

# Research

Person Centered Excellence: Progress and  
Priorities of Disability Service Organizations



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of disability service organizations**

Carli Friedman  
CQL | The Council on Quality and Leadership  
cfriedman@thecouncil.org

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## **Person-centered excellence: Progress and priorities of disability service organizations**

Carli Friedman, PhD

*CQL, The Council on Quality and Leadership, Towson, Maryland, United States of America*

**Abstract:** In the United States, the disability long term supports and services system has shifted dramatically from an institutional model which granted limited rights and opportunities, to a community-based model which aims to promote community integration and person-centered practices. Yet, in today's fiscal landscape many disability services organizations are struggling to implement changes in order maximize the quality of life of people with disabilities. The purpose of this manuscript was to explore the priorities and progress of disability service organizations in the United States. Secondary survey data from approximately 7,400 stakeholders (people with disabilities, family members, service organization staff and leadership, and community partners) were analyzed to examine organizations' achievement of eight topics (person-centered assessment and discovery; person-centered planning; supports and services; community connections; workforce; governance; quality and accountability; and, individualized budgets) and how perceptions diverged according to different stakeholder groups. Findings highlighting key obstacles to the community integration of people with disabilities as well as illustrated the growth of person-centered practices in the industry. There were also a number of differences across the stakeholder groups in terms of total ratings, revealing different stakeholder groups have very different perceptions of successful service provision. As disability service agencies struggle to allocate limited funding, agencies need to pay particular attention to person-centered practices. There also needs to be a concerted effort to achieve community integration.

**Keywords:** Disability service organizations, long term services and supports (LTSS), person-centered practices, community inclusion

**Correspondence:** Carli Friedman, PhD, Director of Technical Assistance and Data Analysis, CQL | The Council on Quality and Leadership, 100 West Road, Suite 300, Towson, MD 21204, United States. Email: cfriedman@thecouncil.org

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### **Introduction**

In the United States, the disability long term supports and services (LTSS) system has shifted dramatically from an institutional model which granted limited rights and opportunities, to a community-based model which aims to promote community integration and person-centered practices. The institutionalization census peaked in the 1960s and has been reducing ever since as a result of advocacy from people with disabilities and their families, an expansion of community alternatives, and litigation (1-3). For example, the landmark 1972 *Wyatt v. Stickney* (2009) ruling led to sweeping changes to institutions, and standardized care across the nation.

Community integration of people with disabilities has also increased because of the Americans with Disabilities Act (ADA; 1990) and the *Olmstead v L.C.* (1999) decision, which both argue segregation is discrimination. Other initiatives, such as the introduction of the Medicaid Home and Community Based Services (HCBS) waiver program which allows states to *wave* the three main provisions of the Social Security Act (i.e., state-wideness, comparability, and income and resource rules) in order to create community-based services packages, allowed states to expand community rather than institutional living (4). Today, HCBS waivers are the largest provider of LTSS for people with disabilities (1).

More recently, the Medicaid HCBS settings rule (CMS 2249-F/2296-F) aimed to increase “meaningful community living” of people with disabilities and older adults(5). The HCBS settings rule, shifts “away from defining home and community-based settings by ‘what they are not,’ and toward defining them by the nature and quality of participants’ experiences” (6). As a result, the HCBS settings rule “establish[ed] a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting’s location, geography, or physical characteristics” (6). As such, the rule has strict requirements regarding community-based settings. The rules introduced a number of heightened scrutiny requirements for organizations to determine if they were truly community-based settings. The rule’s regulatory changes also emphasize person-centered planning, requiring LTSS be directed by individuals’ preferences and goals (5). As such, organizations may need to shift how they provide their services to ensure community participation, employment, education, and healthcare are person-centered (5).

The rules may also require additional and large-scale changes to the ways disability service organizations operate and provide services. Based on the rules, providers are required to make changes so that people with disabilities have leases for their homes, keys to their homes, choice of living arrangement, the ability to furnish and decorate their homes, control over their schedules and activities, and access to visitors at any time. Despite these requirements, the rules do not describe how organizations are expected to implement such changes, or suggest practical methods to do so. Many disability services organizations are questioning how to implement these changes, especially as the settings rule does not increase or reallocate the funding they receive. This is especially pertinent as organizations already face an increased burden due to a limited fiscal landscape and astronomically high direct support professional (DSP) turnover rates due in large part to the poor wages they receive (7).

As a result of the significant changes in the disability field, as well as the increasing workforce pressures disability services agencies face today, the purpose of this manuscript was to explore the priorities and progress of disability service organizations in the United States. To do so, secondary survey data from approximately 7,400 key stakeholders, including people with disabilities, family members, service organization staff and leadership, and community partners, were analyzed to examine the following research questions: 1) what are the most/least achieved disability service organization priorities?; and, 2) how do perceptions of progress differ according to stakeholder groups?

## Methods

Data was collected over a two-and-a-half-year period (January 2015 – July 2017) from organizations that provide any type of services to people with disabilities. In total, 7,384 participants volunteered to complete this survey. Participants were from the following groups: DSPs (29.1%,  $n = 2,127$ ); people with disabilities (those receiving supports) (26.7%,  $n = 1,950$ ); organization leadership team members (20.1%,  $n = 1,471$ ); family members of people with disabilities (15.2%,  $n = 1,114$ ); the organization's community partners (6.8%,  $n = 499$ ); and, the organization's board members (2.0%,  $n = 145$ ). While 23 states were represented in the sample, the most frequently represented states were North Carolina and New York.

## Measure

In addition to asking about the participant's location and group information (i.e., DSPs, people with disabilities, organization leadership team member, family member, community partner, board member), the survey measure asked participants to rate their organization on eight varying topics or factors regarding service provision and person-centered excellence.

The eight topics were (1.) person-centered assessment and discovery; (2.) person-centered planning; (3.) supports and services; (4.) community connections; (5.) workforce; (6.) governance; (7.) quality and accountability; and, (8.) individualized budgets. Participants rated all eight topics on a four-point Likert scale: one star / not consistently occurring; two stars / needs improvement; three stars / promising results; and, four stars / effective/measurable results.

## Analysis

The secondary survey data were transferred to the researcher with no identifiers; as such the author's institutional research board (IRB) determined it was exempt from full review. The data were analyzed to examine the following research questions: 1) what are the most/least achieved disability service organization priorities?; and, 2) how do perceptions of progress differ according to stakeholder groups? First, data were analyzed using descriptive statistics. Then to explore the first question, a one-way analysis of variance (ANOVA) was conducted to determine significant differences across the eight topics (i.e., person-centered assessment and discovery; person-centered planning; supports and services; community connections; workforce; governance; quality and accountability; and, individualized budgets). Post hoc Tukey's HSD was then conducted to compare each of the topics.

To explore the second question, a one-way multivariate analysis of variance (MANOVA) was conducted to determine significant differences between the six participant groups (i.e., people with disabilities; family members; DSPs; organizational leadership team members; board members; and community partners) on the eight topics (dependent variables): person-centered assessment and discovery; person-centered planning; supports and services; community connections; workforce; governance; quality and accountability; and, individualized budgets. Following the MANOVA, ANOVAs were conducted for each of the dependent variables as follow-up tests. Finally, post hoc analyses using Tukey's HSD were conducted to compare group scores on the univariate ANOVAs for each topic.

## Results

Overall 48.8% of participants ( $n = 3,606$ ) thought their disability service organization was effective, 34.6% promising ( $n = 2,557$ ), 12.0% needed improvement ( $n = 884$ ), and 2.3% 2343 not consistent ( $n = 166$ ) (Table 1). According to a one-way ANOVA, there were significant differences across the eight topics,  $F(7, 57904) = 83.55, p < .001$ , partial  $\eta^2 = .010$ . According to post-hoc Tukey's HSD person-centered discovery and assessment scored significantly higher than person-centered planning ( $p < .001$ ), community connections ( $p < .001$ ), workforce ( $p < .001$ ), governance ( $p < .001$ ), and individualized budgets ( $p < .001$ ) (Table 2). Person-centered planning scored significantly higher than community connections ( $p = .008$ ), workforce ( $p < .001$ ), and individualized budgets ( $p < .001$ ). Supports and services scored significantly higher than community connections ( $p < .001$ ), workforce ( $p < .001$ ), governance ( $p < .001$ ), and individualized budgets ( $p < .001$ ). Community connections scored significantly higher than workforce ( $p = .001$ ) and individualized budgets ( $p < .001$ ). Workforce scored significantly higher than individualized budgets ( $p < .001$ ). Governance scored significantly higher than workforce ( $p < .001$ ) and individualized budgets ( $p < .001$ ). Finally, quality and accountability scored higher than workforce ( $p < .001$ ), governance ( $p < .001$ ), and individualized budgets ( $p < .001$ ).

A one-way MANOVA was conducted to determine the effect of six participant groups on the eight dependent variables (topics). There was a significant difference in scores based on the different participant groups,  $F(40, 29416) = 16.75, p < .0005$ , Wilk's  $\Lambda = 0.91$ , partial  $\eta^2 = .019$ . ANOVAs were utilized to conduct follow-up tests to the MANOVA for the dependent variables. Using the Bonferroni method, each ANOVA was tested at the 0.0063 level. Every topic was significant: person-centered assessment and discovery ( $F(5, 6755) = 46.45; p < .001$ ; partial  $\eta^2 = .033$ ); person-centered planning ( $F(5, 6755) = 22.44; p < .001$ ; partial  $\eta^2 = .016$ ); supports and services ( $F(5, 6755) = 24.12; p < .001$ ; partial  $\eta^2 = .018$ ); community connections ( $F(5, 6755) = 18.13; p < .001$ ; partial  $\eta^2 = .013$ ); workforce ( $F(5, 6755) = 56.44; p < .001$ ; partial  $\eta^2 = .040$ ); governance ( $F(5, 6755) = 17.55; p < .001$ ; partial  $\eta^2 = .013$ ); quality and accountability ( $F(5, 6755) = 28.11; p < .001$ ; partial  $\eta^2 = .020$ ); and, individualized budgets ( $F(5, 6755) = 35.76; p < .001$ ; partial  $\eta^2 = .026$ ). See Table 3.

Post hoc analyses to the univariate ANOVAs for each topic were calculated using Tukey's HSD. The mean scores for person-centered assessment and discovery were significantly different across participant groups (Figure 1). DSPs scored significantly lower than people with disabilities ( $p < .001$ ), family members ( $p < .001$ ), organizational leadership team members ( $p < .001$ ), board members ( $p < .001$ ), and community partners ( $p < .001$ ). Organizational leadership team members scored lower than people with disabilities ( $p < .001$ ), family members ( $p < .001$ ), board members ( $p = .001$ ), and community partners ( $p = .014$ ). The other groups were not significantly different from each other for this topic.

The mean scores for person-centered planning were significantly different across participant groups. DSPs scored significantly lower than people with disabilities ( $p < .001$ ), family members ( $p < .001$ ), organizational leadership team members ( $p < .001$ ), board members ( $p < .001$ ), and community partners ( $p < .001$ ). Organizational leadership team members scored significantly lower than people with disabilities ( $p = 0.14$ ), board members ( $p = 0.002$ ), and community partners ( $p = 0.002$ ). The other groups were not significantly different from each other for this topic.

The mean scores for supports and services were significantly different across participant groups. DSPs scored significantly lower than people with disabilities ( $p < .001$ ), family members

( $p < .001$ ), board members ( $p < .001$ ), and community partners ( $p = .001$ ). Organizational leadership team members scored significantly lower than people with disabilities ( $p < .001$ ), family members ( $p < .001$ ), and board members ( $p = 0.001$ ). There were no other significant differences.

The mean scores for community connections were significantly different across participant groups. DSPs scored significantly lower than people with disabilities ( $p < .001$ ), family members ( $p = .039$ ), board members ( $p < .001$ ), and community partners ( $p = .001$ ). Family members scored significantly lower than board members ( $p = .045$ ), and community partners ( $p = .041$ ). Organizational leadership team members scored significantly lower than people with disabilities ( $p < .001$ ), family members ( $p < .001$ ), board members ( $p < .001$ ), and community partners. The other groups were not significantly different from each other for this topic.

The mean scores for workforce were significantly different across participant groups. DSPs scored significantly lower than people with disabilities ( $p < .001$ ), family members ( $p = .039$ ), board members ( $p < .001$ ), and community partners ( $p = .001$ ). Organizational leadership team members scored significantly lower than people with disabilities ( $p < .001$ ), family members ( $p < .001$ ), board members ( $p < .001$ ), and community partners. The other groups were not significantly different from each other for this topic.

The mean scores for governance were also significantly different across participant groups. People with disabilities scored significantly lower than family members ( $p = .018$ ), board members ( $p < .001$ ), and community partners ( $p = .013$ ). Family members scored significantly lower than board members ( $p = .004$ ). DSPs scored significantly lower than people with disabilities ( $p = .009$ ), family members ( $p < .001$ ), organizational leadership team members ( $p < .001$ ), board members ( $p < .001$ ), and community partners ( $p < .001$ ). Organizational leadership team members scored significantly lower than board members ( $p < .001$ ). There were no other significant differences.

The mean scores for quality and accountability were significantly different across participant groups. DSPs scored significantly lower than people with disabilities ( $p = .009$ ), family members ( $p < .001$ ), organizational leadership team members ( $p < .001$ ), board members ( $p < .001$ ), and community partners ( $p < .001$ ). Organizational leadership team members scored significantly lower than people with disabilities ( $p < .001$ ), family members ( $p < .001$ ), and board members ( $p = .001$ ). The other groups were not significantly different from each other for this topic.

The mean scores for individualized budgets were significantly different across participant groups. Family members scored significantly lower than board members ( $p = .029$ ). DSPs scored significantly lower than people with disabilities ( $p < .001$ ), family members ( $p < .001$ ), board members ( $p < .001$ ), and community partners ( $p < .001$ ). Organizational leadership team members scored significantly lower than people with disabilities ( $p < .001$ ), family members ( $p < .001$ ), board members ( $p < .001$ ), and community partners ( $p < .001$ ). The other groups were not significantly different from each other for this topic.

## Discussion

The aim of this study was to explore the priorities and progress of disability service organizations in the United States. Findings from key stakeholders not only measured how well disability service organizations were doing in different areas, they also mirrored the state of the disability field, highlighting key obstacles to the community integration of people with disabilities as well as illustrating the growth of person-centered practices in the industry.

According to approximately 7,500 people, one of the areas disability service agencies are most frequently achieving is *quality and accountability*, which includes data tracking and accountability for some of the ‘non-negotiable’ practices, such as general safety. Service organizations have long been required to track and report basic quality metrics, such as evacuation drills, or incidences of abuse and neglect, to the states in which they operate. As these procedures are traditional forms of accountability, it is not necessarily surprising it was one of the most frequently achieved topics. However, with deinstitutionalization, legislation and litigation such as the Americans with Disabilities Act (1990) and *Olmstead v LC* (1999), and advocacy by people with disabilities have come increased expectations of quality, autonomy, non-discrimination, and inclusion (10, 11). Thus, more attention is needed beyond just these non-negotiables.

Mirroring these shifts, and the expansion of participant direction in the disability field, *person-centered assessment and discovery* was another one of the most frequently achieved factors in this study. Yet, while more than three-quarters of stakeholders noted agencies were effective or had promising practices for person-centered assessment and discovery, agencies did not do as well at actual *person-centered planning*, or ensuring supports and services were person-centered. These findings indicate more work is needed to ensure participant direction is not in name only – services and supports are truly person-centered, and focused on the community. Proper participant direction should “transform” people with disabilities from passive recipients of services to active consumers (12).

*Governance* was a middle-ranked topic – it was neither the most frequently achieved area nor the least. Governance included the mission/vision of the organization, particularly promoting person-centered supports and systems, as well as the roles people with disabilities and their family play in the organization. Both DSPs and people with disabilities rated this topic as least frequently achieved compared to the other stakeholder groups. These findings suggest that although it may not be the penultimate priority disability organizations need to focus on, significant improvements are still needed to ensure people with disabilities are seen as the most important to the agencies that support them.

Less than half of participants believed agencies were effectively supporting people with disabilities to make and have *community connections*. While the institutionalization of people with disabilities, especially intellectual and developmental disabilities, is at an all-time low, people with disabilities still fail to be *meaningfully* included in and engaged with the community (1). In fact, *community connections* was one of the least frequently achieved topics according to people with disabilities and family members, indicating more improvement is needed over some of the other areas. Moreover, across all of the participant groups, organizational leadership team members rated this the lowest, highlighting that agency management are aware of these shortcomings. For true social inclusion, there must be a complex combination of equitable access and quality, “wherein success is measured through self-determination and empowerment” and “access in this instance is about social capital” (13, 14). Moreover, the Centers for Medicare and Medicaid Services, one of the largest funders of LTSS for people with disabilities, recognizes,

“innovative strategies” must be “develop[ed] and implement[ed] to increase opportunities for Americans with disabilities and older adults to enjoy meaningful community living” (6).

Two of the lowest ranked – least achieved – topics were *workforce* and *individualized budgets*. These factors are intertwined as both are intimately tied to funding. Organizations’ ability to provide quality services are dependent on a stable and qualified workforce. In the disability service field, there is currently a DSP ‘crisis’ wherein turnover rates have skyrocketed, and there is a shortage of support workers (7). This crisis is due largely in part to the poor wages DSPs receive to do taxing work, and a lack of training and career ladder opportunities (15-18). These struggles are mirrored by the findings that DSPs ranked these two priorities – *workforce* and *individualized budgets* – as the least achieved. Unfortunately, agencies cannot simply increase their wages because the rates and funding they receive are often set by the state (7). While we recognize agencies face an increased burden in the current fiscal landscape, research has found a number of small yet creative activities can increase workforce stability. For example, DSPs that feel respected, and have a sense of self-efficacy due to training, are more likely to stay with an organization (16).

Agencies that are scrambling for funding are also probably less likely to assist people with disabilities to control their own funding and budgets. Organizational leadership team members in particular ranked this as the least frequently achieved item. In order to minimize risk and maximize interest, most agencies put peoples’ money in an agency commingled account rather than let the person with disabilities control and direct the funds (Dunbar K. 2017, oral communication, April 17). However, they do so despite the Social Security Administration outlining representative payees do not have “have legal authority over earned income, pensions, or any income from sources other than Social Security or SSI” (19); similarly, the Medicaid HCBS settings rule notes people with disabilities must have the same control of personal resources as nondisabled people (5). Thus, *individualized budgets* is an area which especially needs to be targeted for improvement and provider education.

Despite these overarching trends, in addition to differences in the specific topics themselves, there were a number of differences across the stakeholder groups in terms of total ratings. DSPs and organizational support team members rated the organizations the lowest across the groups and topics; it is likely that as the people on the ground these two groups are more intimately familiar with both the daily lives of the people with disabilities who they support and the structural problems and struggles on the operational side of the organization, such as resource allocation in a reduced fiscal landscape. Meanwhile, board members commonly believed organizations were doing significantly better than any other stakeholder group. While board members may be familiar with the organizations’ policies, these findings suggest they need more education about actual organizational practices. This is particularly pertinent as board members frequently guide the priorities of organizations and the provision of resources (20). As boards “are entrusted to oversee and ensure that the organization remains true to its mission,” our findings indicate more work is necessary to ensure boards are aware of the lived experiences of the people with disabilities their organization supports (21).

### **Limitations**

When interpreting our findings, a number of limitations should be noted. First, this was a secondary data analysis; as it was pre-collected, the researcher did not have the ability to add additional research variables in order to control for confounding variables, or to examine interactions. Moreover, while the survey was designed to be accessible – the topics were

described in plain language with images and the rating scale included different levels of stars – it is possible one of the confounding reasons people with disabilities scored higher than a number of other groups is because the survey was not accessible enough. As demographic information about disability type or impairment severity was not collected with the original data that was presented to the researcher there was no way to examine this. Another limitation was that the sample was not representative of the United States as a whole. Moreover, it should be noted that participants in our study were recruited through organizations that provide LTSS, and partnered with the Council on Quality and Leadership (CQL) to pursue accreditation. As a result, these organizations may not be representative of service providers in general. Moreover, there may have been a response bias as organizations volunteered to partner with CQL, and thus may already be more proactive. In an attempt to counter this, this study focused more on comparisons across groups than creating benchmarks for each topic.

### **Conclusions**

As disability services agencies struggle to allocate the limited funding available to them, agencies need to pay particular attention to their person-centered practices. There also needs to be a concerted effort to achieve community integration, rather than simply community placement. Many organization management team members seem to be cognizant of these needs, while also recognizing the need to attend to workforce and budgetary issues. Their concerns mirror current crises in the disability service industry. For example, as a result of these strains some agencies in Illinois have considered increasing settings sizes to counter the lack of workforce infrastructure (22); they do so despite state and family interests in small settings. A community infrastructure is necessary to meet the demands of community services; “many of the quality issues” such as “lack of person-centered planning to allow [people with disabilities] to live in the most integrated setting;... difficulty placing and supporting people in the community who have significant medical or behavioral needs;... lack of meaningful participation in the community;... [and,] lack of integrated, competitive employment opportunities [are because] providers are often taking a one-size fits all approach...because they don’t have sufficient staff to support more customized and integrated...opportunities” (23). States need to recognize the strain and limitations these budgets place on disability service agencies and their workforce, and increase their funding accordingly. In the meantime, disability service organizations need to utilize creative low-cost solutions to maximize the empowerment of the people they support.

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**Table 1. Organization achievements**

	Not consistently occurring (1)		Needs improvement (2)		Promising (3)		Effective/results measurable (4)	
	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>
Person-centered assessment and discovery	1.4%	103	9.2%	672	35.4%	2,382	53.9%	3,931
Person-centered planning	1.3%	95	10.8%	785	38.1%	2,771	49.7%	3,613
Supports and services	1.4%	103	11.3%	818	34.5%	2,510	52.8%	3,835
Community connections	2.0%	148	13.1%	951	36.0%	2,615	48.9%	3,549
Workforce	2.9%	209	14.8%	1,074	35.4%	2,569	46.9%	3,397
Governance	2.6%	189	10.9%	789	37.2%	2,683	49.3%	3,559
Quality and accountability	1.8%	127	10.5%	760	34.3%	2,482	53.4%	3,862
Individualized budgets	5.0%	357	17.1%	1,221	34.3%	2,444	43.5%	3,102
<i>Average</i>	<i>2.3%</i>	<i>166</i>	<i>12.0%</i>	<i>884</i>	<i>34.6%</i>	<i>2,557</i>	<i>48.8%</i>	<i>3,606</i>

**Table 2. Topic means**

Topic	<i>M</i>	<i>SD</i>
Person-centered assessment and discovery	3.42	0.72
Person-centered planning	3.36	0.73
Supports and services	3.39	0.74
Community connections	3.32	0.78
Workforce	3.26	0.81
Governance	3.33	0.77
Quality and accountability	3.39	0.75
Individualized budgets	3.16	0.88
<i>Across topics</i>	<i>3.33</i>	<i>0.58</i>

**Table 3. Topic means by stakeholder group**

Topic	People with disabilities	Family members	Direct support professionals	Organization leadership team	Board members	Community partners
Person-centered assessment and discovery	3.53	3.53	3.24	3.40	3.65	3.52
Person-centered planning	3.43	3.42	3.24	3.35	3.60	3.50
Supports and services	3.50	3.46	3.28	3.32	3.58	3.43
Community connections	3.39	3.36	3.27	3.20	3.56	3.48
Workforce	3.47	3.38	3.10	3.11	3.52	3.30
Governance	3.31	3.41	3.23	3.37	3.66	3.44
Quality and accountability	3.51	3.44	3.26	3.37	3.63	3.46
Individualized budgets	3.30	3.27	3.02	3.02	3.51	3.30

**Figure 1. Trends by stakeholder group. (Relevant means can be found in Table 4.)**

