

NATIONAL LEADERSHIP CONSORTIUM



ON DEVELOPMENTAL DISABILITIES

◆ ◆ ◆ *An Affiliate of CQL*

FACILITATORS AND OBSTACLES TO COMMUNITY SERVICES AND SUPPORTS

Exploring What Leaders Need to Progress Toward Change

2024

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Gilden, C., Mesa-Alvarez, M., & Bailey, C. (2024). *Facilitators and obstacles to community services and supports: Exploring what leaders need to progress toward change*. The National Leadership Consortium on Developmental Disabilities. <https://www.natleadership.org/reports.html>

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.



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

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Introduction

High performing leadership, from the executive level to frontline supervisors, is a catalyst to quality supports and services and contributes to positive outcomes for people with intellectual and developmental disabilities (Agranoff, 2013; Bigby & Beadle-Brown, 2016; 2018; Gillett & Stenfert-Kroese, 2003; Humphreys et al., 2020; Thompson Brady et al., 2009), but more research is needed to understand how to best support leaders in their work. This qualitative study explores the resources and supports disability field leaders need to help direct the field toward quality services and systems practices in the next several years, and how they see their roles in advancing quality of life for people with disabilities. This research was funded by the May and Stanley Smith Charitable Trust.

Dataset and Recruitment

This study uses secondary data from the National Leadership Consortium originally collected with the primary purpose of assessing the long-term impact of the National Leadership Consortium's intensive week-long leadership training, the Leadership Institute. During the Leadership Institute training, participants learn from a faculty of national experts in best practices in service delivery, policy, and advocacy for people with IDD and their families. Leadership Institutes incorporate a mix of lecture, discussion, interactive activities, personal assessment, and skill building sessions. Participants gain knowledge, resources, and skills to impact meaningful organizational and systems change towards services and supports that promote inclusion and self-determination for people with intellectual and developmental disabilities.

The dataset contains responses about the personal and organizational impact of the Leadership Institute training, organizational change since the training, change in perspectives on leadership and the field since the training, and networking since the training. The interviews also contained broader questions about the direction of the field and how participants viewed their roles in the field. Specifically, this study examined responses to the following open-ended questions from the interviews:

1. How do you see the disabilities field changing in the next 5-10 years?
2. What resources and supports do current and future leaders need to get where you think we should be in the field?
3. How do you see your role in this change?

Responses from 45 self-advocates, frontline managers, and executive leaders who were interviewed from the fall of 2020 through the fall of 2021 were included in analysis. Participants were recruited through the listserv and online Community of Practice of the National Leadership Consortium. Interviews were conducted via Zoom teleconferencing and audio recordings were transcribed for analysis by the National Leadership Consortium research team.

Participants

Interview data from 45 participants was used for this study. In terms of professional positions, the largest number of participants are directors of organizations (40.9%), followed by executives (31.8%), with smaller percentages in frontline and managerial positions (6.8% each), and an additional 6.8% falling into the "Other" category. Half of the participants were female (50.0%), and at least one quarter were male (25.0%), while gender identities for the remaining 25.0% was unknown. There was a predominant presence of White participants (77.3%) with a minority identified as Asian (4.5%), and a remaining 18.2% of participants whose race was unknown. A substantial portion of the participants' age was unknown (63.6%), while those with identified ages are spread across different brackets, ranging from at least 4.5% aged between 26-35, 56-65, and 66-75, to at least 11.4% aged 36-35 and 46-55. The geographic distribution of participants spans various states and countries, possibly impacting the generalizability of findings due to wide representation of states and the inclusion of international locations such as Canada and Australia. Within the U.S., the geographic distribution spans various states, with notable concentrations in California (15.9%), Maryland (15.9%), and Pennsylvania (9.1%). There is a high proportion of unknown values in demographic data of participants, particularly in age and race categories, since these questions were not asked in the original study but found by cross checking with another data source from the National Leadership Consortium.

Table 1: *Sociodemographic Characteristics of Participants*

Characteristic	Full sample		Characteristic	Full sample	
	<i>n</i>	%		<i>n</i>	%
Position			States		
Director	18	40.9	Arkansas	1	2.3
Executive	14	31.8	California	7	15.9
Frontline	3	6.8	Colorado	1	2.3
Manager	6	13.6	Florida	1	2.3
Other	3	6.8	Hawaii	1	2.3
Gender			Indiana	3	6.8
Female	22	50.0	Iowa	1	2.3
Male	11	25.0	Maryland	7	15.9
Unknown	11	25.0	Minnesota	1	2.3
Race			Missouri	1	2.3
White	34	77.3	New York	1	2.3
Asian	2	4.5	North Dakota	2	4.5
Unknown	8	18.2	Ohio	1	2.3
Age			Oklahoma	1	2.3
66-75	2	4.5	Oregon	3	6.8
56-65	2	4.5	Rhode Island	1	2.3
46-55	5	11.4	Pennsylvania	4	9.1
36-45	5	11.4	Virginia	1	2.3
25-36	2	4.5	Washington	2	4.5

Unknown	16	63.6	Canada	3	6.8
			Australia	1	2.3

Analysis

Thematic Analysis was used to code the data and identify themes (Braun & Clarke, 2006; 2021). First, the research team familiarized themselves with the data by reviewing transcripts and audio recordings. Researchers then generated initial codes of interesting features of the data, Research then reviewed and refined codes during a second round of analysis. Codes were then collated into potential themes, which were reviewed by the research team, and drafts of thematic maps arranging the themes and codes for each research question were generated. Themes were refined through the ongoing analysis of interviews and discussion with the research team, with a clear definition and names for themes emerging from the analysis process. The online qualitative platform Dedoose (www.dedoose.com) was used to facilitate analyses. Final themes and related content were organized into thematic maps for each question.

Changes in the Disabilities Field Over the Next Five to Ten Years

Policy evolution and the efforts of advocates, self-advocates, and family members have led the disabilities field to a state of constant transformation and growth. In such a dynamic and rapidly evolving landscape, the field is poised for even more transformative shifts over the next years. Due to their active involvement with all components and actors in the disability system, leaders have a comprehensive understanding of the potential changes that can occur within the next 5-to-10 years in the field. To gain insights into these anticipated changes, we asked leaders at the forefront of the disabilities field: **“How do you see the disabilities field changing over the next five to ten years?”**

Leaders provided a positive outlook of things achievable in the near future, with an emphasis on more participation and inclusion for people with disabilities and policy change. Five key themes of potential field changes emerged, providing a holistic vision for the future of the field: 1) Changed Outcomes for People with Disabilities, 2) Improved Service Delivery, 3) Organizational Change, 4) Systems Change, and 5) Societal Change (see Figure 1).

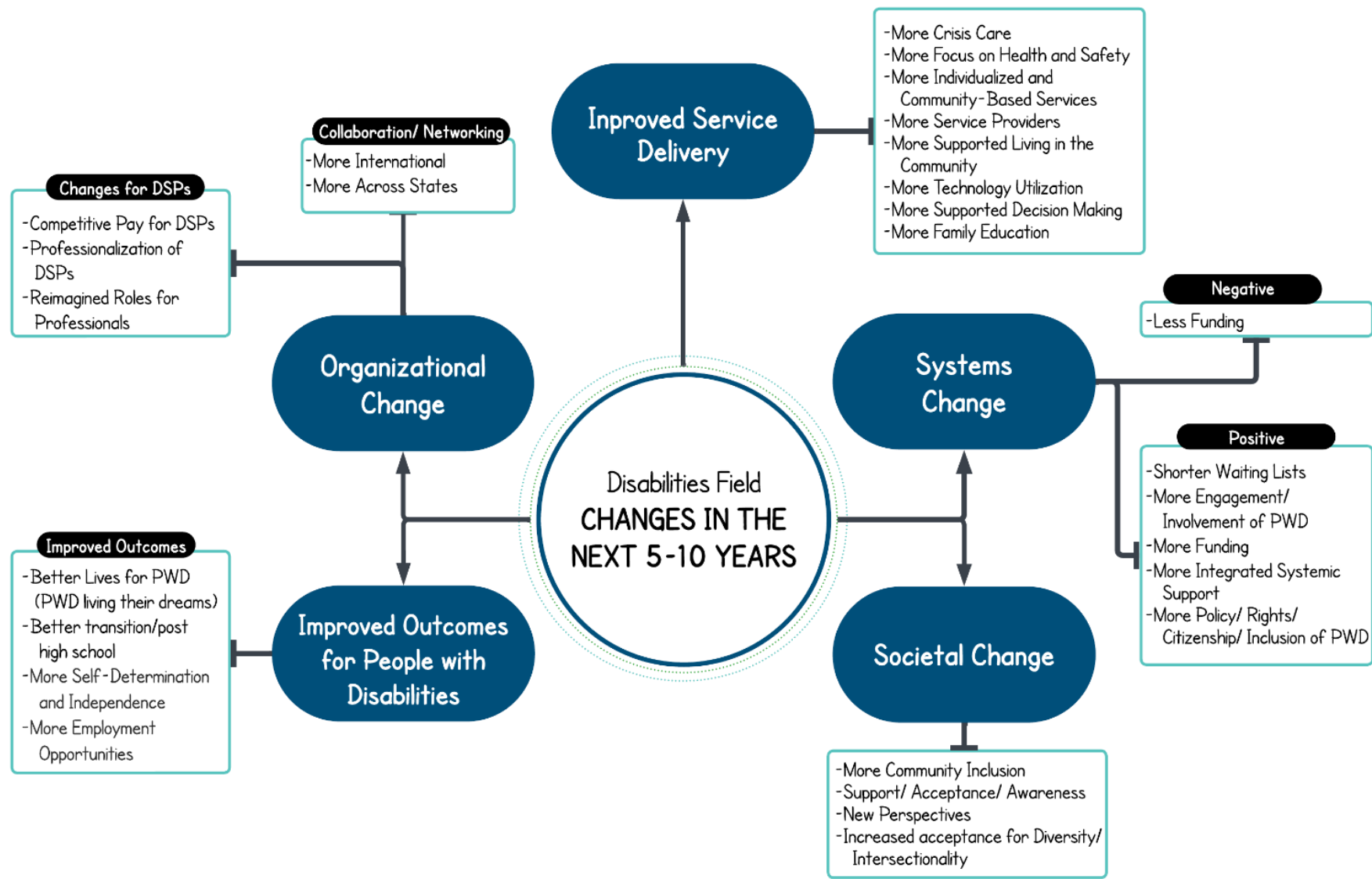


Figure 1: Thematic Map of Leaders' Perspectives about Potential Changes of the Disabilities Field Within the Next 5-to-10 Years

Improved Outcomes for People with Disabilities

In a positive outlook for the future of the field, leaders discussed improvements in outcomes for people with disabilities towards increased autonomy, choice, self-determination, community inclusion and participation. Leaders in the disability services field anticipate a shift towards empowering people with disabilities to *“live their dreams.”* Participants discussed fostering supportive environments that enable people with disabilities to pursue their aspirations, contributing to more fulfilling lives. One participant shared: *“I feel like it is definitely time for our individuals to be able to have more choices, to be able to lead independent lives as much as they can, and, you know, again, to be able to do what they need to, do what they want to and, and the community is there to support them and help them through that.”* Other expectations related to improved outcomes include improved support systems for people with disabilities transitioning from high school to adult life. *“I think figuring out how to bridge the gap for employment and marriage and independent living from high school through post college is going to be the next frontier.”* Participants talked about developing programs and services that address the unique needs of individuals during this critical period, ensuring a smoother and more successful transition.

A focus on self-determination and independence is predicted to become more pronounced in the near future. For instance, one participant said: *“I don't think it's good enough to be person centered anymore, I think it needs to be person directed. So, I want to know that every single person that receives services is directing, whether that's them personally doing it, or it's their family member advocate doing it on behalf of them, and that agencies are honoring those choices and meeting them.”* Leaders discussed changes related to providing the people with support with the tools and skills necessary to make choices and lead independent lives, promoting of autonomy and control. Another interviewee stated: *“I definitely see it changing. Some of the changes coming as a result of the CMS final rule, maybe or the HCBS compliance, but I feel like it is definitely time for our individuals to be able to have more choices, to be able to lead independent lives as much as they can, and, to be able to do what they need to, do what they want ... and the community is there to support them and help them through that. [We] need to move away from telling people, ‘This is what needs to happen,’ or ‘This is what can happen,’ because there's no limit to what somebody can do and that applies to individuals with developmental disabilities as well. We have self-determination programs. So, I think we are all moving in the same right direction. And, if all these programs were not there, if the CMS final rule was not there, self-determination, we were not talking about it, I think, then that's what we would have been talked about when we come together, but I think all of these different roles and programs are helping further that. So, it all comes together.”*

Leaders also talked about an increase in employment opportunities for people with disabilities: *“I do think we'll see more employment outcomes, which is going to be great. And that will drive its own.”* Participant discussions about employment also included creating inclusive workplaces, addressing barriers to employment, and emphasizing the abilities and contributions of individuals with disabilities. *“I think we will continue to see, hopefully, more community integration in terms of acceptance from an employee standpoint, or employer standpoint, less hesitancy for hiring individuals with disabilities, and we will also see a hesitancy from individuals with disabilities not wanting to work, like, ‘I'm okay with getting my SSI check or my SSDI check.’ Well, ‘Are there other things you'd like to get to support yourself to do those things that you want?’ So, I'm hoping that things will go in that direction and employers will be able to hire individuals full time with real benefits and things like that and get them out of that continuous loop of social service support.”*

Organizational Change

Changes towards acknowledging the roles of Direct Support Professionals (DSPs), including improving working conditions and pay were extensively discussed by participants as upcoming organizational changes in the field. Also, leaders mentioned changes related to strengthening collaboration and networking between organizations across states and internationally.

Changes for DSPs

Leaders recognized the importance of competitive pay for DSPs to attract and retain skilled employees, ensuring the quality of support services. Like one interviewee said, *“Some of the things that we're hoping for [is] a real change in how the workforce is looked at and supported and compensated, that would be some amazing change. That would definitely make changes in the field and would go to help drive that more self-directed kind of movement for people with disabilities.”* Participants also discussed efforts to professionalize the role of DSPs involving recognizing their expertise and providing opportunities for ongoing training and development. *“I think one of my hopes would be that the people empowered decision makers, funding entities, and even private industry health insurance providers really begin to recognize the importance of both compensating training and in providing opportunities for our direct care workforce. Because they're a linchpin in our economy in ways that I think people don't recognize. And not only do the people that we support directly benefit from well compensated and well-trained staff, but our entire economy does.”* The roles of professionals within the disability services field are expected to evolve, incorporating new responsibilities and approaches to better meet the changing needs of individuals with disabilities. *“I think we're going to see a larger push for more trained staff and not just hire anybody. I really feel like we're going to see a change from the DSP just being an entry level position to a certified or almost licensed position. From what I'm seeing just now, most of the in-home supports that are being asked for are being people who need intense either behavior supports or medical supports and it's not something just your average employees are able to handle. And I see that being more and more the trend over the next five years, especially depending on where the election goes, and the budget cuts go.”*

Collaboration/Networking

Leaders envision increased collaboration and networking on a global scale, fostering the exchange of best practices and innovative ideas in the disability services field. *“There needs to be more of a kind of global or universal or international understanding of how our work is affected and affects people not just in the United States, but throughout the world, and how we can learn from others.”* Collaboration and networking between states are anticipated to strengthen, promoting the sharing of resources and strategies to address common challenges.

Systems Change

Leaders also discussed upcoming changes at the systems level. Several positive changes related to improving service delivery are expected to occur in the disabilities system. However, some leaders foresee negative changes related to a decrease in funding.

Positive Systems Change

Positive expected changes include a reduction in waiting lists for services, ensuring that individuals with disabilities receive timely and necessary support. *“I hope to goodness that we don't have a waiting list of 19,000, but we figured out a way to provide all people some level of service.”*

Leaders expect increased engagement and involvement of people with disabilities in decision-making processes, ensuring that services are more responsive to their needs and preferences. *“I’m hoping we make at least as much progress as we did in the last five years with, just being more person centered, being more focused on the client’s needs versus the agency’s needs, and hopefully, having more people with disabilities themselves involved in the agencies and decision making would be helpful.”* Another leader said: *“I think my hope for our field is that we can get to a place where the actual people who rely on services are the ones that have the leading decision-making voices and the work that we do.”* Also, anticipated increases in funding are crucial for expanding and improving disability services, meeting the growing demand for support. Efforts to enhance integrated systemic support involves creating a cohesive and interconnected network of services that address the holistic needs of individuals with disabilities. In that regard, a participant said: *“I think providers need to come together. There needs to be more collaboration, there needs to be more sharing. You know, some have it figured out and some struggle so much. And then there’s always the behavior, how health diagnosis is just, again, another area that needs focus and attention.”* Finally, at the systems level, leaders foresee advancements in policies and rights, promoting the citizenship and inclusion of individuals with disabilities in all aspects of society. *“There is an increased sense of citizenry and, and the rights and obligations that go with it that is driving a lot of change — and it’s wonderful. It also will mean that people will be much more at risk, potentially, and with it, I think there’ll be some constraints and resources will become tighter, so people will have more possibilities with less resources available to them. So, the opportunities will open, but the resources to access them will disappear or shrink.”*

Negative Systems Change

Concerns about potential decreases in funding highlight the need for advocacy efforts to secure adequate resources for disability services. As one leader discussed: *“I feel like we are going to see a pendulum swing back away from all some of the person centeredness things we’ve done There’s a push to push so far. I feel like budgets and other things, they’re going to pull it back a little bit.”*

Societal Change

Leaders expect a societal shift towards greater community inclusion, breaking down barriers and creating more opportunities for individuals with disabilities to participate fully in community life. *“I think community services will become a bigger and bigger part of the services that we provide — everything community based.”* Another participant said, *“You’re going to see the continued movement from the institutionalized notion of service towards a more community-based service and more inclusive and practice service, and hopefully, something that will spawn more belonging, which is really the attitudinal change, and is it happened in the society around us.”* Increased societal support, acceptance, and awareness are crucial for fostering a more inclusive and understanding environment for individuals with disabilities. *“I feel like it is definitely time for our individuals to be able to have more choices, to be able to lead independent lives as much as they can and to be able to do what they need to, do what they want to and, and the community is there to support them and help them through that.”* Participants anticipated acceptance not only in the community at large, but also at the top of organizations to appreciate the unique experiences of individuals with disabilities from different backgrounds. *“I think there needs to be an acknowledgement and a real push given to diversifying leadership as to how to welcome and be inclusive of a diverse set of leaders.”*

Improved Service Delivery

Leaders also discussed some of the potential changes to service delivery for the next 5-to-10 years. For instance, anticipated changes in service delivery include an increased emphasis on crisis care, ensuring that individuals with disabilities receive timely and effective support during challenging situations. Also, leaders expect a heightened focus on health and safety within service delivery. According to one participant, *“How do we get back to health and safety is number one.”* This involves implementing measures to address the specific health needs of individuals with disabilities and ensuring their overall well-being. Moreover, one quarter of interviewees talked about a shift towards more individualized and community-based services. This involves tailoring support to the unique needs and preferences of each individual and fostering community integration. *“I think there's all these great pushes with the HCBS ruling for really making sure we're not recreating institutions right in the community and that people really have opportunities and access to the good life that they want to have. So, I think I'm hoping that there's more individualized supports and services.”*

Leaders also foresee a rise in supported living arrangements within the community. They claim that it will require providing the necessary assistance for individuals with disabilities to live independently while remaining connected to their communities. *“Providing people services that make sense to them and access to their community and supporting them to live the lives that they choose. People don't always live in the settings that they choose. There are a lot of people who live in group homes that they don't necessarily choose. I would hope in the next five to 10 years that everybody is living in a setting that they choose and that makes sense for them.”*

Participants also spoke about how the integration of technology is expected to play a larger role in service delivery, offering innovative solutions to enhance the quality of life for individuals with disabilities. *“I think that technology will probably play a big part in the changes to the disability field. I think now that a lot of us have started to use it and I've seen that it's very useful and that a lot of our folks can use it. It just gives an extra layer of support we've found. So, I really think that will play a big part. Whether it's just connections or safety for people who are living independently.”* Moreover, leaders also anticipate an increase in efforts to support individuals with disabilities in making decisions about their own lives, promoting autonomy and self-advocacy. *“Well, my hope is, they'll continue to be a lot more work through for self-determination, doing supported decision making. I feel like our country was very poised, to really do a lot more for self-determination, you had you the HCBS community role, you more work with self-direction and recognition of self-direction, and a movement towards supported decision making with more and more states recognizing the legality of supported decision making.”*

There was also an emphasis during interviews on providing education and support to families of individuals with disabilities, ensuring they have the knowledge and resources to assist their loved ones effectively. *“Because if that is also trickled down to how special education provides service, and how parents look at the methodology of instruction for kids, also super important. All those things are happening right now. So, I think that's going to happen.”*

According to the participants, within the next 5-to-10 years the disability services field is hoping to experience an increase in the number of service providers to help advance these improvements service delivery. Leaders discussed expanding the network of organizations and professionals dedicated to supporting individuals with disabilities. *“I do hope more and more providers will come on board and provide services the right way and give people options.”*

Resources and Supports for Future Success

Understanding what is needed from leaders who are directly delivering services allows policymakers and funders to better target limited resources that will promote positive change in the disabilities field, ultimately leading to better quality of life for people with disabilities. To learn the perspectives of field leaders about what is needed to advance future change, participants were asked, **“What resources and supports do you think current and future leaders need to get to where you think we should be in the field?”** Responses were diverse, ranging from concrete things like increases in funding and training in active reflexivity, to less tangible things like societal acceptance and increases in interagency collaboration. Responses also ranged in scale from suggestions related to employees delivering services, service provider agencies, communities, systems, and to societal opportunities for change. Resources and supports named by participants fell into four broad categories of 1) Professionalization of the Field, 2) Organizational Change, 3) Systems Change, and 4) Improved Outcomes for People with Disabilities (see Figure 2).

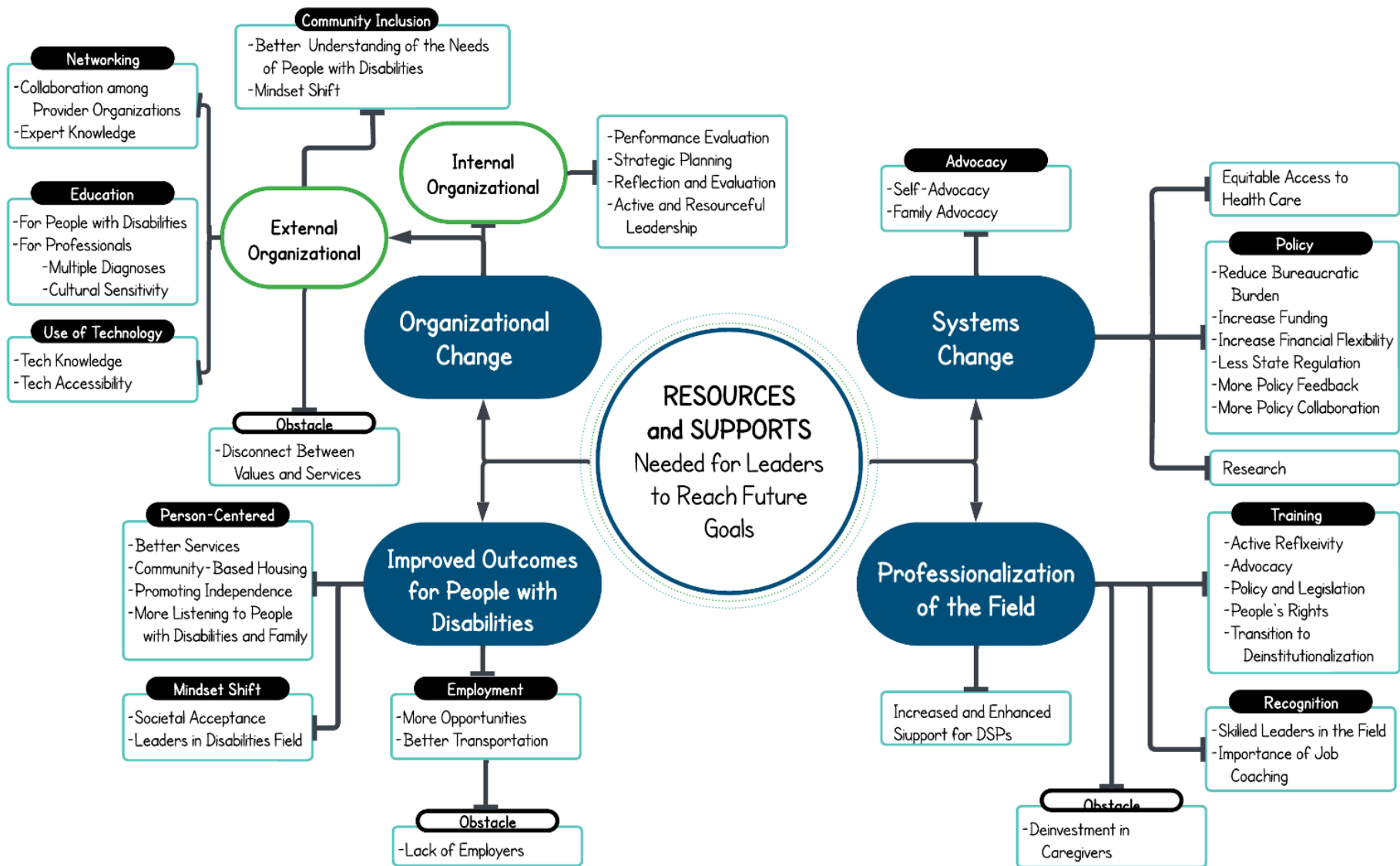


Figure 2: Thematic Map of Resources and Supports Needed for Leaders to Reach Future Goals

Professionalization of the Field

Participants spoke often about the need for the role of frontline employees to be recognized as more of a long-term career rather than a short-term job. More training, recognition, and increased support were ways mentioned in the interview that could improve professionalization of the field. Specifically, more training in active reflexivity (self-assessment), advocacy, policy and legislation, rights of people with disabilities, how to navigate the transition to deinstitutionalization, and training about the realities of the position were mentioned as areas where more training for professionals was needed. *“We would need a workforce that understands that this job isn't just the rainbows and sunshine that they see in our job advertisements and in our stories, that there are going to be people who do require more intense supports that that has to be normalized. Before we gain an understanding across our workforce, we're not gonna be able to make an impact to support people until we as leaders and agencies anticipate and train and build up for that reality.”* One participant also mentioned the importance of job coaching and that it should be recognized more to help advance competitive community employment.

Some participants spoke about the position of DSPs becoming professionalized through university programs and national accreditation. *“There needs to be a concentrated professionalization of field. Direct support professionals need to be recognized and not just as essential workers, which they are, which has been highlighted by COVID-19, but that they have skill sets and they have job responsibilities and job skills that are very unique. Basically, if you were to put a mosaic together of a DSP and each responsibility was a puzzle piece, you would have 100 puzzle pieces ... I don't think people understand the level of complexity to be excellent in serving someone with an intellectual or developmental disability. And there isn't schooling for it. That's part reason why this is a minimum wage gig. There's this assumption that it's caregiving or babysitting, and it's not.”* Many thought degree programs or accreditation along with extra funding for higher wages would help DSPs gain the recognition and compensation their skills deserve. *“It is an acknowledgement that this workforce not only has something meaningful, but that they're providing a skill that's universally recognized. That to me is one of the things that's an overarching hurdle that needs to be overcome in order for this field to have any kind of traction and legitimacy in the labor market that ignores us.”* A barrier to gaining professionalization in the field mentioned by some in the interviews was disinvestment in caregivers of people with disabilities.

Organizational Change

Participants felt that external organizational change in the areas of education and training, use of technology, networking, and community inclusion, as well as internal changes in organizational practices were necessary to reach future goals. Leaders also mentioned that a significant obstacle standing in the way of organizational change was the disconnect between organizational values and the services it provides.

“A lot of traditional service providers have a traditional model. To break that up requires really fresh thinking that I don't think we've seen in the field yet.”

“I feel that there has to be a commitment to change ... It's about pushing hard and overcoming the fear while the system around us is calcified due to the power differential between the status quo and the mission of transforming lives.”

External Organizational Change

Education for people with disabilities receiving services and for families to learn how to navigate different service systems related to health and behavioral health to get appropriate services and supports, and more training to enable and empower people receiving services to take control of their services and *“own their lives”* were noted as needs during interviews. Experts also desired more specialized training for professionals providing services to people with multiple diagnoses and traumatic backgrounds, as well as cultural sensitivity training to learn how to best support families from different cultural backgrounds. More training in technological supports was also named by many participants as needed to achieve better outcomes in the future.

The recent COVID-19 pandemic brought a shift from in-person office operations and services to more technologically based interactions, making more training about technology and support for both professionals and people receiving support necessary. Unable to meet in-person during the pandemic led to an increase in telehealth and hybrid or totally virtual support models for people with disabilities. Many professionals saw the potential of this move toward technology to lead to better connectivity for independence for people supported, an *“extra layer of support”* that offered connections and safety features for people living independently, and a new way to expand the definition of “community.” One participant said, *“I think that community in the traditional sense is going to change in that community doesn’t necessarily equate to being out in your neighborhood, it can also equate to different social groups online.”* However, participants were also realistic in noting that additional technological advances also bring the need for more training and support, especially for the aging disabled population, and more creative solutions for funding, added efforts to avoid feelings of isolation for people receiving services, and training to support employees remotely. Networking with other agencies and keeping community inclusion at the forefront of services can help inspire more innovative solutions.

Learning from experts in the field who have experience building community connections and influencing change can be valuable in advancing community inclusion. One leader said, *“We need to talk to those old school people ... I don't know what you'd call them — 'gurus' in the field? ... You want to learn from them because they've made mistakes along the way and they figured it out and they did different things. I just feel like they could teach us younger people who are so passionate so much.”* Several participants discussed the value of interagency collaboration, with leaders communicating with other leaders, is key to bringing about success in the field because everyone can learn from each other. *“There needs to be more acceptance and acknowledgement that leaders in disability and other community services are actually really skilled,”* one participant said. This sharing of expertise can be especially valuable for provider agencies who are still working to transition from congregate services and working to gain a better understanding of how to meet the individual needs of people with disabilities better, something noted in the interviews as a need. Shared knowledge and experience can also help build community partnerships and grow pathways for things like more community-based housing and contribute to a broader mindset shift in society at large. One participant said, *“The prejudice of low expectations of people with special needs starts when they're born and it doesn't end until they die. Somehow, we have to shift the culture to be more inclusive of those people who look different and are differently abled.”*

Internal Organizational Change

Participants named specific areas of growth for leaders that could contribute to positive internal organizational change, including increased strategic planning, performance evaluations, self-reflection, and active, resourceful leadership. Many leaders mentioned the importance of evaluating their organization's performance in the past through evaluations that serve as a *"scoreboard of how the organization is transforming,"* in the present by paying more attention to check biases and perspectives and *"reflecting on why we're doing what we're doing,"* and in the future by being creative about how to get and use funding and more resources to advance services and other goals in strategic plans. One participant said, *"We need to always innovate and change. So, no matter what we're doing that we think is great, always question, 'Is it good enough?'"*

Systems Change

Leaders frequently mentioned the need for increased advocacy by people with disabilities, their families, and organizations to bring about policy change related to funding, financial flexibility, and equitable access to health care. One participant said, *"I think encouraging families to gather and to go to the state capitol and lobby and to be that that voice for their children [is important]. They are a very, very powerful voice together."* Another participant said, *"People focus more on the billing aspect versus the person aspect of the job and it's unfortunate."*

Respondents blamed bureaucracy, licensing rules, and over regulation for robbing them of the autonomy and time needed to give the personalized support they wanted to the people receiving services. One frustrated participant said, *"I think one of the resources that we all need is time. We're so busy trying to handle the workforce crisis and the new regulations and whether it's 123 page document that we just received two weeks ago from CMS for ICS that is effective immediately. And so now you're spending all your time in the organization focused on compliance rather than quality and services. We need more resources and more policy change on going from compliance to quality."* Another participant said it was difficult to balance regulations and organizational values: *"[We need] more autonomy to do things as an organization that you feel really aligned with your mission, vision, and core values. More opportunity to do what you feel is right, as opposed to doing what you need to do to remain in compliance with regulations."* Another participant also said, *"The trouble is that the intention gets lost in the application."*

Participants suggested tapping into self-advocacy organizations as well as increasing their own self-advocacy efforts was needed to approach state officials and policy makers to make their needs and their financial priorities known. One participant said, *"It's about getting good thinkers together to help create public policy initiatives that promote health and safety, general welfare, and social justice issues that are aligned with what we want for our people, which is just like anybody else: opportunity. Opportunity is what's missing — access and opportunity, and that needs to be that needs to be enhanced and developed."*

In addition to more advocacy, more research was mentioned as a need to understand where the field is and how it is advancing toward improvement and inform policy change.

Improved Outcomes for People with Disabilities

Participants named increased funding, being more in tune with the needs of people with disabilities, more opportunities in the community, and shifting the mindsets of service providers and in

society in general as being needed to bring about improved outcomes for people with disabilities in the future. They said that lack of employers in the community made it difficult to find employment opportunities, as well as a lack of transportation to employment being a barrier to improved future outcomes for the people they support.

One participant said more funding was needed to ensure the right to community-based housing: *“I think one of the supports that needs to be in place is the capital, either in the hands of individuals or in system, to develop appropriate housing. Community-based housing is such a core human right to have quality housing, and it just isn't there.”* Another participant added, *“It would be an amazing move forward to give people the respect of living in a decent place of their own.”*

Another need noted by leaders was to really listen to people receiving services to find out what they wanted and needed and deliver truly personalized services. *“I see me and our center as taking our lead from people who have developmental disabilities and being able to adjust our practices based on what their needs are. So really being tapped into the person who has the disability and finding out what they want, not what we think, [is best] for somebody.”* Another leader said, *“We've been using the term person-centered planning for a long time, but I think was just a term that no one really knew. I think we knew what it was, but we really do much with it. So we've just engaged with Life Course Nexus out of Missouri and we're going to go through about a 12-to-18-month process with them, where it will touch everyone throughout our organization from our CEO to the guy that sits back in the print shop and everything in between and hopefully get to a place as an organization where we all go about our jobs through that person-centered lens. And we all realize that what we do has a direct impact on the people we support regardless of our role.”* Maintaining a focus on the goal of independence was also named by a few participants as critical to personalized services. One participant said, *“[We need to] continue to help individuals live up, push the envelope on what they can do, and give them support and competence to be more independent.”*

Many participants spoke about the need for a mindset shift in provider agency leaders and in people in the community, like employers, to increase independence and opportunities in the community for people with IDD. A couple of participants spoke about the difficulties faced in finding community employment for people they supported and that they needed the backing and buy-in of community members and funders to expand opportunities for community inclusion. Participants also understood that as provider agency leaders they played a large role in this culture shift by doing what they could to work toward community inclusion. *“Let's think about communities different. Let's think about services different. Let's break any kind of mold from being developed because it will never be good enough until there's full inclusion.”*

Role of leaders in Changing the Disabilities Field

To understand leaders' perspectives regarding their participation in the upcoming changes they previously described, they were asked: **"Where and how do you see your role in this change?"** Compelling insights regarding the efforts that need to be deployed and the areas of action that must be explored to advance the field for the upcoming five to 10 years were offered. Leaders identified their roles in upcoming changes in four distinct categories: 1) Advocates, 2) Resources, 3) Facilitators, and 4) Leaders (see Figure 3). Participants discussed several areas of development under this under these different main roles. For instance, they recognized their role as advocates for policy and services change, as well as for the advancement of Diversity, Equity, and Inclusion (DEI) practices. They foresee their role as a resource for families and PWD, for the community, their organizations, and as educators for policymakers. Also, leaders describe their position as change facilitators within their organizations and the overall field. Finally, leaders identified their contribution to incite change from their leadership roles and by promoting flexible and person-centered support.

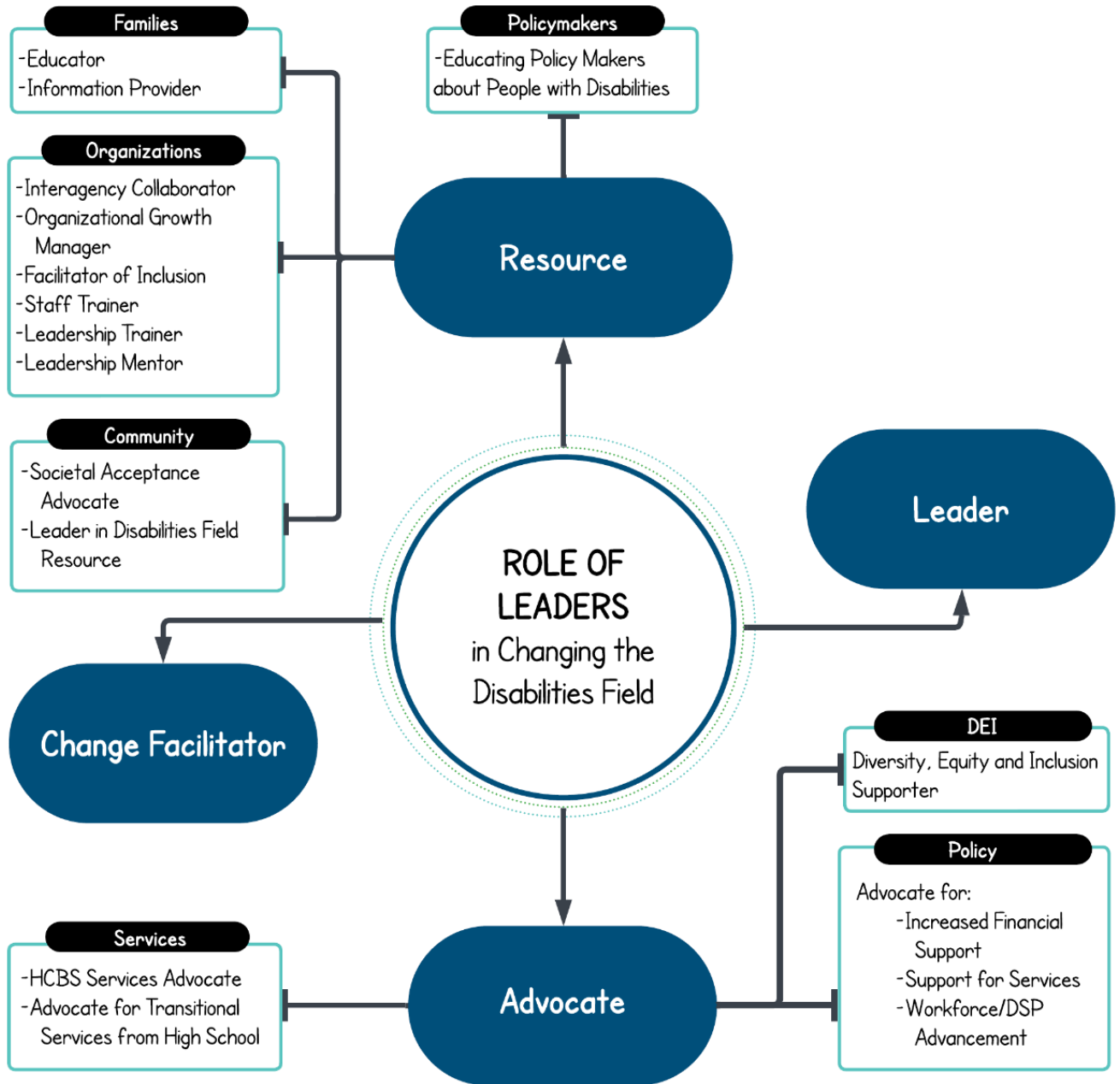


Figure 3: *Thematic Map of the Role of Leaders in Changes in the Disabilities Field Within the Next 5-to-10 Years*

Advocate

Leaders described their roles as advocates for the enactment of policies and services that would lead to increased financial support, improved services, and the advancement of the field workforce. Also, several leaders discussed their roles as supporters of the advancement of inclusive practices and initiatives.

Policy

As advocates for policy, participants stressed their role in the advancement of policies that may lead to an increased financial support. They anticipate that their role would involve actively engaging with policymakers to emphasize the importance of allocating adequate funds to disability services. Some interviewees described the importance of collaborating with other advocates, organizations, and policymakers to ensure that financial resources meet the growing demands of the disability services field. One leader said, *"...As an advocate, my job needs to be to get with our legislators, state and federal do everything I can to try to get the proper services or the funding for services for the individuals we serve."*

Another aspect related to policy advocacy as the role of leaders in advancing upcoming changes was advocating for the advancement of the Direct Support Professionals (DSPs). According to several participants, this role involves championing competitive pay, professional development opportunities, and recognition of the crucial job of frontline employees. An interviewee described their role as, *"continuing to educate and advocate wherever possible. So that hopefully one day we will, the people that we support, and the people who care deeply about providing this support, no longer have to operate from a model of poverty in order to do what we do."*

Finally, some leaders discussed their potential role as policy advocates for the improvement of services and supports. In this regard, they discussed advocating for policies that lead to both improved services and improved outcomes for the people receiving services. According to interviewees, this involves influencing policies to prioritize and enhance crisis care, individualized services, and technology utilization. Specifically, one participant mentioned: *"I really want to be able to give options for flexibility of supports and services, and service delivery. But I also want to make sure that people are being supported, and not being neglected or in isolation, but meeting their unique specific needs."*

Services

Leaders also identified their roles as advocates for Home and Community-Based Services (HCBS) and the transition from High School to adult services. As HCBS advocates, leaders acknowledged that their roles would directly connect with improved service delivery and societal change. They emphasized the importance of community-based services and their role in fostering community inclusion for people with disabilities through service expansion. Several leaders saw themselves advocating for transitional services related to a better transition or post-high school outcomes. They saw potential opportunities from advocating to collaborate with educational institutions, policymakers, and community organizations to ensure that transitional services effectively prepared individuals with disabilities for adulthood. One participant said, *"We're going to start tackling services for kids getting ready to transition out of high school, which I think is going to be huge. A lot of times they graduate at 21 and then they're kind of socked in the face with adult services. And I think we can do that better. That's one of the first things I'm looking to tackle."*

DEI Supporter

Participants identified their roles as leaders in the future as being DEI supporters, promoting societal change. They foresaw their work as connecting with community organizations, businesses, and policymakers to foster a more inclusive environment, challenging stereotypes, and advocating for increased acceptance for diversity and intersectionality. For instance, one participant spoke about becoming an intermediate for the Latinx community. They said, *“I work with my Spanish speaking community and what I do is translate the most relevant information that is going out every day. And I feel like we need to have access to that so we can stay on the same page of like the rest of the community.”*

Resource

Participants identified their roles as leaders in advancing upcoming changes in the field by serving as a resource. Specifically, they discussed being a resource for the community, for families and persons with disabilities, for policy makers and for service providers. In general, they discussed, their participation as a resource for the education, training, and mentorship of actors in the disabilities system. Several participants stressed their involvement in facilitating overall understanding for systems and stakeholders.

Families

As an information provider for families, leaders saw their role as crucial for connecting families with resources and support services. For families, leaders would be a source of information by ensuring that families are well-informed about available opportunities. Providing accurate and meaningful information to families would lead to improved outcomes for PWD and improved service delivery. One participant stated, *“I’ll give them information that’s trustworthy, because we know that many of these people get their information in in less constructive ways. So, we’ve been working with the CDC to help find ways to be able to do that.”* Educating families was another related role that leaders mentioned; they referred to fostering understanding and acceptance within families and communities.

Community

Interviewees discussed serving as a resource for the community by bridging improved service delivery with societal change. They described their participation in mediating collaborations with local organizations to provide information, support, and resources that promote community inclusion and acceptance. Some participants stressed their intent to drive community change as an advocate by challenging stereotypes and promoting a more inclusive and accepting environment for individuals with disabilities.

Organizations

Collaborating with various organizations and leading organizational change and improved service delivery was another way participants anticipated their participation in the futures changes in the disabilities field. They mentioned fostering partnerships to create a more integrated and cohesive support system. For instance, one participant said, *“I see my role is still trying to push the envelope, push the groups together ... we can bring the different groups together, we do a lot of training and education. We host a lot of regional training from various topics. We collect a lot of data so we can bring the groups to the table. We can host regional training and get the conversation going.”* Other interviewees identified themselves as a resource for managing organizational growth and ensuring that the organization can meet the increasing demand for services. Leaders also saw their roles as being facilitators of inclusion, working to create environments that are more accepting and inclusive for

individuals with disabilities within organizational settings. Several participants foresaw their intervention as trainers and mentors. Leaders would be most likely providing training for staff to drive organizational change and workforce advancement, ensuring that professionals are equipped with the skills and knowledge needed to support individuals with disabilities effectively. *“Providing technical assistance, to provider organizations and linking and providing webinars and trainings on best practices is how we can better support people to do outcomes.”* They also talked about training leaders and promoting effective leadership that drives positive changes within the organization and the broader community. Being a mentor for leaders within organizations was another role identified which would contribute to organizational growth and improved outcomes for people with disabilities, fostering strong leadership that can navigate challenges and drive positive change. Leaders who were interviewed claimed that they have the knowledge and experience required to accomplish these tasks. One of them stated, *“I want to be able to use my knowledge of what I've put together to be able to do some mentoring and coaching by job as well. Right now, the job coaches work in the markets and that's a cool thing because I've got the right experience. I've got the employer side and I've got the service provider side, so I'm in a good place.”*

Policy Makers

As a resource in educating policymakers, leaders see their role directly aligning with policy advocacy and ensuring that policymakers are informed about the needs and priorities of people with disabilities. One leader claimed, *“My job needs to be to get with our legislators, state and federal, and do everything I can to try to get the proper services or the funding for services for the individuals we serve.”* These efforts may contribute to positive systemic changes and increased financial support.

Change Facilitator

As change facilitators, leaders showed a commitment to operating at the organizational level, coupled with a passion for people-centric approaches, and underscored by a clear preference for practical, impactful change over bureaucratic processes. For instance, one participant said, *“I see myself not at that high state level and not that interested in the bureaucracy. I love people. So, I like to create, I like working at an organizational level to facilitate change.”* Also, leaders foresaw positioning themselves as “translators” and bridge builders. As change facilitators, leaders would deploy a valuable skill set in navigating the gap between conceptual system design and the actual realization of intended outcomes, contributing to the effectiveness of their role. *“I feel like I'm a translator, or a bridge. I work with systems thinkers, and systems thinkers sometimes create these beautiful systems, but they don't work. Then I come in and say, ‘That's a beautiful system. But guess what? We're not having the outcomes that were intended people at this. These things that we're trying to address are still happening.’ So, I see myself as a person who really tries to implement changes that are real.”*

Leader

Finally, more than a quarter of the participants described their role in the upcoming changes as leaders. While this may be an expected response within this population, there were nuanced perspectives within their leadership roles that were mentioned. Some participants described roles as managing organizations towards change, others as leadership experts, and other participants described it as leadership support. For instance, one interviewee said, *“I see my role is being very active and stirring up the water ... I love to do that ... Through leadership, I see development, helping to develop new leaders in my field. Being supportive of that, sharing my expertise and my experience as a way to drive change.”*

Implications

The findings of this study provide insight into the perspectives of field leaders related to where they saw the disabilities service sector going in 2020 and 2021, the support and resources needed to get there, and their role in leading for the future. The implications of these results are twofold, first they offer a deeper understanding of the thoughts, hopes, and concerns of field leaders, perspectives that are generally collected anecdotally, but less so empirically. Second, these results indicate a clear need to extend research efforts to systematically understand the perspectives of leaders as well as the individual and organizational qualities, characteristics, and practices that are essential to advancing the field toward services and supports that promote the rights and dignity of people with disabilities.

Results of this study showed some clear trends among the perspectives of field leaders. Leaders were deeply focused on improving services for people with disabilities and improving the recognition, wages, and training for Direct Support Professionals and frontline leaders. They also understood that their values, priorities, and actions are critical to enacting many of the needed changes that were noted and to achieving the hopeful outcomes shared. While leaders named several challenges impacting the field, they tended to be optimistic about their views of future services and supports for people with disabilities. Their optimism shows that forward movement is anticipated, even though current and future challenges such as workforce shortages and funding fluctuations are expected. As the field continues to move toward prioritizing and regulating more person directed, community-based, and inclusive services and supports, understanding the collective perspectives of leaders is useful to inform training, funding, technical assistance, and support needed.

While the disabilities service sector has many regulations that mandate inclusion, choice, and person-centered supports for people with disabilities, the implementation of these regulations via services offered to people with disabilities are greatly influenced by the leaders working in the agencies that provide, research, advocate for, and govern supports. Over the last several years, numerous studies have cited the importance and impact of leaders on transforming systems and organizations (Agranoff, 2013; Parish, 2005; Walker, 1993), determining the quality of services (Bailey & Gilden, 2018; Bigby & Beadle-Brown, 2018) and outcomes experienced by people with disabilities (Friedman & Gilden, 2024), and more. However, there are limited evidence-based studies that demonstrate and categorize the values and actions of leaders who impact organizational and service delivery excellence, or the conditions, characteristics, and practices of organizations that support people to live fully self-determined and included lives. The results of this study provide some insight into some of the leadership and organizational practices that are necessary to advance our field, however, future studies should expand this topic and investigate what is needed at the individual and agency level to get there. This and future research could have implications for policymakers and funders working to impact change from a systems level, as well as for trainers, researchers, and organizational leaders who want to better understand what is needed to enact effective practices in our field.

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