in the field. Practices were grouped into four categories based on their focus: operations, services, employees, and systems.

Table 3: Unique Organizational Practices That May Contribute to Individualized, Inclusive Supports

Op	Flexibility	Implementing creative approaches when old methods no longer work. *"I think that one of the things that a lot of us just say is, wait a minute, maybe in 2005 this was considered unique or even radical, I dare say. But the fact that I'm still, for example, helping people with disabilities to participate in their own recruitment of staff, and I still hear these stories of these HR departments saying, 'No, they can't be hired.' And it's like, 'Wait, what?! Like, all other things being equal, the background checks clear, they have a valid whatever…' So, I don't know if we're doing things in this unique way, as much as I just can't believe that others are doing the same things over and over again and expecting different results, which we know is the definition of insanity. Maybe what makes us so unique is we're willing to be like, 'Oh, well, that's not working. We need to do something differently.' And I do feel like, at least with some of my local peers, I don't see that happening, and I tend to hear the same arguments over and over again. I'm like, 'Dude, we stopped doing that five years ago. It's the best thing we ever did.'"*
	Intentional communication	Using words effectively to attract people with a mindset that is aligned with organizational values. *"One of the things we do, that I think is very unique, is we pick words carefully. I would advertise for a 'DSP Supervisor,' and I would get the bossiest people ever. I would get bossy managers that had this different mindset of how to manage people that never aligned with mine. So, we've changed the words to a 'DSP advocate.'"*
	Data-informed decisions	Using data to not only fulfill requirements, but to improve organizational functioning and the services provided.

		"We have a PhD who got his start in social work and is helping us to see that data and being data informed can actually make our services better. We've traditionally been the type of social work people that are like, 'Get away from me with your paperwork and your stats! Like, that's not what I'm here for.' But we kind of made a leap and said, 'Hey, if we bring somebody on that could actually help us.' It's required of the funding source [to collect data]. So how can we make the most of that so that we can actually use that to be better and not just do it because we're required to? To me, that's kind of unique, because we're trying to go with and use it to our advantage."
	Internal tech platforms	Using an internal network within the organization where information can be shared and incentives can be earned. *"We have an intranet, an internal platform, that people can log into. We give them some training there. For example, if they're supporting somebody that has a specific diagnosis, we've got resources that will automatically be sent their way in that platform based on that matching criteria. But then we have a currency where if we want to thank somebody for something, we incentivize. If we want to digital signatures, then we send you something digitally and you use DocuSign and you automatically get some of this currency. And then they have a bank and they can buy swag or merch from the organization. But they can also buy leadership books that we are circulating and they can get gift cards as well."*
	Flat organizational structure	Having a flat, less hierarchical organizational structure where employees can become specialized in their current positions instead of becoming managers or executives. *"I think the leadership team is unique because it's not a traditional — it's flatter. It was very important to me that when I assumed the position from the previous executive director, that I wanted to build upon that concept of not having too many layers of administration and keeping it flat. So, one of the things we're exploring is, how can we give DSPs who say, 'I don't want to be a manager,' more of an opportunity to specialize. That's where the Community Connections Specialist role fits in. We're also looking at a DSP becoming more skilled in behavioral principles. And so instead of saying, 'You gotta become a manager,' broadening the opportunities for somebody as a DSP who wants to really explore more direct support work. In some cases, that has led to some*

		growth within other departments. I think that all my departments understand what they do contributes to the overall services to people. So, we've had some really nice connections, actually. Like, my county department has several relationships now where people come and have lunch, which is something I don't see in other organizations. I feel like in other organizations, it's very siloed, but each of my departments has a very positive connection with quite a few people in the organization. So, when they come in, it's not like they're visiting, it's like they're just part of the whole organization."
	Competitive rates for employees with IDD	Ensuring people with disabilities who work for the organization are paid the same as people without disabilities, and paying a competitive rate to frontline employees. *"Noone's expertise is good enough for them to come for free. It's an opportunity that you provide someone [with a disability] that when they speak, then you should pay them what you would pay anyone else to speak. So, we worked that in at competitive rates. … We've raised the support staff's rate too. … So it feels very good to be at a meeting where every single person feels good about what they're getting paid."*
	Meaningful representation of people with IDD	Meaningfully employ people with disabilities in organizational positions and on the board to contribute to advancing the organization. *"We employ several people that receive services, and I feel like we have gotten past the tokenism of that. Originally, I would say it was sort of token and we didn't know we had to learn how to make it super meaningful. But we actually have a PCT [person-centered training] department, it's a focus. And we have a person that receives regional center services who is in a supervisory role, does training, and she also mentors. … For us, it was a lift to figure that out. … Having [people we support] being trainers I think has been very unique to our agency, and very meaningful. We do have people with disabilities on our board. And I thought this was kind of common across the state of Alaska, but they make sure they're on the board, but they're not voting members. So, I was like, 'Well, that's crazy. Like, what's the point?' Our board members are not token board members, they're voting board members. People are proud of [saying], 'Oh, yeah, of course, we have*

		representation on our board.' It's interesting [because if you] ask if they have voting ability on the board, a lot of them do not. A lot. That's what I found across the state; I was shocked."
Se	Creating affordable housing	Developing integrated housing options for people with disabilities. *"Our new housing development will be 40% individuals with disabilities, 60% low income seniors, and 60% workforce housing focused on nonprofits in the area, so providing housing for nonprofit workers so that the individuals that we're trying to help make sure that they are known. We find often with other affordable housing options, the individuals we support are put on the back burner and not given the opportunity to get into those affordable housing units. But we also don't want to set up a situation where they're only living with other individuals with disabilities. So trying to make sure that we're having an inclusive community where they are a part of the community that they're a part of, not apart from the community."*
	Ensuring good matches	Decline providing services to people if their values do not align with the organization's values. *"We definitely are not a match for people who have people around them who will not see any other way than other people controlling them. … I think we're our messaging to customers right off the bat is like, 'This is how we are.'"*

	Deliver services locally	Meeting people where they are by hiring employees who are local to the person being supported. *"Our mission statement, and it has been for many, many, many years, is that we believe people should live in the community of their choice. So many years ago, we started providing services in the communities of their choice, and so that could easily be just one person living in a community, and then we would hire a staff who lives in that community to support them. … When we began to serve more people, soon we came to the point where we just couldn't — we had more people we wanted to support. And the Division of Developmental Disabilities in South Dakota asked us to take on maybe a special program and we knew we couldn't hire staff in Huron, so we've gone to local communities and helped people rent apartments in a complex there and started 24 hour supports in local communities. … Maybe [other organizations] provide supports at a distance. It seems to be really taxing for them and really a difficult thing to figure out. And we're like, it's really pretty easy. You got somebody here, they need support, and you find somebody to support them, and you have a part time staff and it's not that tough. So, yeah, we've done a lot of that."*

	Person-centered clinical supports	Providing person-centered clinical support to ensure that people with disabilities receive appropriate, bias-free care. *"We recently launched a suite of clinical supports. So, OT, PT, speech, language, diet, nutrition, behavioral, mental health, nursing, all overseen by a medical doc — that's pretty damn unique. That is crazy making in my head. And it's not that we think we can do those particular supports better than an occupational therapist down the street, but here's what we know: We know that health, science, education is conspicuously absent any meaningful address of human beings who happen to have intellectual and developmental displacements. And so it makes accessing these supports that are culturally accessible and responsive [is difficult]. … The clinical services themselves are not unique, but what is unique is the framework through which we hope to deliver them. It's really about meeting the human again, where the human happens to be, and understanding this magnificent intersection of the presence of Down Syndrome and all of the physiological issues that tend to come with it, lived experience, where and how I live. Turns out, it matters a lot about health equity and health status. And by the way, what does David with Down Syndrome want? 'You're not gonna make my Down Syndrome go away, and I'm worried about my cardiovascular issues because they're serious and significant, but by God, I want to lose weight, and I would like to exercise. So can someone help me understand what this means for me?' Unfortunately, I don't think this stuff is particularly innovative; I think it fundamental. But you know, it depends on who we're comparing ourselves to."*

	Centering relationship building	Making building relationships among employees and between employees and the people they support a priority. *"I haven't heard of other folks at group home with you sometimes being allowed to eat meals with folks out in the community. That's probably unique — being able to go out for a meal together. I think that just really normalizes what you're doing together, and kind of breaks down that barrier of staff and individual. I think also there's just more intentionality to break that down, especially folks who are living with their families, to invite them into our community events, and even though they might not live in our homes to make sure that they feel like really connected to our other folks and are able to build meaningful relationships with staff and other core members. I don't know that other agencies have as much ability to make some of their work helping folks build relationships with each other, with peers. I just don't think that maybe because they aren't themselves a larger network, or it just takes time to be able to bring folks together and it's not that easy to host large events for people with IDD and their families, or create environments that aren't over stimulating, or just be able to even set it up for a couple folks to go out for dinner together. It's surprisingly difficult to coordinate staffing and time. So I think we really, really center relationships, which manifest in really silly ways, like being able to eat a meal that's paid for, and then also in bigger ways, in terms of creating those events that folks can come together, and not just our own core members will have, like dances or community nights where anyone in the community is able to come participate."*

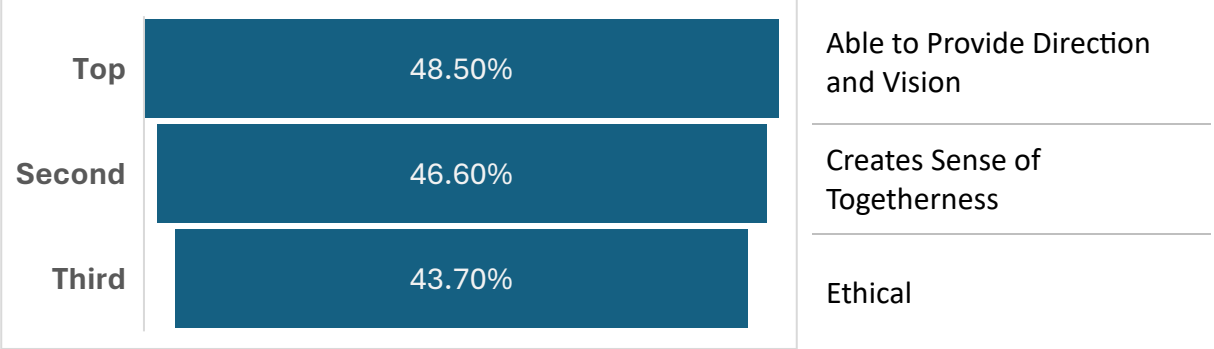
Er	Success Coaching	Creating a Success Coach position to help support people with disabilities, as well as staff, in their work and their personal development. *"I feel like we've always been ahead of the curve. One of the things I think that we have kind of taken on is an unofficial philosophy in administration. And it started with the Success Coach position. The thinking is, well, we started with a project on community connection. So we were looking at community connections for people, and saying, how do we connect people to their community? How do we get into these natural supports? We know there's only so much pie, there's only so much money. People need more. They need community. We all need it. So that's where it started, and it led us to the Success Coach project, where we said, 'Well, if we're going to do this for the people we support, we have to also do it for our employees, because we need to take care of everyone here.'"*
	Friends Training	Implement a training to help build empathy in employees and teach them how to effectively build connections. *"We came across this training called 'Friends.' It's written by someone at the University of Missouri. … And so we based a lot of training around this, Friends training on how to connect people to have friends in their community. Every new hire goes through Friends training. It fills our empathy, [which is] required thinking; I think it's extremely innovative."*

Sy	Advocacy	Continuously advocate for legislative changes that will support individualized, inclusive supports. *"We fight. We fight at the plan level. We fight at the payer level. We fight at state level. We fight at national level. We really have the sense that we're not just trying to provide services. We're trying to protect a way of life that's dying. We see it. Arkansas has not made any adjustments to reimbursement rates or innovations for services since before the pandemic, but they made multiple rate increases for institutional staff at the state run ICFs, the Human Development Centers, and they amended the waiver to expand the definition of group home from four people living in a single location receiving shared staffing to eight people living in a single location with shared staffing. One of the consequences of managed care here has been a shared staffing rate that was introduced when managed care came online that is lucrative for providers. So we've watched our colleagues go from somebody living in their own apartment and receiving DSP support in their apartment being told that if you want us to continue to support you, you're going to have to move into this group home setting to maintain those supports. And so congregate care is the focus of services here. … Our commitment is really fighting to make sure that that people here continue to have access to live the lives that they want to live, the way they want to live them."*

Leadership Qualities and Practices

Leadership qualities, skills, and practices can greatly impact organizational culture and the success of individualized, inclusive supports. Participants of the interviews named many qualities, such as humility and creative thinking, and leadership skills, such as collaborative practices and leveraging their power, that leaders should demonstrate. Survey participants were also asked to select leadership characteristics and skills that they thought were essential to promoting inclusive services. Survey participants were asked, "*In your opinion, what are the **TOP 3** leadership characteristics listed that are essential to leading organizations that provide individualized and inclusive services?*" and given ten choices based on leadership research and an "*Other*" write in option. The top leadership characteristic chosen was "*able to provide direction and vision*" (48.5%), with "*creates sense of togetherness*" (46.6%) chosen second, and "*ethical*" (43.7%) chosen as the third most popular leadership characteristic that promoted individualized, inclusive services (see Figure 18). "*Other*" leadership characteristics written responses included: promoting innovation, and "able to promote and advance common shared projects with families and team."

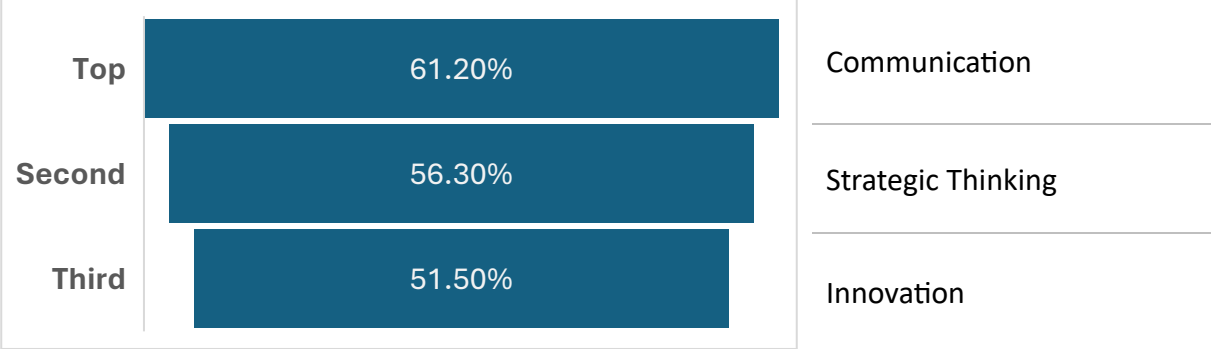
Figure 18 Top 3 Leadership Characteristics that Promote Individualized, Inclusive Services



Survey participants were also asked, "*In your opinion, what are the **TOP 3** leadership skills listed that are essential to leading organizations that provide individualized and inclusive services?*" and given ten choices based on leadership research and an "*Other*" write in option. The top leadership skill chosen by survey respondents was "*communication*" (61.2%), with "*strategic thinking*" (56.3%) chosen second, and "*innovation*" (51.3%) chosen as the third most popular leadership characteristic that promoted individualized, inclusive services (see Figure 19). "*Other*" leadership skills written responses included: empathy, clarity in values and principles in practice, and "Leaders doing all the work alongside all the staff. Providing back-up/fill-in support, no job too small for leaders to do — this shows and demonstrates we are all in this

together, and individuals' families receiving services feel more confident and supported. It creates a ‘we’ culture.”

Figure 19 Top 3 Leadership Skills that Promote Individualized, Inclusive Services



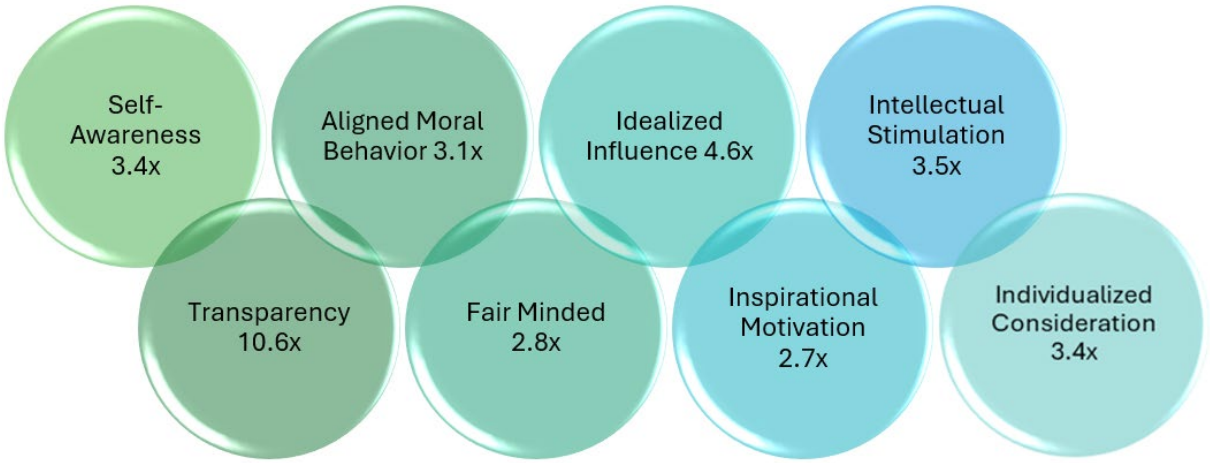
We took a closer look at the leadership characteristics that were important to promoting inclusive services by analyzing responses from people who said their organization delivered individualized, inclusive services to more than 70% of the people supported and comparing them with responses from people who said their organization delivered those services to less than 70% of the people they support. Responses from these two groups related to the Transformational Leadership skills (*self-awareness, transparency, aligned moral behavior, being fair minded, idealized influence, inspirational motivation, intellectual stimulation,* and *individualized consideration*[1]) of their executive leadership were analyzed and significant differences were found.

Results from ordered logistic regressions show that organizations that provide mostly inclusive services (more than 70%) are more likely (3.4 times) to exhibit *self-awareness* (i.e., seeks feedback to improve interactions with others and accurately describes how others view their capabilities) than organizations that do not provide as many inclusive services (see Figure 20). Additionally, leaders of organizations that provide more than 70% of inclusive supports are 10.6 times more likely to show *transparency* (i.e., say exactly what they mean and are willing to admit mistakes when they are made), 3.1 times more likely to have *aligned moral behavior* (i.e., demonstrates consistency between beliefs and actions and makes decisions based on personal core beliefs), 2.8 times more likely to be *fair minded* (i.e., solicits views that challenge personal positions and listens carefully to different points of view before coming to a conclusion), 4.6 times more likely to demonstrate *idealized influence* (i.e., serves as a role model for their team), 2.7 times more likely to exhibit *inspirational motivation* (i.e., communicates a clear and inspiring vision for the future of their team), 3.5 times more likely to employ *intellectual stimulation* (i.e.,

[1] Walumbwa, F. O., Avolio, B. J., Gardner, W. L., Wernsing, T. S., & Peterson, S. J. (2008). Authentic leadership: Development and validation of a theory-based measure. *Journal of Management, 34*(1), 89–126. https://doi.org/10.1177/0149206307308913

encourages teams to think creatively and challenge the status quo), and 3.4 times more likely to show *individualized consideration* (i.e., attends to each team member's individual needs and fosters their development) compared to organizations that provide less inclusive services.

Figure 20 Likelihood of Respondents from Organizations Providing Individualized, Inclusive Supports to More than 70% of People with Disabilities Rating Transformational Leadership Skills of their Executive Leaders Higher at Their Organizations



Participants were also asked to rate themselves in comparison to the executive leaders at their organizations. On average, survey participants rated themselves significantly higher than their executive leaders on all eight Transformational Leadership skills (see Figure 21). The largest difference in ratings (0.69) is between *transparency* of myself (8.0) versus *transparency* of my executive leaders (8.69), indicating an area where executives may need to work on saying exactly what they mean and being willing to admit mistakes when they are made. The highest ranked skill was *aligned moral behavior*, where the average rating by participants about themselves was 9.02 out of 10. The lowest-ranked skill was for individualized consideration, where the average rating by participants about their executive leaders was 7.69 out of 10, indicating another area of need for leaders to better attend to each team member's individual needs and foster their development.

Figure 21 Participant Average Ratings of Transformational Leadership Skills that Promote Individualized, Inclusive Services

Barriers to Individualized, Inclusive Supports

Barriers to Transformation Toward Individualized, Inclusive Services

Many service providers continue to offer congregate services that are not based in the community, even though these services are contrary to what is regarded as best practices in the field. To reveal why congregate services remain, this study asked survey and interview participants, "*If your organization still provides congregate supports: Why are these types of services still provided?*" and given 10 choices and an "*Other*" write-in option. The top three selected reasons for still providing congregate services were: "*families ask for them*" (53.4%), "*funding is available for them*" (45.2%), and "*people request/prefer to be with other people with disabilities and/or their friends*" (44.4%) (see Figure 22). "*Other*" write-in responses included: "I don't know," limited access to low income housing, "We partner with housing developers to offer affordable housing for adults with IDD," "We provide a small day program option for individuals who do not currently have funding or resources to access Supported Living services," "Some families and persons whom services are provided for have been accustomed to an old way of thinking and are complacent in sticking to what they know (i.e., group home residential setting), and "Person entered planning requires the participation of family, extended family, friends etc. It is difficult to marshal the required supports for people who have very small networks of friends and families." These top choices may reflect the remnants of old policy, service, and education models, where people with disabilities were grouped together and isolated, and may also be a result of under-education, miseducation, or lack of support for families supporting people with disabilities. These responses from survey participants were also reflected in the interviews.

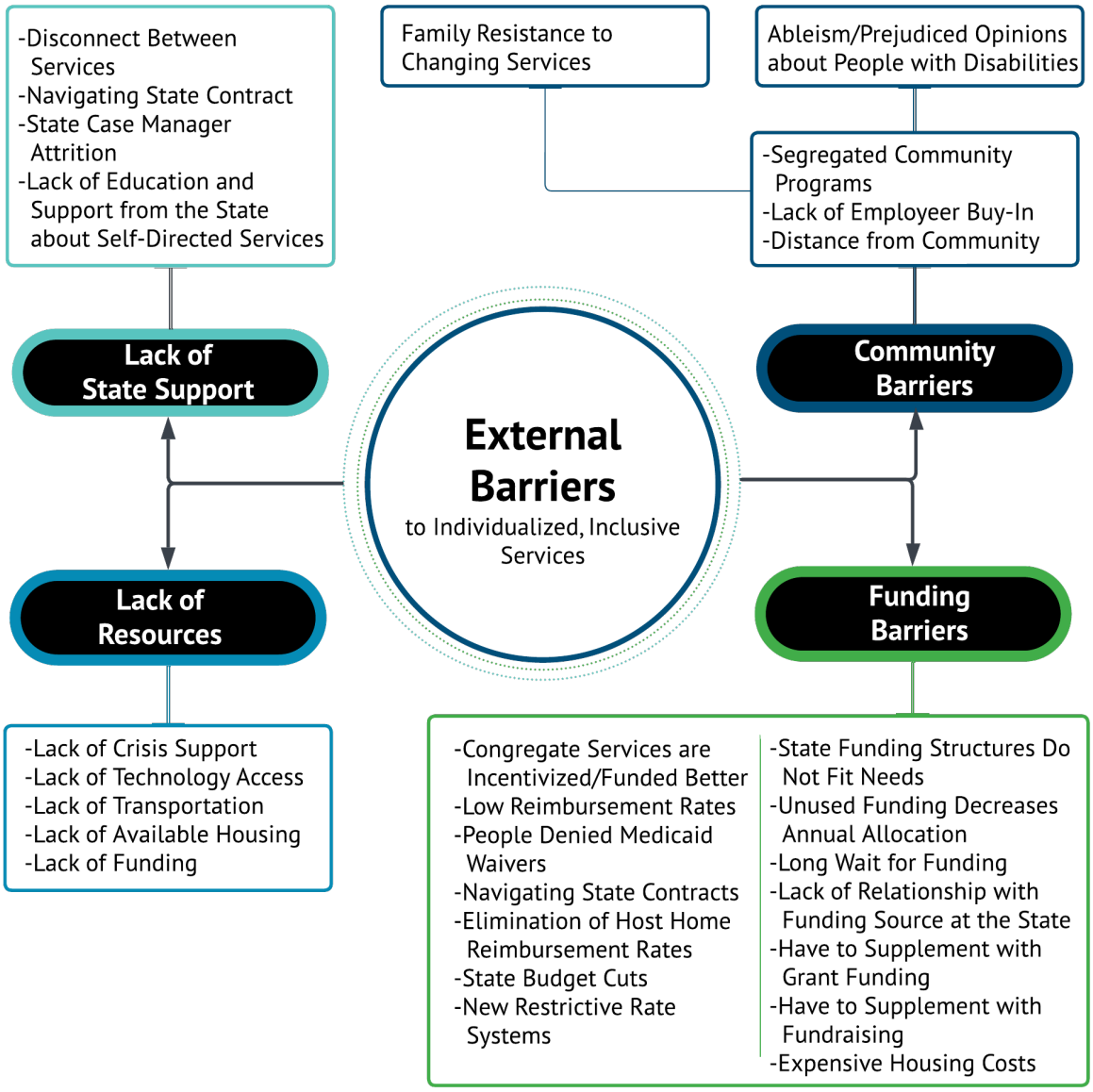
Figure 22 Top Three Reasons Organizations Still Provide Congregate Services

1. Families Ask for Them	52.4%
2. Funding is Available for Them	45.2%
3. People Request/Prefer to Be with Other People With Disabilities and/or Their Friends	44.4%

External Barriers

Interview participants were asked to name things that were external to their organizations that made it harder for them to deliver individualized, inclusive services. The factors named were categorized into four main groups: funding barriers, lack of resources, lack of state support, and community barriers (see Figure 23).

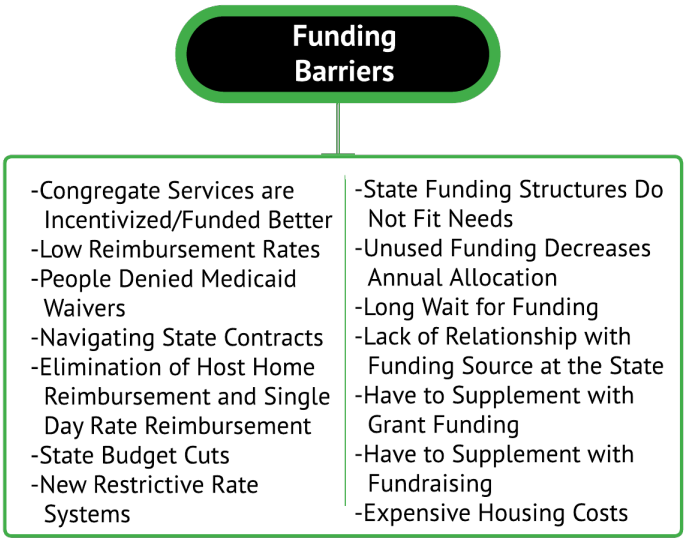
Figure 23 External Barriers to Individualized, Inclusive Services



Funding barriers are commonly identified as one of the biggest challenges to service providers delivering individual services. Interviewees shared that while policy regarding services is progressing toward more individualized, inclusive supports, old funding structures do not support them and instead incentivize congregate services (see Figure 24).

"I would definitely say the number one barrier is the state system and the way it's set up — it definitely favors the more day training program versus the supported employment program. The number of people enrolled in supported employment has continued to fall statewide. And again, I don't know if that is because of barriers at the state level, or that is people just having a hard time getting a job and then choosing to walk away from the program, but I would definitely say that that is a big barrier to that program."

Figure 24 Funding Barriers to Individualized, Inclusive Services



"We still have a lot of evolving of the managed care system to do, because essentially, what they did was they came in and they took the old state structure and they plopped it down into the new model. They pulled out a few things. You know, previously we had a daily rate reimbursement that included everything in a single daily rate reimbursement. They pulled out a few components of that, which we've been able to build a little bit on, but we still really need to continue to push and drive because the consequence of that, this is a whole rabbit hole. The consequences of that are that we are over supporting people right that I don't have any funds or resources within this problematic funding structure to create a tier of access to support. So, if you're a person who absolutely can be in your own home independently, you don't need anything right then in that moment, but you there are some pretty significant functional limitations, and you might need something within the next eight hours. Well, you get a DSP for eight hours because that's the only way that we can guarantee that you get that support when you need it. And so the funding structures actually are counter beneficial to the payers in the long term, but we can't get anyone to really believe in the value of human beings enough to empower that, so you get into this place where either you have these functional limitations and you need to be monitored and supervised all the time, or you're independent, you don't need any services and we really struggle to be able to evaluate and quantify what services really potentially could look like, and the progressive development of people's lives that could occur if we could see the value that human beings possess right there, where they are, despite limitations, despite me. Right now we just struggle to really develop that in people's lives on a 15 minute unit-based supported living billing structure, where the only way we have financial resources to access is if you have a DSP that's providing direct support."

"Prior to 2018, we were state funded. The funding for services was just full stop DSP — either you have a DSP providing direct services and you could bill for that, or you couldn't bill for anything, which really kind of stymied the growth of the organization in pretty key areas. If you're thinking about training and development and employee communication, all of the admin stuff are for decades, our administrative processes have been skeleton crews really starved, which negatively influenced us. When you talk about reimbursement rates for supported living, home and community based services, everybody wants to talk about DSP wages, which are grossly inadequate and inappropriate, but that's really only a part of it. Those rates, if you're operating clinical services, if you're operating residential facilities, if you're operating those kinds of models, the funding structure is very different, and there are various aspects of operation that you can bill for right there. There are resources that come in to address the actual physical building, because people are living there, but funding for solely home and community based service providers is for direct support professionals. That's what you get paid for. And if you are not delivering direct supported living services, then you are not billing anything at all. And because of that kind of underfundedness and lack of resources, it certainly contributed to the DSP workforce issue in a very compounded way. It's not just that we don't pay folks enough, but we don't train folks enough, we don't support and supervise folks enough, we don't encourage them enough, we don't provide them benefits. It also creates this really skewed vision, at a state level, at a funder level, at a payer level, and it interferes with our ability to innovate."

"I think our contract with the state and just how we have to navigate that is always going to be somewhat of a barrier. It makes it so we have to be pretty strategic with the individuals that come in."

Participants also discussed people being denied Medicaid waivers and the long wait time for public funding for those who do have waivers being barriers to services, as well as state budget cuts and eliminating funding for specific programs, like host home reimbursement.

"Funding from the state is continually a challenge, even folks getting Medicaid waivers. I know it's different in every state, and I'm not as involved on the Medicaid Waiver side, but the families have to apply for them and it's difficult. You often get denied without an expressed reason why you've been denied. And now in Missouri, they've severely limited the amount of people who can move into homes per year. It's just very complicated."

"I have to say our state system [is the biggest barrier]. I don't even think they recognize the mess that they created with doing away with that host home reimbursement rate and moving people to these inflated group home. I don't think they recognize it. They're very easy to work with, but when decisions are made like that, without fully understanding those unintended, intentional consequences, we can get into kind of a mess. … So I feel like oftentimes we're so reactionary as a state and even as provider agencies, because we're trying to solve these big problems and we

create long term system challenges as an organization and as a state that's almost impossible to undo."

"There is some housing money we can tap into to build low income supported housing, but, man, it takes three years to get that from start to finish. So, the big money is out there, but it's just not available when people need it, which is like now. So we don't tap into that as much."

"Every state goes through the through the cycle of, 'How much budget do we have for the spend in the upcoming year?' So if there are budget cuts at the state level, it'll have a percolating effect on our funding and that will result in either an attrition or layoffs. So, on one hand, the demand is greater than supply. You have case manager attrition, and at the same time, they want to reduce caseload and increase the number of case managers. … These are all moving parts, but at the high level, the financial barometer in the state, right at the governor's level, impacts our budgets."

Some leaders spoke about how they previously depended on relationships they had with people who had influence on funding in order to get the flexibility they needed to provide more individualized, inclusive services. However, since employees and policies have been changing recently, it has been harder to leverage relationships with state organizations to get needs met, which is leading to people with disabilities being turned away from services.

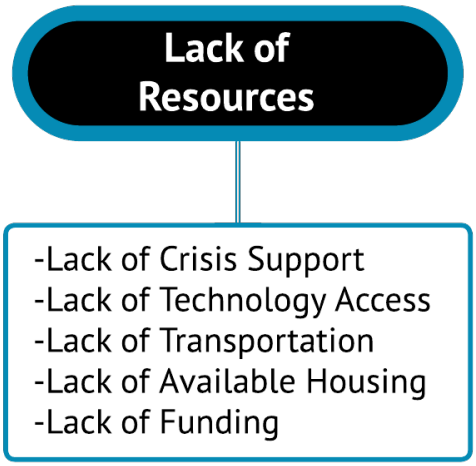
"Within the last year, South Dakota is going through a huge change in the way that we're paid for supports, and before this, we had a really good relationship with a Division of Developmental Disabilities. They would have a challenging person to support. They would call us up, and we would say, 'Okay, we think we can figure something out and support them.' And then they would say, 'Well, how much money is that going to cost?' And we'd say, 'Well, it's going to cost this much money.' And they'd say, 'Okay, we can do it for that much money.' And we had a lot of individual things like that and they just really met us where they were at and they were called 'special rates.' In the last year, those have gone away, and everybody is just put into the same categorization, the same formula. So we're figuring out a way to continue to provide supports to those people, because we really don't want to discharge people, and where people are going to go, but we definitely are not taking on new situations like that because we can't afford to and they don't pay us for that. And so I'm not sure what they're going to do with those challenging situations, but they're not paying us to do it. We can't afford to. … I got a story to tell you. They used to just think outside the box and now they just won't. We had a person with some mental illness stuff, and honestly, he was fine, he was great. But he was not comfortable with overnight; he just felt like I need somebody there. So we came up with a solution to do some live camera monitoring and hooked him up with a company who did the monitoring. And that would cost $14,000 a year. I talked about the $5,000 amount that each person has, and we'd be exceeding that by about $10,000 but we asked for that, and the state said, 'No, we can't do that, because,

yes, we have that $5,000 but it can't be spent on an ongoing thing like that, ongoing monitoring.' I said, 'So, what about this funding source? What about this?' And we had a meeting and brainstormed, and the answer was always, 'Nope, we can't do that. Can't do that, can't do that, can't do that.' They said, 'Maybe you just need to apply for a one-on-one, a one person, 24-hour group home for him. And we're like, 'Okay,' and that would cost them $3 million. And that's what they did. Rather than spending $14,000 and figuring out some way to come up with $14,000, they spent $3 million that fit in their box. And it's like, okay, that does not make any sense to us. I sure hate to see my tax dollars being spent that way, but in that case, that was the decision they made. So that's really frustrating."

"I would say lack of partnership with funding source [is a barrier] because it feels like when you are open and you reach out and say, 'Hey, we've discovered this problem. We're trying to fix it. How can we partner that?' If you don't get partnering, you get a slap on the hand. In my earlier years in the career, I felt like we had a lot more relationship with the funding source, but they have turnover issues as well, and it's just become increasingly challenging to actually know somebody that you are supposed to be collaborating with for the same goal. It just doesn't feel like collaboration."

Lack of resources to support individualized, inclusive supports, like lack of housing, transportation, funding for employees and other services, crisis support, and technology access, continues to be a large barrier, interviewees reported (see Figure 25).

Figure 25 Lack of Resources to Individualized, Inclusive Services



"Housing, I would say, is [a barrier] for us. I don't know if this is true in other parts of the country, but man, in California, this is we get a lot of referrals that if, if they don't have housing, we say, well, you'll have to go on a waiting list. But we don't want to carry a waiting list. And in California, our kind of claim to fame is nobody has to wait for services here, because we have the Lanterman Act. But you do have to wait if you don't have housing, because to get a voucher,

you could be on that waiting list for six or seven years, and then you have to still find it. That doesn't mean you're going to find housing. It has become a real challenge to people living in the community here. I think the whole country is feeling that squeeze, disabilities or not, especially in the main areas, where the stuff is at, like in the major cities and stuff. And then, one of the things that our funding source has said is, 'Then people need to live together.' They're encouraging four and five people to live together. And my response back is, 'Isn't that congregate living?' I mean, when you do that, it is almost impossible not to get back in that mindset. Because what happens when we don't have the collaboration is then we get people that are sharing, and they say, 'Well, now we're going to reduce the support hours, because they can share support.' But when you do that, then you're limiting choice. So, they say they want us to do that, but then whenever they can save the money, they restrict that freedom."

"And the other big thing is, is there is not there's no support. So, it used to be when someone was having a crisis beyond what we could keep them and the community safe, there was the ability for them to go back to the institution for 30 or maybe 60 or 90 days. A lot of times, do a med adjustment, or maybe some other things, and then they would come back into our supports, and that's not an option anymore. So, there's just a lack of support for crisis situations. And we're really not being paid in the first place, plus a lack of support [is a barrier]. There used to be some organizations like would specialize in things like sexual issues, and somebody else specialized in in traumatic brain injury, and so if we were having an issue with that, potentially, that person could move to that organization. We really, really don't like to discharge people, and we really haven't done that. We really look for another option for people. But when there aren't any other options, that makes us say we're just not going to enter into those situations in the first place, because there's just no good outcome. I don't think that reality has really set in, because we're only talking about the last year, but it's, it's a drastic change."

"I think a lot of the work we do with individuals is over the phone and over technology, which can be a barrier for some of the individuals we serve and to give the best support. So should we do in-person meetups? That kind of gets a little tricky too, because we have a small team and we're in different areas, and then with transportation and things like that, is that the best use of our time? So, I think we struggle with that."

"I wouldn't say that our community is 100% accessible. As somebody who's traveled around the world, we're better than some communities, but it's hard because people in this country are so reliant on cars, and we know that our workforce is starting to be able to not afford a car, and then the people we support can't afford cars, and so then what's their public transportation? I love Uber and Lyft. I wish we could leverage it even more, and I think we're trying to. We have a partnership with United Way. We actually have a program where if your car breaks down, we can get you some Lyft cards to get you to work. … Just that idea of this entrepreneurship that's

happening with transportation, could it help us as a community? So, transportation can be barrier, but it can also be an asset if you have it."

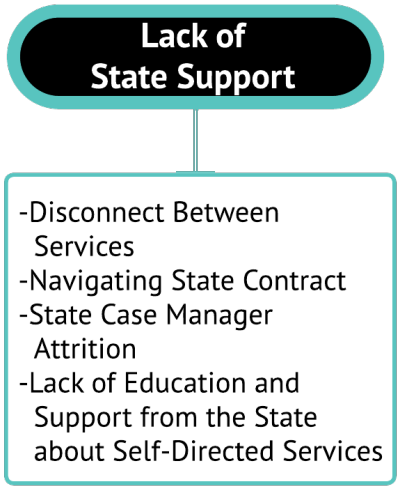
Many leaders of organizations we spoke with explained that they fill in the funding gaps left by public funding with private fundraising.

"Reimbursement for staffing is also not incredible, and as I mentioned before, for whatever reason, for those who live in the community, they don't get transportation reimbursement, which, as an agency, we're able to overcome. But I don't know that all agencies fundraise as much as we do, and we're 60% funded by the state, and then fundraise the rest. And so that helps, but not every agency can do that. If the state had higher reimbursement rates, could pay staff more or kind of use our fundraising differently. So, we do pay a fairly competitive wage for the industry, but some of that is because we fundraise to be able to compensate our staff better, but I think more money from the state would allow us to use those resources to change kind of our office space, make it as accessible as possible. There's having better, reliable transportation — I'm thinking of the vans we rely on to bring folks everywhere, and that's just not something that's ever going to be perfect, but I just think if the reimbursement rates were better, services could be a little bit more targeted."

"It's been seven months and we're not getting paid or reimbursed by the state for any of that [supported employment] work [that gets done before they get the job], and that's the bulk of the work. It's easy once they get the job and we can be in there and because it's a supportive employer, and they're willing to work with us. And here's the accommodations, and that's the part we get reimbursed for, but keeping that ball afloat after is [a barrier], and the beforehand stuff is all outside stuff that we're not getting reimbursed for. This is why we have to apply for grants, why we have to have fundraisers and things like that, and that's a huge struggle for us."

Interview participants spoke about the **lack of state support** in other ways besides funding, such as lack of education efforts, navigating the disconnect between service sectors, difficulty navigating state contracts, and lack of support due to state case manager attrition (see Figure 26).

Figure 26 Lack of State Support for Individualized, Inclusive Services



"I think the barrier comes for the person when that's all they've been supported to do, and there's still some tug and pull there. So, it's like you can self-direct, but only to this degree. There are a lot of myths carried over from congregate services that really do affect a team and the person. So that's definitely a challenge. Our DDA, the administration, doesn't step in. And what I mean by that is offering public service announcements on what it should be. We think that kind of support would be really useful. We ask for it regularly. And the answer is, 'We're in a transition.' … But I think more information would be great, so that we don't have so far to start from with not have knowledge about what support brokering is or should be. … There's not a real concrete knowledge of what [support brokering] is and what's allowed. There's a lot of flexibility that people don't exercise. …there are enhancements that we could all be pulling together for people to make it easier and more informative."

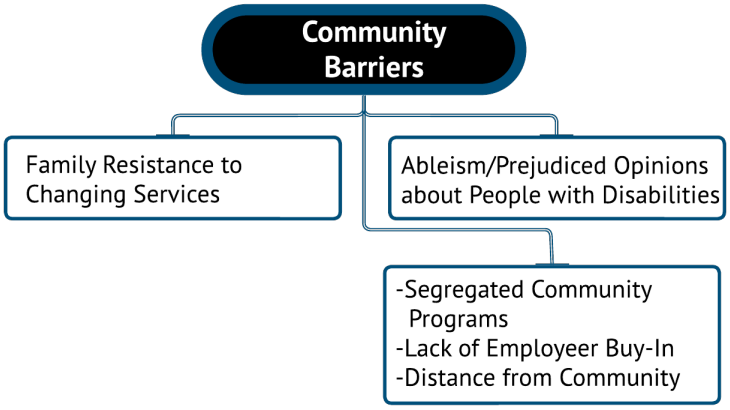
"I would say that [state services are a barrier] because there are so many departments. I'll give you a vivid example that will make the sort of drive home the point. So there's a client who's 38 years old and he has been living with his mom for many years, but his mom is aging, and she's saying, 'I can't really take care of him anymore, and I'm going to just leave him with his dad, who lives separately, he has no resources, and I'm just going to walk away.' So she's at that point in her life, and they've tried adult family homes and so on. But for every step, I have to create a referral packet, and it's sent to another team. And for that, you were to fill out another form. And all of the data exists already in in the system. I do all the assessments; it's all there. Anybody can log in and get it, but then I would cut and paste it in a three page form and send it to my supervisor, who'll then send it to another to another team, and there they send out the referral package to all the different providers. And their decision making takes time, and most of the time they look at the behaviors and say no. So, on one hand, we want to be person centered, but we won't be. We will not fund person's a positive behavior support plan, and that's left to somebody else, and the family has no resources. So a PBSP is just, you know, it's just a frosting

on the cake, and that is not available on in any store near you, right? … It's inhumane, while we are a human services organization."

"Very often we work with a finite list of certified providers. So, for example, if a family has caregiver stress and they want to take some time off, or they want to take a break, finding a paid provider from a home care agency becomes a challenge because they are often not willing to commute to that location. And also, if a person wants to learn coping skills, the provider will be at a longer distance and there'll be a age limit, or some other limitation like they'll work only from 8am to 5pm and mom and dad work on weekdays and they're not open on weekends. So, they may have the benefits package, but they're not using the benefits package. And if they don't use the benefits package, then the following year the annual allocation will go down. The system is so flawed that they are disincentivized to receive services. And it leads to an emotionally depleted bank account."

Participants also mentioned many community barriers to individualized, inclusive supports, including family resistance to changing services, ableist or prejudiced opinions about people with disabilities, and access to programs and employment (see Figure 27).

Figure 27 Community Barriers to Individualized, Inclusive Services



"I would say the other barrier could be families. We oftentimes don't find that families either believe that their individual has the ability to do what we're trying to help them do, or their expectations are so limited or specific that they can be harder to meet. So, we've had a couple individuals who are like, 'I want a job, but I will only work at this place.' Or their families are like, 'I only want them working at this place,' or 'I only want to work doing this very specific thing,' and are not always willing to take the steps needed to say it's okay to open up the field a little bit to get the experience with that as your goal in the long term. And we had a couple individuals who have been in either the transitional program or the supported employment

program who have kind of taken a step back because their circle supports are not understanding the need for flexibility."

"I would say family attitudes one of the most interesting [barriers] that I'm coming across here as well. Families were key to the integration move in the 50s and 60s, but many of them, not all, have swung the other way now. For example, we're very interested in looking at residential situations that are different from congregate care, which is, they're built around two people who say, 'I really want to live with this person,' rather than, 'Oh, I have a vacancy.' But we're also looking into and are using technology to enhance rather than saying that you need a paid person with you all the time. What technology can help you be independent in your environment? Sometimes when families come and talk to us, they're like, 'No, no, no. I want them in a group home, and I want it staffed all the time.' And so I would say that's something else we're really combating, the fact that there is this resistance to anything that might be new or different by family members and sometimes individuals themselves."

"I would say the community itself [can be a barrier]. Sometimes people are not as welcoming to people with disabilities. But I would say I've been proven wrong more than I've been proven right with that, so that's actually very encouraging."

"The other thing is just sort of this maddening societal presumption of incompetence. I just don't know how to burn that down. … There's still such a palpable element of the eternal child construct. It's still there and that's a hard one. I'm not sure how to get rid of it, other than to just keep plugging along and keep trying to do work at a local level. And hopefully, if there was enough of us doing work at a local level, we begin to change the narrative. But there's a stiff headwind."

Ableist and prejudiced opinions of potential employers have been experienced by providers, limiting employment opportunities for the people with disabilities they support.

"I think externally right now one of the barriers is always going to be employers and how inclusive they want to be. So, yeah, we can provide great services for the individuals, but we're always going to run into to road stops with the employers that are going to kind of slow down our process with getting people jobs sometimes and things like that. And I think a lot of our job is actually, instead of giving great support for the individual, it's knocking on those doors of employers and helping them understand what the benefits of hiring someone with a disability are. So I think that it's really hard because we don't get reimbursed for that. That's like, kind of like charitable stuff. So I think that's a huge one — our average of placing someone in a job is seven months, and for individuals that have college degrees, so all those outside things that we can't control. … And I think that, you know, those outside pieces and like the application process now there's AI filtering through some of these and our individuals that we're serving aren't face

to face with employers, where I feel like that might be super beneficial to them getting in the door for some of these jobs. So I think there's so many outside pieces and like that."

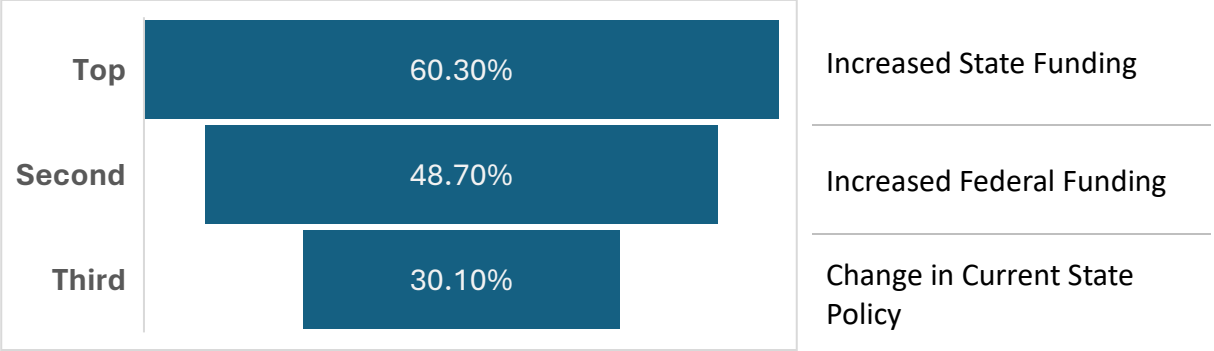
Providers said they sometimes have to work to combat prejudiced approaches of community programs, which often remain segregated.

"I would like to see a little more education to some of the vendors, as far as setting up these services from that [inclusive] mindset. … I'm trying to work with a city program to get them vendored. Ideally, in the best case scenario, what I would like to see is that we can figure out a way with our system and billing, where the individual can register for a class through a city program. You know, when you get a city magazine in the mail at home locally as to what the Parks and Rec is doing? So, if I have, say, an adult with a disability of some level who needs support but wants to take a city recreation program. … But, the city comes back to me, and so this is even the city structures, saying, 'Well, we have a specialized adaptive program.' And so then that's what they want to get vendored for, rather than setting it up open with allowing somebody to have a companion in a class that could support funding."

Survey participants were also asked to name negative external influences. Participants were asked, "*In your opinion, what are the **TOP 3** external, community, systemic, or societal changes that would need to be made for your organization to stop providing congregate services and provide **ONLY** individualized, inclusive services and supports:*" and given 15 choices, a choice that read, "*No changes need to be made*," and an "*Other"* write-in option. The top three selected changes were: "*increased state funding*" (60.3%), "*increased federal funding*" (48.7%), and "*change in current state policy*" (30.1%) (see Figure 28). "*Other*" write-in responses included: fire codes, being considered a vendor organization rather than being certified/approved by DDA, "Affordable housing is always the issue when helping adults with IDD live independently — the system tends to force them into shared living or shared services due to lack of funding for such," "We need a radical shift in how and with what resources people are equipped to develop social capital. And, if we say we believe in self-determined lives, it simply must be paired with a regulatory and social environment that embraces the consequences fully (even those that are at odds with our historical focus on 'health and safety')," "Connection and building of community relationships with businesses and other community organizations," and "In a perfect world, the management practices of the agency will not be micromanaged as a connection to the funding. Agencies have to be given autonomy to run a business without audits and verifying spending by documentation that takes the time and effort of employees. Individualized support training starts at the onset of a personal relationship that feels natural and real. When EVV [California Electronic Visit Verification] and other systems come into people's homes, it creates an automatic feeling of work, undermining

the focus on relationship first." These top choices echo top barriers named repeatedly in the interviews.

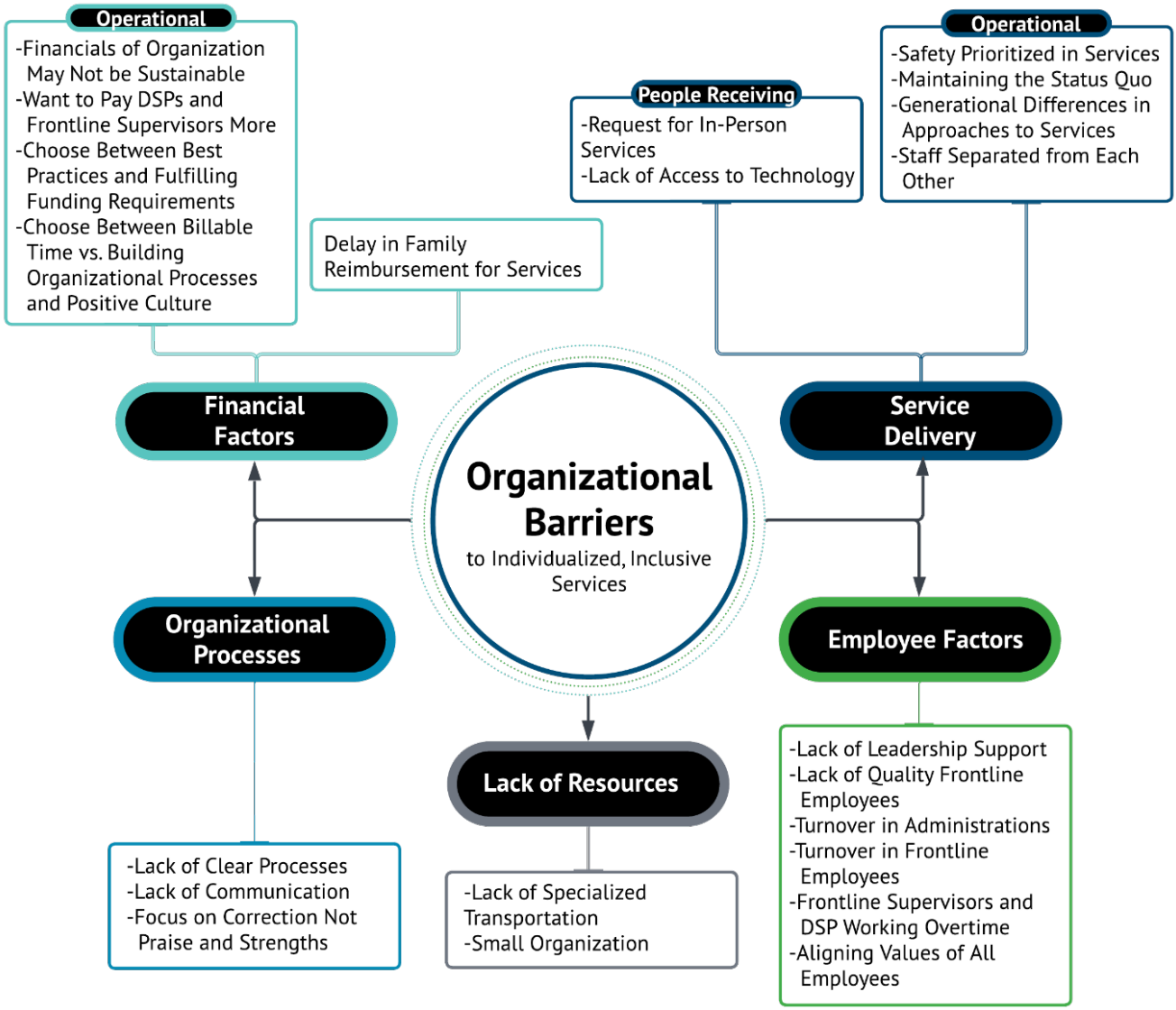
Figure 28 Top Three External Changes Needed to Switch Completely to Individualized, Inclusive Services



Organizational Barriers

Executive leaders who participated in the study discussed organizational barriers that hinder the implementation of individualized, inclusive services. Five major categories of groups were identified: financial factors, organizational processes, service delivery, employee factors, and lack of resources (see Figure 29). Each of these themes is composed of several specific factors that have impacted the organization's capacity to provide better services for the people they serve.

Figure 29 Organizational Barriers to Individualized, Inclusive Supports

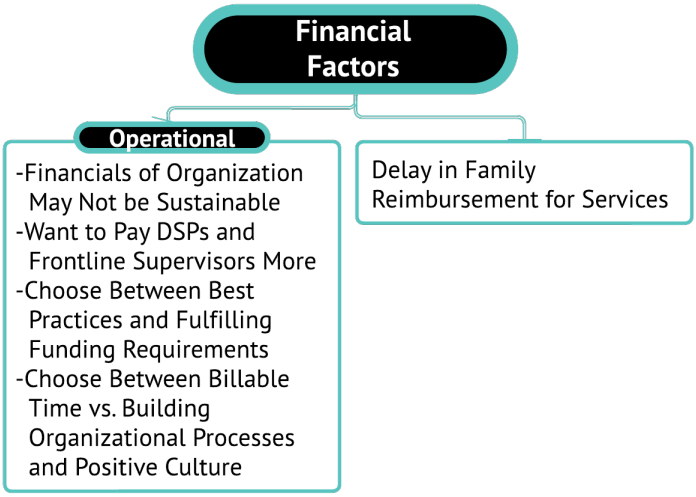


Financial Factors

Participants described most financial factors as operational processes that considerably influenced the capacity of the organization to implement individualized and inclusive services.

The lack of sustainability within the organization's financial status and the failed desire to raise the salaries of frontline supervisors and DSPs are some of the most critical aspects that the interviewees discussed. Also, according to participants, organizations have to face the tradeoff between best practices and fulfilling funding requirements. Another critical trade-off a participant mentioned was that organizations must choose between billable time versus building organizational processes and positive culture (see Figure 30).

Figure 30 Organizational Financial Factors that hinder individualized and inclusive services



We found that a significant internal barrier faced by small service-based organizations is a trade-off between billable time and the essential work of building organizational infrastructure and culture. One participant described the tension between maintaining financial viability through billable hours and the need to invest in critical organizational processes like HR and bookkeeping. This underscores the challenge of sustaining internal operations while ensuring staff have the time and capacity to contribute to a positive organizational culture.

"So, we are a support broker service, and it's fee for service, so it's an hourly rate of work. So, with such a small organization, billable time is essential. It's almost like a job coach has to work 90% billable. What does that mean for an organization where there's also organizational responsibilities? So, we contract with people for HR. We have three voluntary HR administrators, they're incredible to us. I know we've never paid for that. And then, you know, bookkeeping is like, there's a finite set of tasks, and I do some of it. So that's a tough thing for us. That is where we need to do some clear planning. Anyway, it works, but it's very tedious. If you're missing an hour here or there, it can upset the whole month."

"Financially that has always been a challenge and there's always question of is it sustainable? I mean, it's definitely sustainable, but is it in the way that we're doing it as an organization like this? So that's been the challenge to actually providing the service in that way. I would say that's

it, and that the outcome for that is that we disband the company and all work independently. So there really isn't a challenge to delivering."

Our study also uncovered that barriers like financial instability within organizations providing disability services significantly impact staff compensation, service delivery, and overall sustainability. Participants discussed how it diminishes the organization's capacity to maintain high-quality, individualized, and inclusive services. One participant discussed that organizations striving to provide individualized, person-centered supports often face financial disadvantages compared to those following more traditional models, making it difficult to offer competitive wages for DSPs and frontline supervisors.

"We are not able to pay them as much as we would like to, and we see other organizations in South Dakota — we used to be the highest paying for our DSPs, now other organizations are highest paying, and they are organizations that don't do things creatively. They serve these people. And everybody here goes to day services every day, and then they go home, and we have a whole lot of individual supports and do what you want and live the life you want, and so financially, that's not to our advantage. And so we would like to pay DSPs more and frontline supervisors more."

According to other participant, bureaucratic funding requirements often force organizations to prioritize meeting numerical targets over best practices, limiting their ability to provide the highest quality care

"It's kind of hard to explain, but we have specific things to fulfill within grants that we receive, and because of that, there's pressure on us to get the numbers up in certain areas, and that interferes with best practices. Sometimes I feel like we're trying to get numbers up in certain areas and certain variables, and it's hard to be best practices and serve some of those things. Something related, like bureaucratic issues in how funding is allocated for services."

Finally, another interviewee said that inefficiencies within financial management service (FMS) structures create burdens for families, such as requiring upfront payments and dealing with delays in reimbursement, which can hinder access to essential supports.

"Setting up the financial support structure [is a barrier]. The FMS financial management service, there's people that agree or companies that agree to be a vendor for Financial Management supports so that self-determination can be used. But there are many frustrations around that model of having a financial management structure, delays and payments. My ideal scenario of a family member with an adult family member with a disability who needs a support but would like to enroll in a city program, the cost can be a factor. I'm told that this financial management service can pay back the costs, but the process is not as effective as it could be. So, the family would have to put out the expense first get reimbursed those types of things."

Organizational Processes

There are many internal barriers or **organizational processes** that hinder the development of individualized and inclusive services. Some factors described in the interviews included a lack of communication, a lack of clear processes, and a punitive managerial perspective focusing on correction, not praise (see Figure 31).

Figure 31 Organizational Processes that hinder individualized and inclusive services

Some participants referred to how a lack of clear communication and structured processes often makes it difficult for staff to navigate responsibilities effectively.

"In this particular organization, we don't have administrative meetings, which I think creates friction and creates discontent."

"So, there seems to be in the last several years, with the turnover that we've seen, but we're growing, but we're having turnover. Your infrastructure suffers. You lose continuity of policies and procedures. You update a policy. Does everybody know that policy has been updated? Has everybody been trained effectively on that up policy? Do you have a process in addition to the job description? You need the process, too, of how to do that job. And are we working on that? Are we making sure that they make sense and that they're usable? Success and succession planning are important, but I believe communication is important about that. You need to talk to your administration about what you're doing, you need to not just have an expectation of 'because I told you.'"

Additionally, an interviewee said that their organization's focus on correction over praise, leads to accountability measures overshadowing efforts to foster a positive and supportive workplace culture, ultimately impacting service quality and staff morale.

"We focus a lot on discipline here, disciplinary action. And there was a time where we were focusing on accolades more, and that's why they've gotten away from that. And I actually just thought about this week, that in the last three executive directors, the two previous I have many letters of accolade, and then the last seven years, not a single one, just corrections. If you've

been somewhere for 29 years, how are all the corrections now? But it wasn't before. So, just thinking about, like, practice, what you preach, kind of thing."

Lack of Resources

Another barrier identified was the **lack of resources**. Participants referred to obstacles such as a lack of specialized transportation and the small size of some organizations (see Figure 32).

Figure 32 Lack of Resources That Hinder Individualized, Inclusive Services

A few participants mentioned how the lack of resources creates significant barriers to delivering individualized and inclusive services. For example, specialized transportation is a significant financial burden for organizations that support people with complex medical needs, as state funding often fails to cover the high costs of accessible vehicles.

"Transportation is a big thing. We have built our reputation on supporting people with significant medical issues, and therefore we do need specialized vans with lifts and utilize law chairs. And so that's a very big part of our expense that's not compensated by the state, and so where other agencies, if they don't take people who have those needs, they can get away with leasing a car, where we need to make sure that, so people have access. We have transit vans, vans with lift systems, and things like that. So that would be another thing. Is not only transportation in terms of our public transportation, but transportation internally as well."

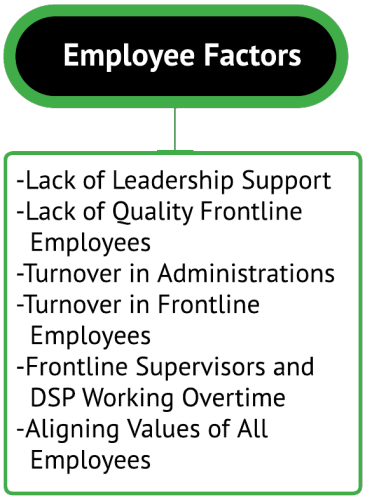
Meanwhile, the scale of an organization presents another challenge. An interviewee said that while smaller providers struggle with limited resources, larger organizations must be intentional about maintaining individualized care amid operational demands.

"I would say scale of the organization. I mean, as we get bigger, you have to be so much more intentional to keep things individualized and not make decisions solely on the mass internal barriers."

Employee Factors

Employee factors such as lack of quality staff, turnover/lack of staff, aligned values with all Staff, and lack of leadership support are other barriers to implementing individualized and inclusive service (see Figure 32).

Figure 32 Employee Factors That Hinder Individualized, Inclusive Services



One participant mentioned that the lack of leadership support challenges staff retention and morale.

"If somebody's complaining to me about their job, I'm always like, 'You can work anywhere you want. You don't gotta work here. Tell me why you're here.' And that's where retention keeps happening. You know, we're saving all these employees. But again, it's like, how do we get everyone else to practice what we're preaching? Because I'm starting to feel like I'm retaining people for the people we support. That's what I'm doing it for."

Another participant said that the lack of quality staff presents a significant barrier to providing individualized and inclusive services. When staff members lack the necessary skills or commitment, it impacts service delivery and the overall experience of the people receiving support, organizations often struggle to maintain a consistently high-quality workforce.

"The other thing is like as getting the right staff who can do that type of job independently. So you have to be independent, self-starter who is willing to be on their own schedule and reliable and actually follow through on what you're doing without consistent supervision, because you're out individually, one on one with individuals, and we've had a couple of issues with staff members who are not really providing the quality service that we would like for them to provide, and it's harder to ensure that when someone's not able to see their work as easily because they're out and about. Right now, I think we're in a really great spot. We have a really great

couple of leaders in that department, but it was definitely a challenge for a while, and it's kind of come back and forth."

Other participants discussed how turnover and the lack of staff remain persistent challenges that directly impact individualized and inclusive service delivery and organizational stability. High turnover rates, especially among DSPs and frontline supervisors, create staffing gaps and disrupt continuity of care.

"Challenges around delivery over the last few years, it's been difficult keeping people for and I can pinpoint probably a host of reasons, and part of it is a lot of people come here, get their training and go. So we have stopped that. So we may be doing things quite different, like we were definitely not hiring anybody else to do that. Well, that's not the partnership we're looking for, but certainly people value our training. So we're looked at like an incubator support broker school kind of thing, where you can train and we knowingly pair you up with people that you can work for and go. So that's a better like readjusting every time someone does that behind our back, right? So that is that's been the biggest challenge, probably."

"I mean retention and turnover is I mean, we always fight it. We have had years that's been like our we choose a wildly important goal every year, and that's kind of the overarching focus for the whole year, and that's been the focus many years, because we just can't seem to win that battle. So, I would say turnovers."

Additionally, the unpredictability of on-call responsibilities burdens DSPs, contributing to burnout and job dissatisfaction, which impact individualized and inclusive service delivery.

"Probably our biggest challenge right now is frontline supervisors. Within the last month, we've had five openings, and there are 20 of them, and now we're getting those positions filled. We are really working on succession planning, because we had openings and no DSPs applied, which is really our preference, rather than having people from the outside come in, that's just a huge learning curve. And then we had a league retreat, which we have every year, we invited potential leads, which we do every year, and we are working on succession planning, giving a way for DSPs to see what the frontline supervisors do and get them more involved in leadership training. Help them to see a track where they can move up in the organization. And the biggest challenge that we've just identified right now, for DSPs, is the amount of time that they are on call and potentially will have to go in to deal with the situation. They're paid hourly, and I see their time sheets, and they're working 40 hours a week, some up to 45 hours, a few up to 50 hours, but not consistently. We really work to keep their hours manageable. And they are paid hourly and paid overtime. But it still is just a weight on their shoulders, the fact that I might get a call, I might have to go in, I might have to deal with, they just don't feel like they have time off. And so that's where we're putting in some energy right now too. That's a current challenge."

Some of the interviewees mentioned that aligned values among all staff are a crucial yet challenging aspect of maintaining a cohesive and mission-driven organization delivering individualized and inclusive services. Participants referred to a perceived disconnect between administrative teams and direct service staff that can create tension, especially when rigid processes and paperwork requirements conflict with the flexibility needed to provide person-centered support.

"My hardest one has been my HR team and the philosophy, it's my admin team when we are supporting the leaders that support the DSPS. It's very difficult for them to be a type of advocate, a DSP supervisor who sits at the desk and pounds out paperwork. Our leaders are not that kind of paperwork people, but I have this admin team that's very paper heavy, and they want you to be connected to your email. So, we have this frustration that happens with the scheduling team that wants just to plug holes, and we start messing with people's schedules, and if a piece of paper isn't submitted on time, then people get yelled at. So, I think it's just understanding, how do I get this administrative team to be as fluid and flexible and truly understand the work that the service team is doing? Because we have to do it differently. We have to be very fluid and flexible and mobile with how we're supporting our DSPS and people we support. So I have this very mobile, fluid team, and then this other team that's like, I don't work with people with disabilities. That's their job. So, it's changing that philosophy internally."

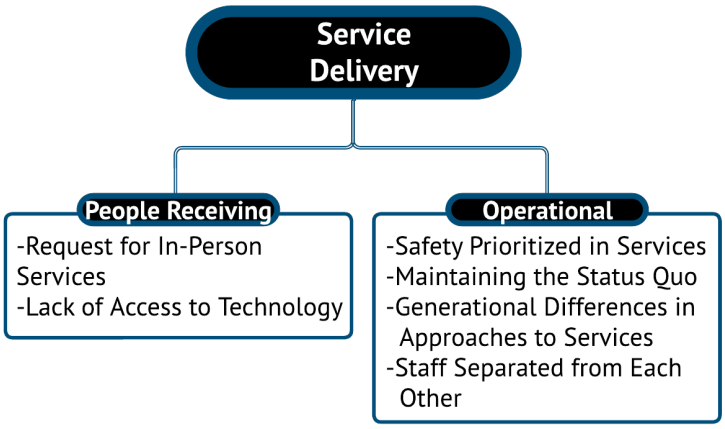
Another participant referred to the challenge of balancing internal staffing needs with outsourcing essential administrative functions and adding another layer of complexity.

"And another thing I struggle with at a leadership level, since we're a non-profit, because nonprofits are set up to be a mini universe that has a fully functioning HR department, fully functioning finance department, we do it all. What I'm finding is that we have to outsource some of those skill sets that are almost impossible for each nonprofit to hold. It's very expensive for our system, and regulations have really intensified over the last 30 years in each of these areas. So how do I balance getting this team to understand I can outsource this I don't need to have a billing department or a payroll department that can all be outsourced, and it saves so much more money. So that switch has also been an internal bugger for me to try to figure out because, well, people will lose their job, but they have to so we can invest more in service delivery."

Service Delivery

We also identified barriers within the actual service delivery that affect the organization's capacity to provide individualized and inclusive services. Participants discussed obstacles in service delivery regarding people receiving the services and operational barriers (see Figure 33).

Figure 33 Service Delivery Barriers Hindering Individualized, Inclusive Services



The operational service delivery barriers identified include spatial disconnection due to staff working separated from each other, generational divides in staff values, organizational inertia to challenge the status quo, and a lack of dignity of risk and prioritizing safety. Respondents talked about how spatial disconnection between staff members presents a significant internal challenge, particularly in organizations with a dispersed, community-based workforce.

"Just the very structure of the blob of the organization is a challenge, the fact that the people that we rely on to deliver the services, not only are we underpaying, under-resourcing, under-communicating with, but we also don't see them? They're not under the roof. Many of them don't see colleagues, supervisors. They don't hear from anybody. And I think maybe it's why I have evolved into this person that just rants all the time, that just beats the drama everywhere she goes, because I have such a sense of need to kind of constantly be putting the message out in any way possible. I record these little videos that we blast out to people in little check in message or whatever, because I know that the people that are most essential for us to execute the mission, vision and the philosophy of the organization are the people that are usually the most removed from kind of the heart and the root of the mission, vision and philosophy. Right now, we're working on several tech projects. We have a tech grant that we're working to build an AI tool that we are creating a safe environment, so we don't have to worry about phi going out into the world wide web. We have very little connectedness to and I think that is by far the biggest challenge internally, even with all the lack of resources and money and not paid enough and not paid for a lot of the stuff that's required to be able to do this work well and right, it is still the spread outness and the disconnectedness of a home and community based statewide workforce that is the biggest challenge."

Generational divides in staff were described by an interviewee as an operational barrier. Differences in experience and perspectives between staff members, particularly between senior leadership and junior employees, can create internal tensions within an organization.

"And then I think also some of the executive director, she's been in this role for 20 some years, and our organization has been around for 26 years. She's on the way out, and she's fantastic, forward thinking and some of the best practices, that changes over time and as much as there's webinars and different things. I mean, age gaps do happen, and I feel like some of that happens internally sometimes. People see different ways to support individuals, I think that's kind of one of the internal problems."

Resistance to change remains one of the most persistent internal challenges, as organizations often default to familiar practices rather than exploring new, innovative solutions.

"So inertia, 'We've always done it this way.' I have a little fine jar over my desk there's two of them. One is a curse jar, and I routinely contribute to it, and the other jar is the 'we've always done it this way' jar. So, when people say in response to a question, 'how can we do it that way?' And someone will pipe up and say, 'Because we've always done it that way,' that's five bucks in the jar. So, I think inertia is the single biggest internal factor, number one."

We also identified an ingrained culture of paternalism within service organizations, prioritizing safety and compliance over individual autonomy. One participant reflected on how these barriers limit opportunities for people to take risks and make their own choices.

"People who move into our space have grown up either observing or in the space being trained into paternalism. Our job is to protect people. Our regulations still refer to health and safety as the prime objective. This is just frustrating, because it creates significant reluctance to try [things]. We wouldn't recognize dignity of risk if it walked up to us on the street and smacked us across that so we have to retrain a whole workforce."

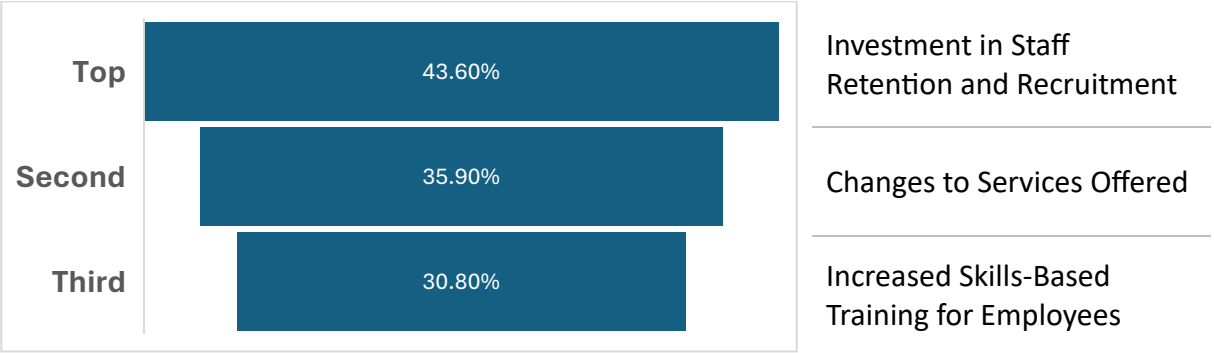
Finally, the limited access to technology and a preference for in-person services of people receiving services create support barriers, particularly in telehealth and remote service delivery.

"Not everyone has the technology available or access to it in their home settings. A couple of years ago, we tried to get a lending program out for laptops for families to be able to have during COVID, to be able to have that support. And even still, with a lack of clinicians, from time to time with speech, OT, PT, etc., they're offering telehealth as their preferred way of delivering service delivery. Still, families, culturally, and even just the technology knowledge is not there to take advantage of that. They prefer in-person visits. They've told the service coordinators. So, businesses are trying to run faster, more efficiently, without having to drive out with missed appointments and things like that. And providers are offering and businesses, if we're supports, are offering telehealth and it's not as pleasantly received as it could be."

Study participants were also asked in the survey to rate the top three organizational changes needed to switch completely to individualized, inclusive services. Top responses emphasized the

need for workforce development, service model innovation, and targeted training as essential steps toward achieving fully individualized and inclusive services (see Figure 34).

Figure 34 Top Three Organizational Changes Needed to Switch Completely to Individualized, Inclusive Services



The top priority, cited by 43.6% of respondents, is investment in staff retention and recruitment, reflecting the ongoing workforce challenges in the sector. The second most named change, at 35.9%, is modifying the services offered to better align with person-centered approaches. In third place, 30.8% of participants identified increased skills-based training for employees as a critical need. This underscores the importance of equipping staff with the competencies required to deliver high-quality, person-centered support. These survey findings highlight key barriers to achieving individualized and inclusive services, which align closely with the challenges expressed in participant interviews.

High turnover and staffing shortages were recurring concerns for interviewees, with participants describing difficulties in retaining quality staff and ensuring leadership support. According to respondents, the lack of competitive wages, excessive workloads, and limited career growth contribute to instability, making it difficult to provide consistent, high-quality services. Organizations need to prioritize workforce investment, leadership development, and improved working conditions to address these concerns.

Regarding Changes to Services Offered, a recurrent theme in interviews was participants' concerns about bureaucratic funding structures, rigid service models, and paternalistic service approaches, which limit individualized support. Interviewees noted that traditional service models often fail to meet diverse and evolving needs, reinforcing the need for greater flexibility, innovation, and policy shifts to align services with person-centered values.

Finally, interview participants also emphasized repeatedly the need for better staff training in areas such as self-determination, dignity of risk, and individualized support strategies. Many noted a disconnect between administrative staff and frontline workers, highlighting the importance of organization-wide training to foster a shared understanding of inclusive practices.

Discussion and Recommendations

Putting it All Together

Inclusion, individualization, and person directed supports should be the most funded services for adults with intellectual and developmental disabilities in the United States, given the current distribution of Medicaid funding to HCBS (64%) vs. Institutional (36%) supports. Yet we know from this study and many others that many organizations struggle to adopt fully integrated service models. This leaves hundreds of thousands of people with disabilities receiving services that limit their right to belong and contribute to their communities, make decisions about every aspect of their lives, and receive services that are tailored to their individual needs.

With a deep commitment to providing quality care and supports, many organizations in this field were founded on congregate service models that inhibit access to a full and inclusive life. Even though our field has made great strides in designing and delivering services that facilitate more control, autonomy, and access for people with disabilities; most organizations continue to provide some sort of congregate, segregated support that maintain a level of control over where, how, and with whom people live and spend their time. This is particularly true for people with disabilities who have more intense medical and behavioral support needs and for people from traditionally underserved groups, including BIPOC with disabilities.

This study aims to contribute to knowledge in the field about what it takes for organizations and leaders to deliver fully individualized and inclusive services. To do this, the characteristics and practices of organizations that provide a range of community supports were examined. Some organizations in this study (40%) provided only individualized and integrated services; about half provided less than 60% inclusive services and less than 50% individualized services.. Ultimately, the study aimed to identify what it takes to transform services, so that leaders working in agencies that provide congregate supports can learn about what is needed to compel change within their organizations. The focus of the study also included the internal factors (policies, practices, values, and more that come from within the organization) and external factors (policies, funding, advocacy, and pressure that comes from outside of the organization) that advance and get in the way of providing fully inclusive and individualized services. The National Leadership Consortium's goal is to use this information to build field leaders' knowledge about what is important to know, do, and develop if they are interested in making inclusion a reality for people with disabilities they support.

This section includes a brief discussion of overall findings and recommendations for leaders in roles across the field to consider as they work to advance inclusion.

What it Takes to Transform

Several executives who participated in the interviews shared that their organizations were founded on principles of inclusion. Thus, their organizations provided individualized person-directed services in people with disabilities' chosen communities from the start. While they shared that there have certainly been challenges (both internal and external) in establishing and maintaining standards of inclusion, they also did not have to do the often-grueling work of transforming a service delivery model.

However, for the sustainability of the field, it is essential that many, even most, organizations providing services to people with disabilities transform their services away from congregate and segregated models to inclusive and individualized supports at some point in their history. To make this switch, results showed that organizations were motivated by values and priorities of people supports, family members of people supported, and agency leaders, as well as sustainability concerns, including state policy and funding changes that incentivized community-based services or disincentivized congregate living and opportunities to increase organizational capacity to meet the needs of more people with disabilities.

The same factors that motivated change also facilitated it. Requests for individualized services, social pressures, commitment to inclusive values, and increased state priorities through funding and policy changes helped organizations transform. Similarly, strategies to help staff and families of people understand the alignment between inclusion and a better quality of life, as well as organizational restructuring and staff buy-in were crucial to the transition to inclusive and individualized services.

What Helps and Hinders Inclusion and Individualized Supports

If transforming services and supports to be fully inclusive and individualized, it is highly likely that these types of supports would be much more widely available to people with disabilities. While many leaders mentioned that field professionals certainly get in the way of promoting inclusion, for example by holding on to what has always been done before, by underestimating people with disabilities, by maintaining longstanding bias and harmful beliefs about people with disabilities,, participants also noted that it is often systemic and organizational challenges, practices, and capacity issues that prevent, slow, or efforts to make services better.

The findings from this study show that many of the challenges that hold organizations back are either the presence or absence of the same factors that facilitate change. For instance, some participants shared that leading organizations in states that provide higher rates for inclusive services are a major facilitator, while others shared that leading organizations in states that continue to invest significant dollars into congregate supports are a major barrier.

What is clear from the results of this study is that transformation is certainly complex and requires commitment and significant effort to build systems infrastructure and organizational capacity. This study contains examples of organizations that provide fully inclusive and individualized supports in state systems that continue to incentivize or support segregated service models. Similarly, there are organizations that hold fast to congregate supports, even when states compel and support organizations to adopt inclusive practices. To lead needed transformation, leaders are tasked with not only convincing people that change is needed, but with navigating internal and external practices, procedures, policies, funding structures, and workforce capabilities that facilitate or hinder change.

Systems Factors

The results of the facilitators and barriers analysis that explored external and systems-level influences have been well documented and remained consistent over the last several decades. State and federal policies, funding structures, rates, eligibility requirements, and the presence or absence of waitlists all play a major role in provider organizations' capacity to transition to and/or provide inclusive and individualized services. In fact, state and federal policies and funding were each listed among both the top three facilitators and the top three barriers to change. Due to trends in ongoing federal investment in Medicaid funding, it is not likely that there will be an influx of funding to grow service capacity or address long wait times for enrollment in public benefits. However, there are opportunities for field leaders to make a case for promoting community-based services through policies, funding, and reimbursement rates as there is substantial evidence that shows that when people with disabilities are supported in their communities, they contribute to the economic and social wellbeing of their communities, and rely on services that, on average, cost less to provide.

Additional factors that influence capacity for inclusion and individualized services, including tangential resources and infrastructure like housing, transportation, crisis support, and integrated service systems (e.g., mental health and disability services), are also important to consider to advance community-based supports. Many states are exploring or have implemented scalable models to address housing shortages, better integrate disability and mental health systems of support, and address the lack of reliable public transportation. A deeper investigation into coordinated state efforts would be helpful to point to specific models and systems efforts that work.

Finally, knowledge and values within systems professionals were commonly noted as either positive or negative influences on promoting individualized, inclusive supports. Within state agencies, it is essential that employees not only understand and can connect people and agencies to service models and options that facilitate inclusion, such as self-directed supports, integrated employment services, and supported living models that support people in their own

homes, it is also critical that they understand that these service options can and should be accessible to all people with disabilities, regardless of the type and level of support needed. State agency employees, particularly case managers, can facilitate or gatekeep access to inclusive services based on their knowledge and beliefs.

Community norms, beliefs, and traditions were also noted several times in the study as factors that promote or inhibit inclusion. Building community awareness, partnering with community organizations, and making it clear that the contributions of people with disabilities to their communities can be an important step to helping communities become more welcoming.

Organizational Factors

A pivotal finding from the study showed substantial differences in practices related to services, sustainability, and executive leadership between organizations that provided primarily community based and individualized supports and those that provided more congregate services. People working for organizations that provided inclusive services to more than 70% of people supported were more likely to:

- Provide services that promote higher quality of life, choice, and control for people with disabilities. For example, they were 27 times more likely to promote autonomy, choice, and control, ten times more likely to promote full inclusion in the community, and six times more likely to include stakeholders in organizational decision making.
- Enact organizational practices that promote sustainability. For example, they were six times more likely to incorporate effective DEI practices and 13 times more likely to incorporate effective staff participation and support practices
- Rate the executive leaders of the organization as having strong Transformational Leadership skills. For example, they were 11 times more likely to give them high ratings of transparency, five times more likely to rate them as a strong moral example, and three times more likely to rate their behavior in alignment with their morals and values.

These results demonstrate the multifaceted benefits of providing individualized, inclusive supports. When organizations are guided by their values, they rate themselves as stronger in several key areas of organizational practice. That is not to say that these organizations do not also face barriers; in fact, they named many of the same barriers and facilitators as those organizations providing fewer inclusive services. However, inclusive practices foster more inclusion and sustainability. Survey participants rated existing service models and current practices of person-centeredness as the top two facilitators for inclusion and individualized supports.

The organizational barriers and facilitators to providing inclusive supports found in this study point to key areas of organizational operation, strategy, and priorities. Leaders can use these

findings to consider current organizational strengths and weaknesses, and to determine what is needed to enhance capacity to provide services that meaningfully connect people to their chosen communities.

Structure and Service Models A major facilitator or barrier to providing inclusive and individualized services is related to how organizations structure their supports; survey results show that the second highest rated barrier to providing these services was changes needed in services offered. Organizations that provide services that are fundamentally individualized, such as self-direction, supported living, support for competitive employment, etc., have an easier time providing inclusive services than those that try to retrofit inclusion into inherently congregate models of supports (e.g., group home services, day centers, etc.). Some participants noted that there is an inherent conflict when organizations own the residences or vehicles in which services are provided. Organizations are incentivized to ensure that the Medicaid dollars entitled to the people they support are used to maintain their buildings. Letting go of a service model entirely, especially when it is tied to brick-and-mortar investments, is a significant challenge for many organizations. Participants at organizations that provided fewer congregate supports noted higher levels of community inclusion and control of services and lifestyle by people they supported.

Operations The results of this study confirm previous studies of organizational practice (Gilden & Bailey, 2018), showing that when operations are guided by principles of inclusion, it promotes organizational capacity to provide inclusive services. Including people with disabilities in meaningful leadership roles, creating specialized employee positions, tracking inclusion efforts, ensuring transparent processes, procedures, and communication, providing training that promotes principles of person centeredness and the rights of people with disabilities, and aligning employee expectations, policies, and procedures with inclusive values ensures that organizations walk their talk from within.

Workforce Support Workforce instability continues to be a critical challenge for many organizations. It was rated as the third highest facilitator for inclusive supports and the top barrier or needed change to providing inclusive and individualized services in this study. Providing individualized services is challenging when there are ongoing staffing shortages and consistent turnover. Study participants noted that consistent efforts to build workforce capacity through training and development, coaching and mentoring, increasing wages, and retention activities is helpful to ensure that an organization can manage the challenges of transforming and can provide inclusive and consistent services.

Resources & Funds State and federal funding typically does not cover the cost to provide quality services and resources needed to support people to become meaningfully included in their communities. Many leaders of provider organizations in this study have found this particularly

true as demand for fair wages for the direct support workforce rises faster than state rate increases. They also noted that systems challenges, such as lack of transportation, housing, and technology (or funding for technology), mean that organizations must often engage in fundraising to supplement costs. Many respondents noted that successful fundraising efforts, including grant writing and community outreach to help people supported with individual costs not covered by public funding, or to provide workforce bonuses, are helpful to advancing inclusive and individualized services.

Workforce Quality In addition to workforce stability or instability, workforce quality impacts how well organizations can adopt, transition to, and provide inclusive and individualized supports. When leaders focus on increasing staff engagement, reducing turnover, promoting strong, cohesive teams, investing in the development and appreciation of frontline and direct support staff, and embedding values of inclusion in staff expectations and performance, they are able to foster a stronger commitment to inclusion.

Leadership and Management Practices The skills, values, and practices of organizational leaders play an essential role in building inclusive organizations. Experts consistently noted that leaders, managers, and those in authority must demonstrate values of person-direction and inclusion in their leadership styles, nonhierarchical strengths-based (over punishment-based) approaches model expectations for how people are treated, both as employees and service users. Further, when employees feel that the people in top leadership roles have the skills needed to set support an organization to carry out a vision for inclusion, such as integrity, accountability, transparency, creativity, collaboration, passion, and dedication, the results of this and other studies show that they are more likely to enact visions of inclusion. Because leadership is a skill that can be developed, many participants also noted that organizational investment in leadership development is crucial. Survey results showed that increased skill-based training for employees was the third-highest rated barrier or needed change to promote inclusive and individualized services.

Recommendations to Promote Inclusive and Individualized Supports

Based on the findings of this study, recommendations to transform and sustain individualized, inclusive supports are included below. Recommendations are included for leaders working in agencies that directly provide services to people with disabilities, leaders working in state and federal agencies, advocacy leaders, researchers, trainers, and other professionals across the field.

While recommendations based on this study's findings are not an exhaustive list for what is needed for effective transformation to individualized, inclusive supports, they can aid leaders in promoting and managing barriers or replicating facilitators to inclusion. They can also open

leaders' minds to considering what other leaders in their position believe are the lynchpins to making inclusion happen. Leaders should not wait to try to change their organizations until these factors are addressed, nor should they expect that successful transformation is inevitable if each of these facilitators in are in place. Delaying transformation due to imperfect conditions will only stall needed change indefinitely.

Compel Organizations to Transform.

Helping an organization make the decision to progress toward more individualized, inclusive services can be influenced by internal and external factors, including state and federal systems, organizational leaders, and more. The following recommendations include actions several different groups can take to compel transformation.

Systems Leaders Leaders working in state and federal agencies should consider requiring or incentivizing change (or increasing requirements and incentives where they already exist). Many states have incentivized change by increasing rates for community based services, providing transformation grants, offering training and technical support, and more. They have also pushed change by mandating the closing of institutions, requiring day employment centers to pay at least minimum wage, requiring organizations to demonstrate quality of life outcomes, and more. Given the results of this study, it is likely that systems' efforts to promote change would be most effective if they focus on increasing access to resources that make the change to inclusion more sustainable.

Provider Leaders Provider leaders seeking to transform services must start with the challenging task of gaining buy in for support. They must work closely with employees, people using services, family members, funders, and more to make the case for inclusion. Helping stakeholders understand how the transformation aligns with the mission and values of the organization and contributes to sustainability in the long run is essential. Experts in organizational transformation also recommend providing space for people to share their opinions, concerns, and ideas about the change on the table; forums, surveys, and data and information collection efforts can inform strategy and help leaders make a targeted case for change that assuages or at least addresses concerns.

Researchers, Trainers, and Field Experts Data, information sharing, anecdotal stories, and strong strategies and skills can build trust and promote buy-in to change. In the disability service sector, there is a wide range of resources that provide evidence-based information and resources about the benefits and opportunities to adopt inclusive and individualized service models. Leaders working in the field who share information and resources as part of their role can help to drive change by continuing to share action-oriented data, resources, and information that promote inclusive and individualized services.

Get The Right People in the Right Seats

Hire People with Lived Experience in Decision-Making Roles In many regions of the country, state agencies and provider organizations are increasing their efforts to recruit and hire people with disabilities to work in leadership and decision-making roles. People with disabilities have long advocated *Nothing About Us Without Us,* which means that people with lived experience should be driving decisions in the field. When agencies hire people with disabilities to lead, help with decision making, or guide efforts, they can support the transformation to inclusion by sharing their personal and professional expertise.

Ensure Participatory Leadership and Management Practices When organizations' operating values match their external-facing values, they are more likely to achieve their goals. Promoting full inclusion and control for people with disabilities feels disingenuous when organizations adopt hierarchical, punitive, and authoritative leadership and management approaches that limit employees' autonomy and opportunity to meaningfully contribute to decisions and changes that impact their work. To truly operate by values of inclusion, organizations will be more successful when they also adopt participatory strategies in policies, operations, Human Resources, and all departments. If organizations and their leaders rely on traditional hierarchies, investing in training and support to reorganize operations and train leaders and managers in participatory practices is an important early step in the transformation process.

Invest in Workforce Development Workforce shortages, high turnover rates, and low retention of DSPs, particularly those working in their organizations for one year or less, threaten and reduce the quality of services that people with disabilities receive. While leading any change in an organization is challenging, leading change in an unstable workforce is even more arduous. Efforts to recruit and retain strong frontline leaders, including wage increases, investing in development, incentivizing longevity, and strong recognition efforts, can promote more sustainable change in the long run.

Navigate State and Federal Challenges to Inclusive Services

Systems Leaders State Agencies should examine how their current policies, practices, funding mechanisms, rates, service options, and staff knowledge help or hinder inclusive services. Reviewing exemplary state practices to understand which service models, funding distributions, or state technical support efforts are helpful to promoting inclusion can help states consider how they can facilitate transformation rather than block or challenge it. Further, ensuring that staff working in all positions and levels of the state are informed about self direction, supported living, effective person centered planning approaches, and other service models and practices that promote inclusion and control is helpful to increase agency-wide investment in individualized services and to ensure that when people with disabilities, families, and provider

organizations reach out to state contact, including case managers, they are informed of the state mechanisms that promote inclusion.

Provider Leaders In every state, there are significant barriers to providing individualized, inclusive services, and in every state, there are organizations that provide completely community-based supports that are tailored and led by the people with disabilities who choose them. Results of this study showed that leaders who work in agencies that provide the most individualized community-based services have figured out how to make inclusion happen within complicated and often disincentivizing state systems. Participants shared that building collaborative networks with other dedicated leaders, inclusive interpretations of regulations and rules, and strong relationships with state agency employees are helpful in working within system challenges. Leaders working in provider agencies should prioritize collaborative and mutually beneficial relationships with other leaders in the field who can share ideas, strategies, and even resources.

Funding for community based services, including Medicaid and other federal and state government funds, has never been in such a surplus that all provider organizations have what they need to fully fund individualized services for everyone they support. Trends in federal support for changes to federal Medicaid funding will likely further limit resources. To supplement government funds, many organizations have sought grants from private foundations and fundraised with community stakeholders. Leaders of provider organizations should consider or continue to increase fundraising efforts and building relationships with local businesses that can help fund or sponsor initiatives by hiring a grant writer or fundraiser or developing the skills of an employee interested in organizational development, and getting involved in business and service organizations to create partnerships that can be leveraged in the future.

Advocacy Leaders Across the country, advocacy leaders have impacted essential changes to state and federal policies and practices through tireless efforts to educate, share stories with, and convince legislators and policymakers that change is needed. Advocacy movements have led to deinstitutionalization, wait list reductions, pay equity requirements, and the elimination of 14(c) services, adherence to HCBS, and more. Advocacy efforts are needed during and between legislative sessions to educate service providers and families and guide policymakers about the decisions needed to improve the lives and inclusion of people with disabilities.

Hold Organizations Accountable to Inclusion

Systems Leaders The passing of the HCBS rule was a monumental shift in how our field understood and mandated inclusive and individualized services. However, in some states, the interpretation of the rule has allowed organizations providing congregate and segregated services to continue receiving community-based funds, which reduces the chances that people

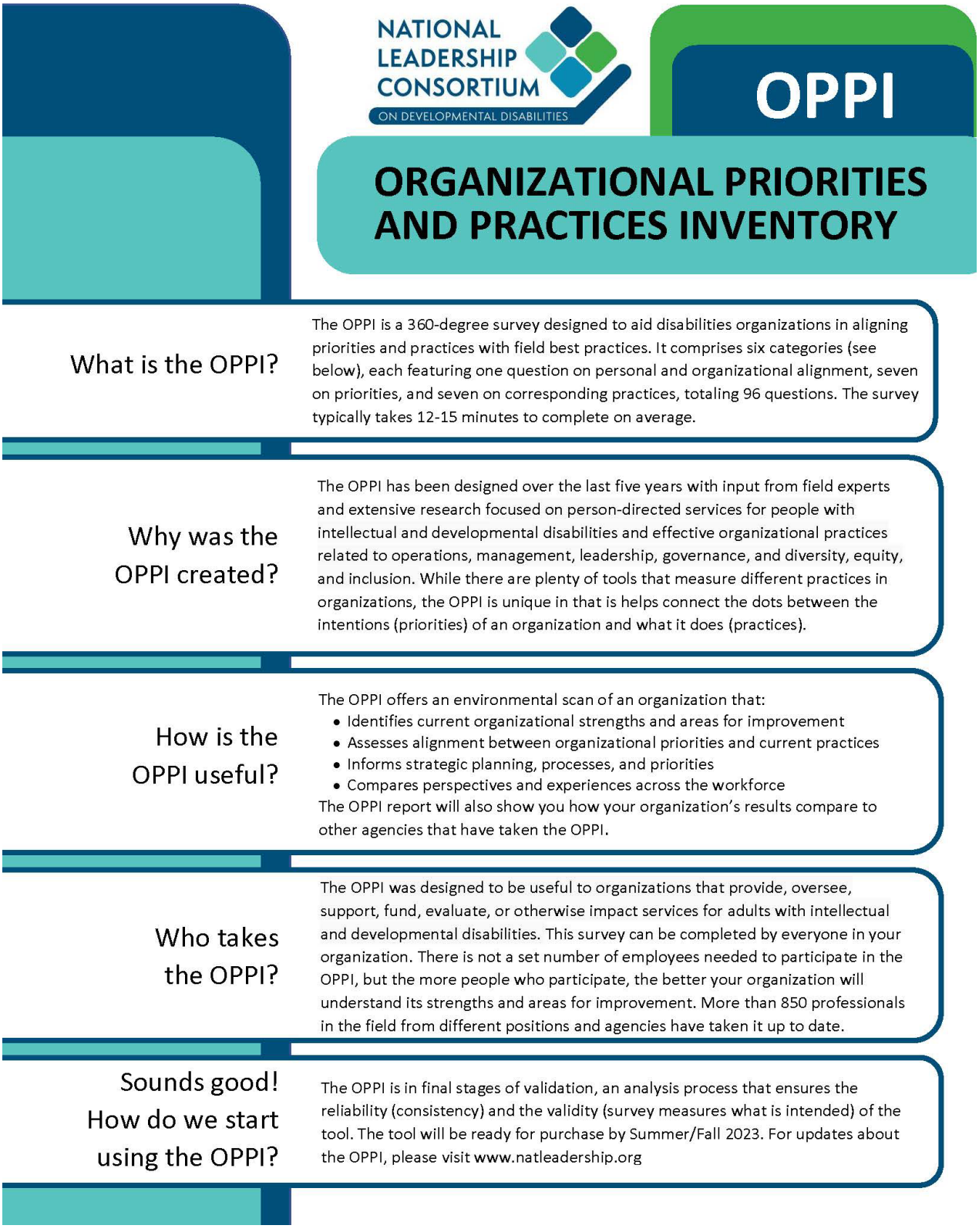
with disabilities using those services will be meaningfully included in their chosen communities. States have an opportunity to promote accountability to inclusive supports by providing organizations with clear definitions, compliance standards and evaluation procedures, and outcomes. Expanding monitoring procedures beyond health and safety to practices of inclusion and person-centered supports can help to raise the standards of support for provider organizations that provide legacy group-based supports.

Provider Leaders Organizations supporting people with disabilities should conduct regular evaluations of their services, operations, and employee experiences related to their inclusion practices. Increased awareness of alignment or misalignment with principles of inclusion and person-centeredness within organizational philosophy, operations, management approaches, and services is essential to helping organizational leaders understand priorities and strategies for change.

APPENDIX A: Interview Schedule

1. Please describe the services and supports your organization offers.
2. About how many people with IDD do you support?
3. [If the organization still offers congregate services (day programs, group homes, etc.)] Why does your organization continue to offer congregate services?
4. When did your organization start delivering individualized, community-based supports?
5. What prompted your organization to start delivering individualized, community-based services?
6. What internal or organizational factors contributed to your ability to first switch to offering individualized, inclusive supports?
7. Can you describe the most important internal or operational thing/things your organization does to achieve individualized & inclusive supports?
8. Can you describe the most important employee-related thing/things your organization does to achieve individualized & inclusive services?
9. Can you describe the most important leadership-related thing/things your organization does to achieve individualized & inclusive services?
10. Can you describe the most important use/uses of funding your organization does to achieve individualized & inclusive services?
11. What (if any) models, frameworks, or value systems have informed your transition to providing individualized, inclusive supports? For example, Social role valorization, the disability justice framework, the normalization principle, self-determination, person centered thinking, other human rights movements...
12. Is your organization doing anything unique that you don't hear about other organizations doing to promote individualized & inclusive services?
13. What internal or organizational barriers or challenges to delivering individualized, inclusive supports have you experienced?
14. What external (community or societal) barriers or challenges to delivering individualized, community-based supports have you experienced?
15. What internal facilitators or things that help your organization to deliver individualized, inclusive supports have you experienced?
16. What external factors (community or societal) contributed/s to your ability to first switch to offering individualized & inclusive services?
17. What external factors (community or societal) contribute to your ability to continue to offer these services? (How have community relationships and partnerships influenced your ability to provide inclusive services?)
18. What are some of the most important qualities that leaders of organizations that provide services and supports to people with disabilities need to demonstrate?
19. How do you see community-based services evolving in the next 5-10 years?
20. What additional resources or supports do you believe are necessary for organizations to fully transition to community-based services?

APPENDIX B: OPPI



Defining Principles of the OPPI

1 Autonomy, Choice, and Control for People with Disabilities	Choice and control for people with disabilities are basic human rights. All people with disabilities should have control over all aspects of their lives, including which services they use, who works for them, where and with whom they live, how they spend their days, who they love, and with whom they spend their time.
2 Community Living, Employment, and Engagement	People with disabilities are better off when they live in and are engaged in their communities. Communities are better off when people with disabilities belong to them. All people with disabilities should be supported to live, work and become meaningful members of their communities and serve in the same valued roles as people who do not have disabilities.
3 Stakeholder Input to Organizational Management and Governance	Organizations in the disability service sector are ultimately responsible to people with disabilities, their families, regulators, and funders. All governing and management practices are informed by people with disabilities and their families and should reflect principles of person-centeredness and self-determination.
4 Staff Participation, Value, Impact, and Support	In order for employees to provide, oversee and support quality, person-directed services that promote the rights of people with disabilities, they have to know that they are valued, important, and supported in their organizations. Organizations assure that all employees have a voice, are valued and respected, influence organizational decisions, receive praise and recognition, receive regular supervision and support and access the appropriate training, development, and support opportunities needed to succeed in their roles.
5 Leadership Strength and Skill Development	The success of an organization depends on the effectiveness of its leaders. Leaders have the skills and values needed to develop and run sustainable organizations that strive to achieve best-practice standards. To ensure this, leaders are developed at all levels of the organization.
6 Diversity, Equity, and Inclusion	Diversity, Equity, and Inclusion Organizations are responsive to the unique cultural beliefs, perspectives, intersectionality and traditions of all people they employ, people they support, and people who are impacted by their work. Ultimately, organizations create and nurture accessible, inclusive, and equitable cultures by combatting oppression and valuing differences. Any manifestation of racism, xenophobia, homophobia, ableism, cisgenderism, misogyny, or harassment are addressed quickly, consistent with policies and procedures, and may result in personnel action up to and including termination.

NATIONAL LEADERSHIP CONSORTIUM
ON DEVELOPMENTAL DISABILITIES