2024

ADVANCING COMMUNITY-BASED SERVICES

A Case Study of North Carolina Service Providers that Support People with Disabilities to Be Fully Integrated and Included in Their Communities

THE NATIONAL LEADERSHIP CONSORTIUM

FUNDED BY THE NCCDD

NCCDD North Carolina Council on Developmental Disabilities

NATIONAL LEADERSHIP CONSORTIUM ON DEVELOPMENTAL DISABILITIES

Cory Gilden, Research and Evaluation Manager, The National Leadership Consortium

Monica Mesa-Alvarez, Research Associate, The National Leadership Consortium

Caitlin Bailey, Co-Director, The National Leadership Consortium

Gilden, C., Mesa-Alvarez, M., & Bailey, C. (2024). *Advancing community-based supports: A case study of North Carolina service providers that support people with disabilities to be fully integrated and included in their communities*. The National Leadership Consortium on Developmental Disabilities.

This initiative is supported at 25% ($2,178.00) by The National Leadership Consortium and at 75% ($6,508.00) by the North Carolina Council on Developmental Disabilities and the funds it receives through P.L. 106-402, the Developmental Disabilities Bill of Rights and Assistance Act of 2000.

Table of Contents

Introduction

Across North Carolina, people with intellectual and/or developmental disabilities (IDD) can access a wide range of services, from fully community-inclusive supports integrated into peoples' chosen homes, workplaces, and communities, to completely segregated services offered in institutional and workshop settings. According to State of the States in Intellectual and Developmental Disabilities data, about 24% of 2019 public IDD spending in North Carolina was for ICF/ID services, and approximately 4,000 people lived in nursing facilities, state institutions, and private ICF/IDs, while just over 8,000 people received supported living or community-based residential services. Even when people receive community-based, waiver-funded services, they may access a variety of supports, from in-home and competitive employment to congregate group homes or sub-minimum wage jobs. This range of supports within the state indicates that it is possible to provide community-living services in North Carolina, even though many people cannot access them, and that there is a significant opportunity for many organizations to transform their services and adopt structures and practices that promote community living. Understanding the factors that enable community living support can help to decrease gaps in access by providing concrete and actionable strategies that agency professionals can adopt and people with IDD and their family members can advocate for and demand.

In the fall of 2023, the National Leadership Consortium was funded by the North Carolina Council on Developmental Disabilities (NCCDD) to launch a five stage, mixed-methods research project to investigate organizational policies and practices that help promote community living in an effort to advance community living services across the state. For the purposes of this project, “individualized, community-based services” were defined as “services that support people who are living in the community to meaningfully belong to their community.” Some examples include services for people living independently/with roommates/in a family home (not institutional or group settings), competitive employment services, and supports for participating in community activities that are not specialized for people with disabilities. This in-depth case study aimed to increase knowledge about organizations that are providing community living supports to help create a blueprint of practical steps for professionals who are not yet providing these supports to understand elements that may be helpful in transforming their services and to help people receiving services to recognize best practices in community living. The five stages of the study are outlined below.

Stage 1: Recruitment and Evaluation Materials Development [January 2024]

Organizations were recruited for this study that satisfied the following selection criteria: 1) The organization delivers direct services and supports to people with intellectual and developmental disabilities in North Carolina, 2) The organization is CQL accredited, and 3) The organization delivers individualized, community-based services and supports. Five organizations in North Carolina participated in this study: 1) The Charles Lea Center, 2) Monarch, 3) InReach,

4) FIRSTwnc, and 5) Triangle Disability & Autism Services (see Appendix A for organizational demographics).

The research team of the National Leadership Consortium developed interview and focus group schedules, as well as an employee survey to be used during Stage 3. Evaluation materials were aligned with goals outlined in the grant proposal to 1) Discover trends in organizations that promote community living, 2) Determine organizational strategies, structures, practices, and values necessary to navigate North Carolina's IDD system to ensure that people with IDD have full access to live and belong in their communities, and 3) Gain a deeper understanding of the organizational and systems-level barriers to more inclusive services. These goals were based on the NCCDD's Community Living strategic goal to build capacity for people with IDD to more successfully live in the community.

Stage 2: Document Review [February-March 2024]

Organizational documents and online materials were collected to evaluate themes and trends in organizations that successfully promote community living. Documents included: vision statements, mission statements, organizational philosophies, employee handbooks, onboarding materials, organizational charts, governance policies, board of directors' materials, job descriptions, pay scales, performance review documents, internal and external surveys, strategic plans and future goals, and marketing materials.

Stage 3: Executive Interviews, Employee Surveys, and Focus Groups [March-May 2024]

In-depth interviews with executive leaders of participating organizations were conducted February through April of 2024 via Zoom (see Appendix B for more about the interviews). Interviews lasted 1-2 hours and were audio recorded and transcribed. Employee surveys were distributed to all employees of participating organizations in March and April of 2024. The first survey was developed by the National Leadership Consortium specifically for this project and contained 16 multiple choice and short response questions (see Appendix C for more about the survey and participant demographics). The second staff survey was the Organizational Priorities and Practices Inventory, a holistic organizational evaluation tool created by the National Leadership Consortium for disability-focused organizations nationwide (see Appendix D for more about the OPPI and participant demographics). Focus groups were conducted with people receiving services and family members of people receiving services in March through May of 2024 via Zoom and were audio recorded and transcribed (see Appendix E for more about the focus groups and participant demographics). Interviews, surveys, and focus groups all asked about organizational demographics and characteristics, organizational policies, and organizational operations and practices.

Stage 4: Analysis [June-August 2024]

A document analysis was conducted to systematically review written documents and online materials to gain insights into how organizations that provide community living services functioned. Thematic analysis was used to identify emerging themes and patterns from interviews, open response questions on surveys, and focus group responses. Descriptive analysis was used to gather results from quantitative questions on employee surveys. Analyses took place during June through August of 2024. For more information about research methods, see Appendix ###.

Stage 5: Reporting [September 2024]

Results from the document review, interviews, surveys, and focus groups and recommendations based on results are compiled in this report, as well as in an accompanying plain language infographics that will be shared with the public.

This comprehensive report outlines key findings from the document review, interviews, surveys, and focus group data, starting with the challenges to community living experienced by executives, employees, and people receiving supports and their families and then highlighting the facilitators to community living. Finally, the report summarizes model approaches to community living and provides recommendations for improving service delivery in North Carolina.

About the Participating Organizations

Organizations providing individualized, community-based supports were selected for participation in this project through discussions with the North Carolina Council on Developmental Disabilities, professionals at CQL (an accrediting agency), and other consultants with expertise about provider organizations in North Carolina. Organizations were recruited via email and met the following requirements:

1. CQL Accredited: Human service providers in North Carolina who have achieved a formal recognition of attaining a specified set of standards through an unbiased evaluation of outside experts at CQL that examined planning meetings, self-assessments, interviews, sit visits, focus groups, stakeholder events, and data analysis (https://www.c-q-l.org/accreditation/accredited-organizations/?state=north-carolina-)
2. Provides services to adults with IDD
3. Provides a range of community-based services
4. May provide some congregate services (residential or day), but also provides a variety of individualized, community-based services
5. Uses words that promote values of self-determination in vision/mission statements on website (e.g., inclusion, community, self-determination, autonomy, independence, choice/ choosing, control, self-directed, person-directed, dignity, rights/ human rights, respect, and quality)

Attention was also paid to locations of services provided by potential participating organizations to ensure geographic diversity in the sample.

Five organizations were selected to participate in this project: 1) The Charles Lea Center, 2) Monarch, 3) InReach, 4) FIRSTwnc, and 5) Triangle Disability & Autism Services. As this study involved an in-depth investigation of each organization, including internal documents, organizations were randomly assigned letters (A, B, C, D, and E) and are referred to by those letters throughout this report (i.e., Organization A) to preserve the privacy of their identities and materials. The basic demographic information for the participating organizations is included in Appendix ### of this report, including number of employees, geographical reach of services, types of primary service delivery areas (i.e., urban, suburban, rural), percentage of part-time employees, gender of employees, age of employees, and race/ethnicity of employees. In the Appendix, each organization was assigned a random number of one through five that is not correlated with the A-E designations to further preserve the confidentiality of each organization's materials and employees.

Barriers to Individualized, Community-Based Services

Executive leaders and frontline employees of organizations that provide services to people with IDD were asked in interviews and on a survey about what they perceived were the barriers to providing individualized, community-based services to the people they support. People with IDD receiving supports from each organization in the study and their family members were also asked about barriers in focus groups.

Barriers discussed were analyzed and sorted into two main groups: “internal,” or having to do with elements within the organization, and “external,” or having to do with elements outside of the organization.

Internal Barriers

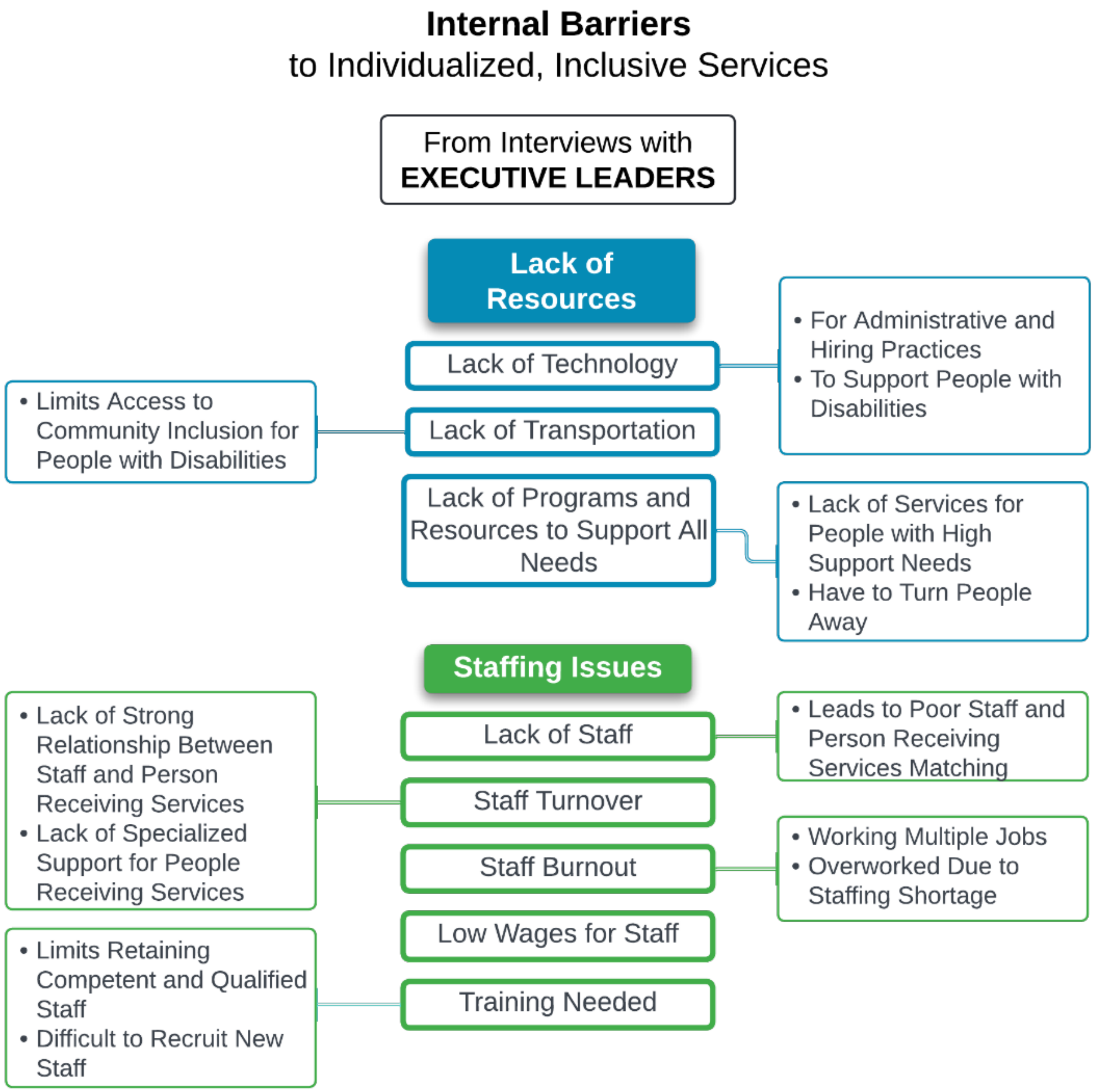
Perspectives of Executive Leaders of Provider Agencies

Executive leaders of the participating organizations were interviewed for 1-2 hours via Zoom and asked a variety of questions related to their services to support community living and inclusion, including questions related to the internal or organizational barriers to providing these services, such as, *“Can you describe any internal or organizational challenges your organization faces when providing community-based services?”* Leaders were also asked questions related to funding for these services, how they support staff in delivering these services, and how the organization’s values guide tasks and decisions related to these services, in order to develop a deeper understanding of the barriers related to delivering individualized, community-based services and supports. Internal barriers discussed by executive leaders in interviews were grouped into two main categories: 1) Lack of resources, and 2) Staffing issues (see Figure 1).

Lack of resources related to lack of technology, lack of transportation, lack of programs, and resources to support all needs. When referring to lack of technology, executive leaders desired more use of technology for administrative and hiring purposes, as well as more technology to support people receiving their services, such as with virtual services and check-ins with the person receiving services in their home. Executives also talked about how their inability to provide enough transportation limits access to the community for the people they support.

Staffing issues discussed by executive leaders during interviews related to lack of staff, staff turnover, staff burnout, low wages for staff, and training needed for staff. All leaders were acutely aware that frontline workers needed to be better financially compensated. One leader said*, “DSPs need to be paid more. We can’t expect professional behavior when we’re paying $13, $14, or $15 an hour. I mean, we pay $18 to $19 an hour, and that is still hard to live on, so you’ve got DSPs working two jobs. They’re burnt out. They’re tired … You’ve got DSPs that have two jobs and have families at home, and they’re running from this place to that place just trying to survive.”*

Figure 1: Organizational Barriers to Individualized, Inclusive Services Given by Executive Leaders of Service Providers for People with IDD



Another leader said, *"Even the funding that we have doesn't support our staff to have a livable wage, and so people are working at Hobby Lobby and McDonalds instead of caring for people."* Another also acknowledged the struggle between wages they could provide and wages they should provide. *"You know, Target is paying $20 an hour in Charlotte. Our goal is to get our wages up to $20 an hour…but right now we're still at $16 or $17…I know people love working here, but sometimes they can't afford to live. So that's our big challenge is finding and keeping staff and the way we're going to do that is we're going to have to pay a living wage."*

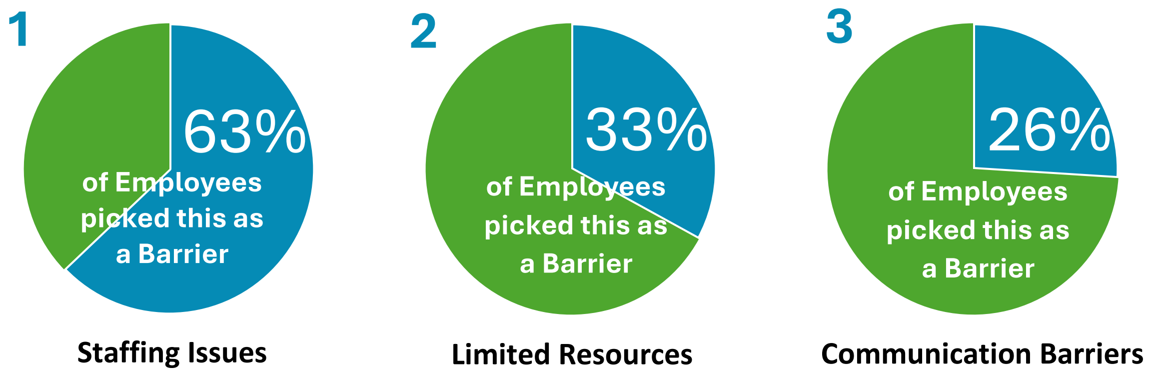
Leaders were also aware of how lack of staff affected services for the people they support, leading to worse matching between the support person and the person receiving services and leading providers to turn away people seeking services. One executive said, *"We've had several families that are really interested in coming to [our organization], and in some cases, we've had to turn them away because we don't have the staff. Staffing is a huge challenge in recruiting and hiring, and that has affected our ability to take in more people sometimes because we can't hire the qualified staff that we want to have in our programs. That is definitely a barrier."*

Leaders not only talked about recruiting and retaining staff, but also making sure the staff they had were well competent in their positions, pointing to the need for more training. One leader also emphasized the importance of training in the field instead of traditional training methods. *"I tell new staff coming in, you can have all the knowledge, you can have all the classes, you can have a master's or doctorate in special education, but you've got no idea until you meet that person. This is a relationship-based field. You can read all the books on autism you want, but the first time you meet somebody with autism, they're not going to be what the book said autism is. These are people, they are human beings and they are going to challenge you in ways that are different. You've got to be able to walk in and form relationships."*

Perspectives of Employees of Provider Agencies

Employees of participating organizations were surveyed about their experiences with and perspectives about their organizations and the services they provide, including barriers related to delivering services that support community living and inclusion. In the survey, the employees were asked, *"In your experience, which of the following organizational challenges have you faced when providing community-based services?"* and given a list of seven common responses, as well as an *"Other"* option where they could write in their own response. The most selected organizational barrier selected by employees was "*staffing issues*" (62.8%), mirroring the sentiments of executives (see Figure 2). The second most selected was "*limited resources*" (32.9%), and the third was "*communication barriers*" (26.4%) (see Figure ###). The least selected barrier was "*toxic organizational culture*" (4.2%). Write-in responses included: too much driving, livable wages/low salaries for staff, out-of-pocket expenses (like gas) while on shift, different rules for different staff, and "*none*."

Figure 2: Top Ranked Organizational Barriers to Individualized, Community-Based Services from the Employee Survey



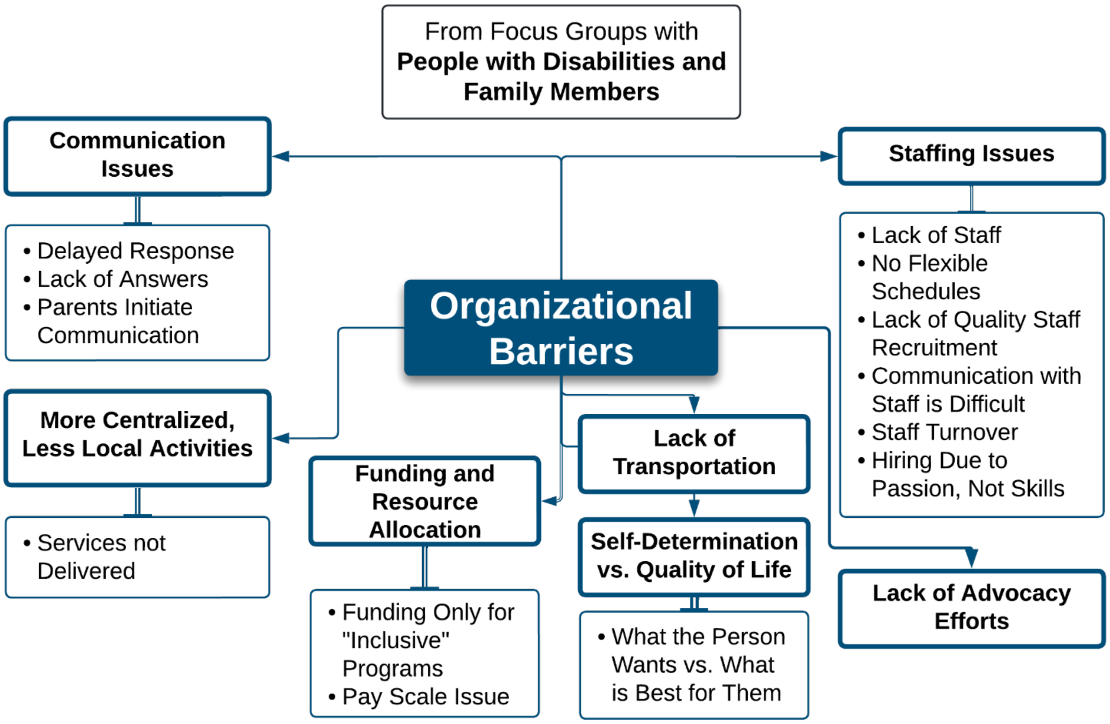
Perspectives of People Receiving Services and Family Members

People receiving services and/or their family members from each organization were also asked for their perspectives about organizational barriers to individualized, community-based services during online focus groups. Their responses were grouped into seven main categories: 1) Staffing issues, 2), Lack of advocacy efforts from organizations, 3) More centralized, less local activities, 4) Funding and resource allocation, 5) Self-determination vs. quality of life, 6) Lack of transportation, and 7) Communication issues (see Figure 3).

Similar to executives and employees, people with disabilities and family members had a lot to say about the barrier of staffing issues. Many noted that they were waiting to begin services or had to suspend services at times because there was no staff available to provide the services. *"We can never get reliable, steady staffing,"* said one family member. Lack of staff became more of an issue after the pandemic, said some participants. One mother talked about how she had to fill in the gap when there were not staff available to provide services: *"At the beginning of the pandemic in 2020, everything fell off and all the services went away pretty much. … Since 2022, I've been providing [community living services and community networking] as his care provider. Not necessarily by my choice, but because they just can't find anyone consistently."*

Participants also shared how many times staff did not know about their or their loved ones' disability or about how to best deliver services, as well as how some staff were difficult to talk to about issues. One participant said, *"Trying to get quality people at the service level is a complete failure."* A few family members attributed lack of skills in staff to organizations hiring staff because they have a person in their life with a disability or because they are passionate about being in human services, which does not necessarily translate into someone who is good at delivering or managing services.

Figure 3: Organizational Barriers to Individualized, Inclusive Services from Focus Groups with People Receiving Services and Family Members



Focus group participants also spoke about short-lived quality supports due to high staff turnover. They also mentioned that professionals’ schedules and work hours do not always match desired activities. One person receiving services said, *“I know that she has certain hours that she can work with me because she helps other people ... so you know, we have to keep it to that time that she’s allowed to work with me.”* Another participant said, *“I’ll do a book reading at the coffee shop with a writer’s club at 6:45 to 8:30 on a Friday, but she’s done with me at 6:00 on Friday. So, there were a few times where I didn’t go to those events. … I understand that she has 10 hours a week with me because she has other people she works with as well. So, I have to work according to her schedule.”* This comment also speaks to the lack of provider transportation available for participants, who also reported that distance to events and programs was difficult for people in more rural areas, especially since some organizations were moving toward having more centralized and less local activities. One mother mentioned how she would have to drive an hour and a half for her son to participate in activities that were in a more central location for the organization, which made it not worth it to participate.

Parents voiced conflicting feelings about the priorities of certain services. One mother wanted to support her adult child’s right to make their own decisions but argued that sometimes staff just go along with it automatically, versus doing what may be best for the person being supported, is not the right way to go. She said, *“That’s one of the things I've long struggled with is the whole issue about human rights and his self-determination and ability to say no to doing* *things. He can be stubborn sometimes. And he'll say no and cross his arms and not get out of the car, whatever it is, and the staff goes along with that. And I appreciate that. And yet, developmentally, he has the ability of a toddler to make decisions. And you wouldn't let a toddler say, 'No, I'm not getting out of the middle of the street.' Caving to his not being willing to do some exercise is very detrimental to him and it sets a precedent for him and you do things once or twice and then it becomes the norm. So, I struggle with how to do that differently."* Another mother expressed frustration with her son's services because she was hoping to get him involved with a program in the community that he had been involved with before and enjoyed, but funding has been *"tricky"* for it because it is not an expressly "inclusive" program, even though there were people without disabilities who participated in it.

Finally, people receiving services and family members in focus groups said that there are often communication issues associated with services, such as delayed responses, lack of answers, and families always having to initiate communication with organizations providing services. To gain more information, we specifically asked focus group participants about the communication they give and receive from their service providers (see Figures 4 and 5). While most people were satisfied with how easy it was to reach their service providers in many ways (e.g., through the support person, in regular meetings, and through phone calls and texts), they also mentioned that they were the ones to initiate most of the communication and were disappointed that feedback, such as satisfaction surveys, was not asked from them regularly (see Figure 4). They also expressed the desire for more information and referrals from service providers about what services were available and how to go about enrolling in them.

Figure 4: Communication From People Receiving Services from Focus Groups with People Receiving Services and Family Members

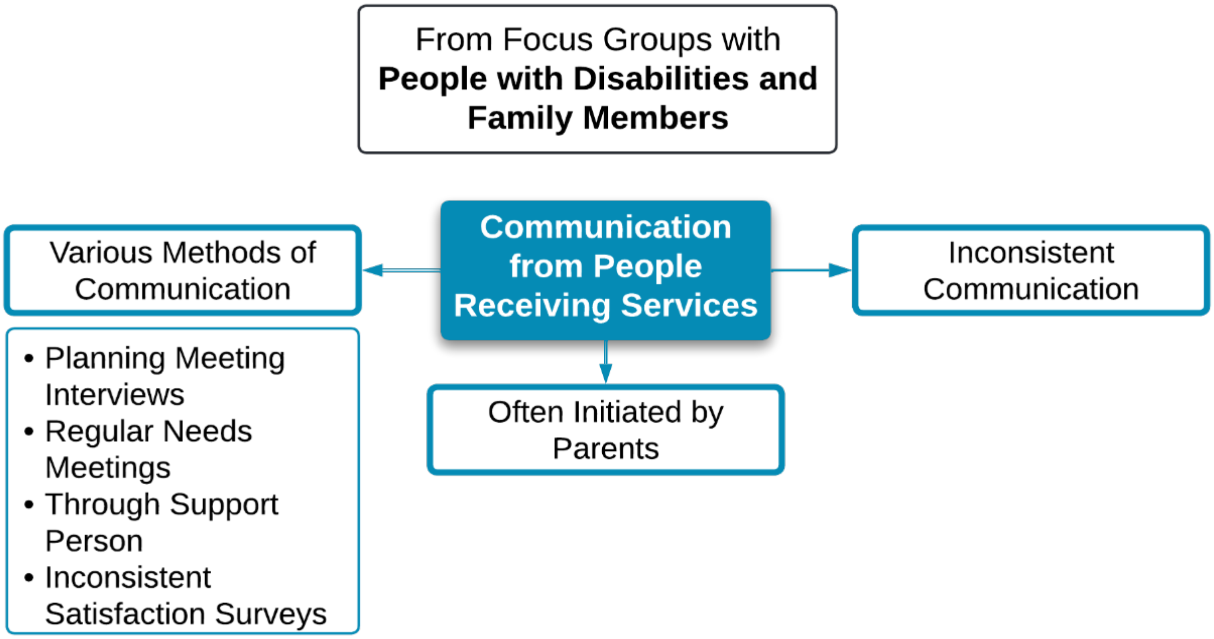
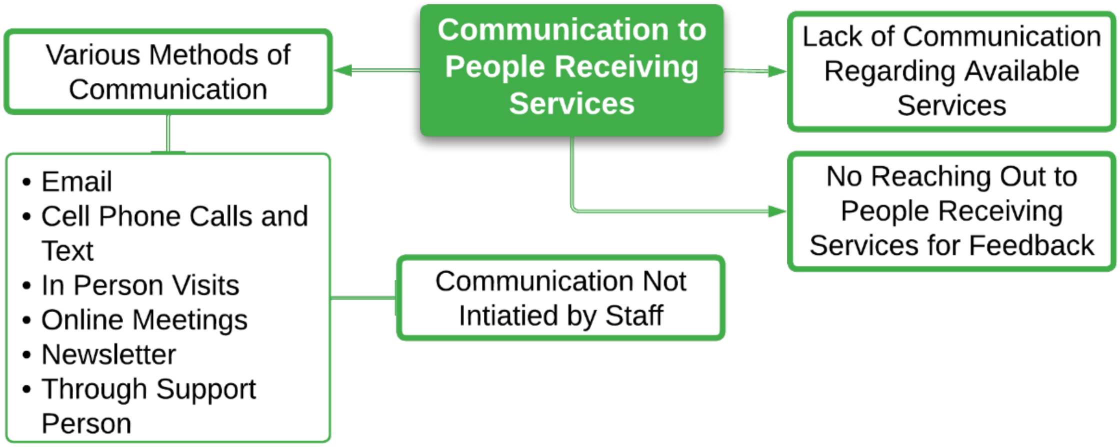
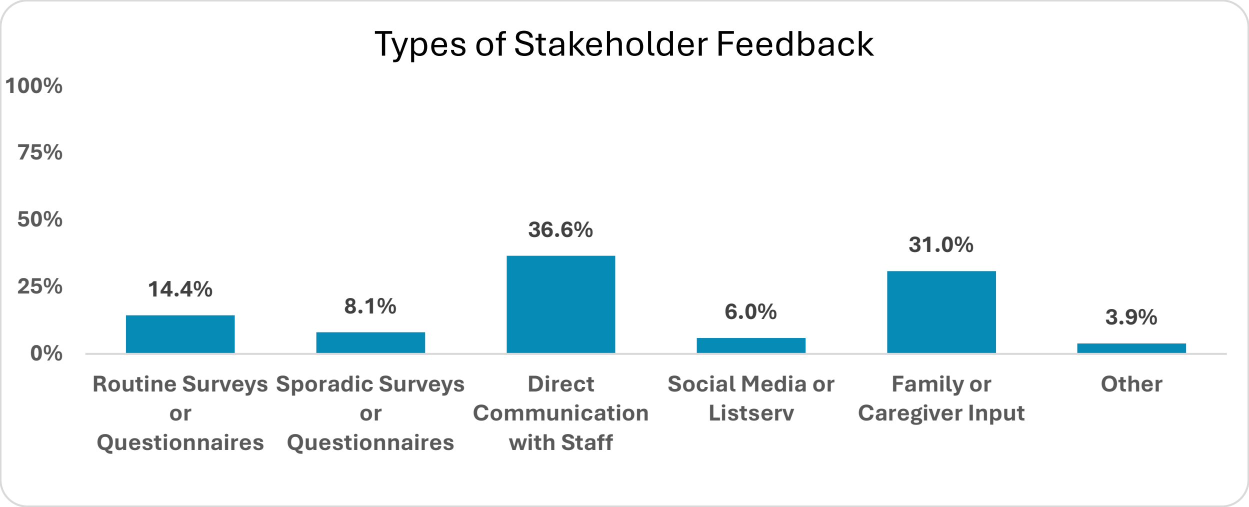


Figure 5: Communication To People Receiving Services from Focus Groups with People Receiving Services and Family Members



When asked, *"How do people who receive services from your organization provide feedback about their community-based services?"* on the Employee Survey, employee responses confirmed that most communication is done through direct communication with staff (36.6%) and is family or caregiver input (31%) (see Figure 6).

Figure 6: Types of Stakeholder Feedback from the Employee Survey



External Barriers

Perspectives of Executive Leaders and Employees of Provider Agencies

Executive leaders of the participating organizations were asked questions related to the external barriers to delivering individualized, community-based services during the interviews, including, *"Can you describe any external, community or societal, challenges your organization* *faces when providing community-based services?"* Employees of participating service provider organizations were also asked questions about external barriers on the Employee Survey, including, *"Please briefly describe any challenges or areas of need outside of your organization that you have experienced when trying to provide community-based services."* External barriers discussed by executive leaders in interviews and by employees on the survey were grouped into four main categories: 1) Systemic Factors, 2) Community Factors, 3) Family Factors, and 4) Individual Factors (see Figure 7). Systemic factors reported by executive leaders and employees included: insurance barriers, government barriers, service barriers, and funding barriers. Community factors included: lack of resources and prejudice or lack of acceptance. Family factors included: (from executives) lack of knowledge, requesting restrictive services, exclusion of families from decision making, and lack of boundaries, and (from employees) lack of family support, and lack of boundaries. And finally, individual factors included: isolation in the community, requesting restrictive services, and high support needs (see Figure ###).

The Venn Diagram in Figure 7 is a summary of external barriers discussed in interviews and on the survey. Figure 8 illustrates these external barriers in greater detail, with themes that were shared in both the interviews with executive leaders and the responses from employees on the survey written down the center of the figure, and concepts shared in interviews with executive leaders on the lefthand side, and concepts shared in the survey of employees on the righthand side of the figure.

Figure 7: Summary of External Barriers to Individualized, Inclusive Services Given by Executive Leaders and Employees of Service Providers for People with IDD

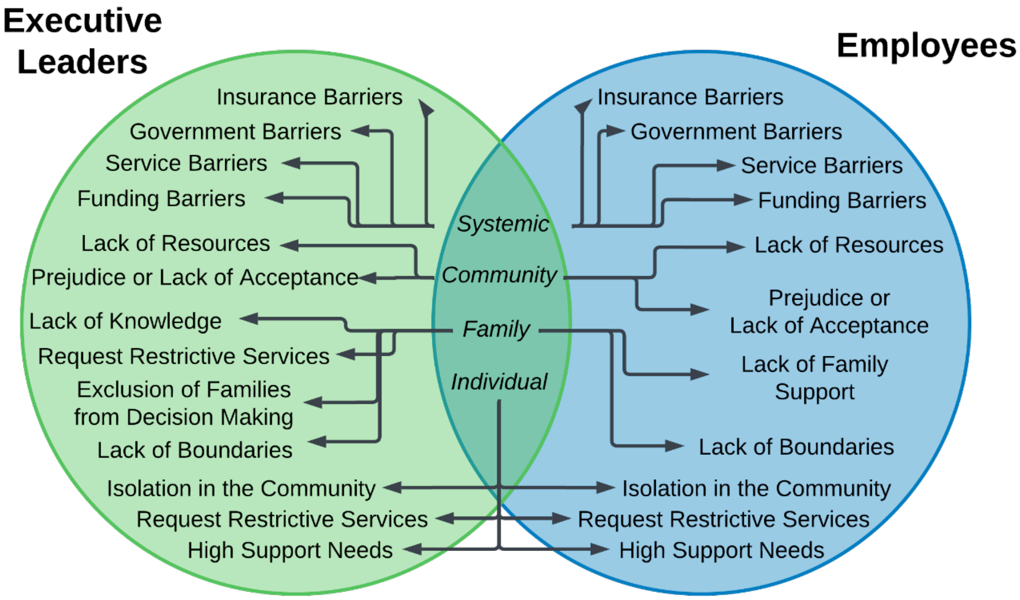
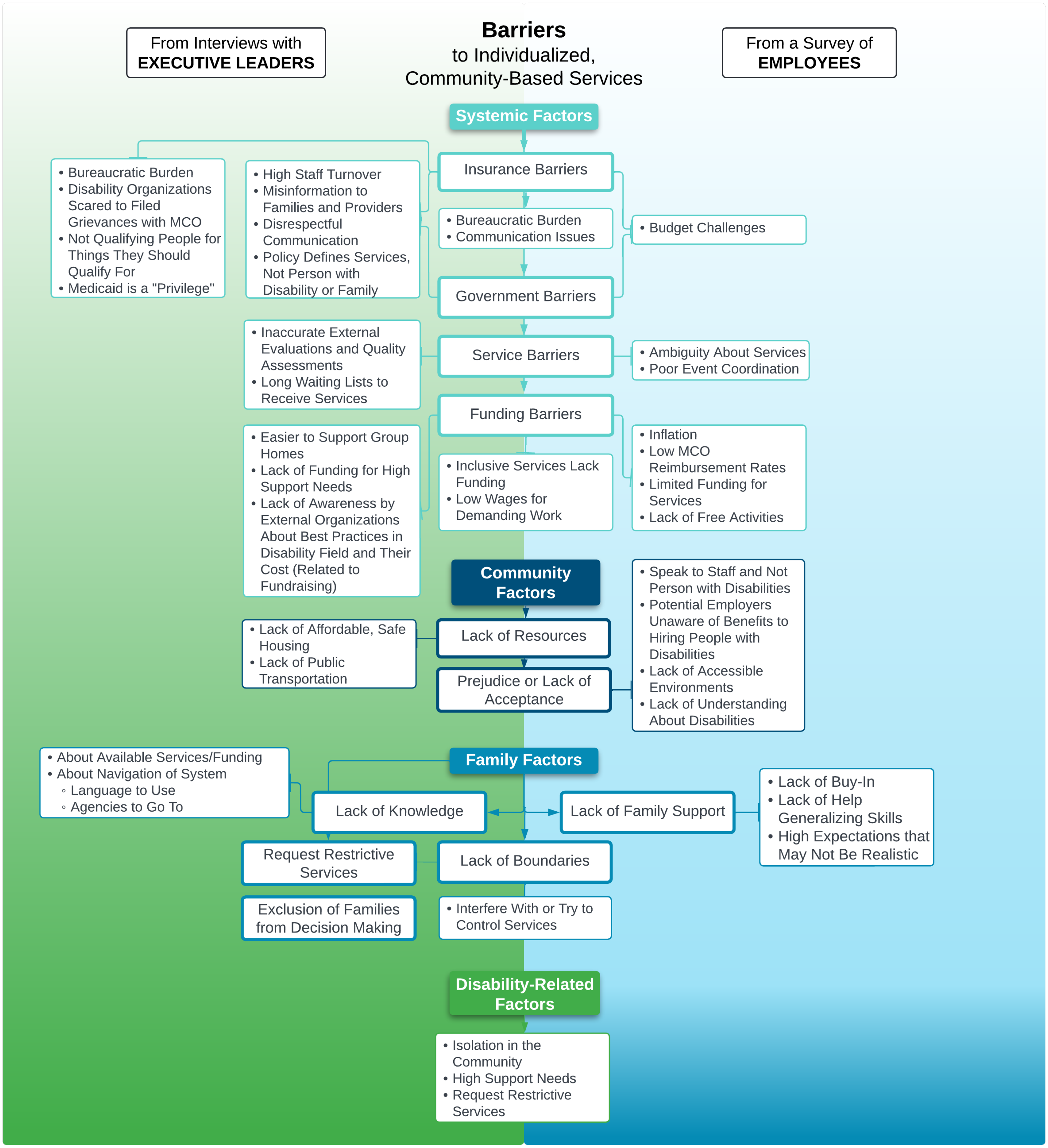


Figure 8: Expanded Map of External Barriers to Individualized, Inclusive Services Given by Executive Leaders and Employees of Service Providers for People with IDD



Related to systemic barriers to individualized, community-based supports, executive leaders and employees discussed **insurance barriers** like a lot of paperwork and bureaucratic burdens, communication issues such as disrespectful communication, inconsistent communication, and misinformation from insurance and government agencies, and not qualifying for services or services not matching the needs of the person; **government barriers** like inconsistent communication or misinformation and policies quality of services; and **funding barriers** like funding is easier to support group homes, there is not enough funding for people with high support needs, low wages for demanding work of DSPs, low MCO reimbursement rates, limited funding for services, difficulty fundraising because of lack of understanding from community businesses about the work being done by provider organizations, and general inflation that is making it difficult to pay for things like gas and events.

"With the cost of living, it's hard for our folks to be able to afford to live in the community. It's hard for somebody with a full-time job to live in Asheville if you're not making big money. Our folks are on a very limited income so being able to live in the community in their own place by themselves is very hard to do. … To many parents, it's easy to put them in a group home because it is an all inclusive package."

"Service delivery starts with early intervention, with an Individualized Family Supervision Plan. And then when you're done with early intervention, they put you into the school system. Then, all of a sudden, now it's only about your child, so there's this disconnect from the time a child turns three. The whole system is broken, in my opinion."

"At one point, we looked into closing group homes and just making everyone independent, but it's financially impossible. … Most of the folks there, if we moved them out to an apartment, we're going to need one-on-one staff or someone to live with them in that apartment. And it's almost impossible to even find staff and then they'd have to pay rent that's astronomical. So, group homes are the best that we can do right now until that changes."

Community factors mentioned during interviews and survey responses included **lack of resources** such as lack of safe, affordable housing in the community, lack of public transportation; and **prejudice or lack of acceptance in the community**, with a lack of understanding about disability, including people speaking to the support person and not the person with the disability, businesses not understanding the benefits of hiring people with disabilities, and a lack of accessible environments and events.

"We have individuals who want very badly to live by themselves but simply cannot afford the real estate in that particular area. It's quite expensive and they can't afford it. … If you have a person with disabilities living out in a community by themselves, you need to feel like they're in a safe environment. It's a big challenge for us."

"Transportation Is always a factor. I think about one place that we have that's [far away], and we do all the transportation there because they don't really have public transportation. We have staff that literally spend an hour to an hour and a half driving to pick people up in the

mornings to bring them to the program and then have to drive to take them back. It kind of is what it is, and we're the only option they have."

Family factors that were barriers to inclusive, community-based services related to **lack of knowledge** about available services and funding, and about how to best navigate the system and know what to ask for; **lack of family support,** meaning that support staff do not have family buy in or participation and families are not helping to generalize or reinforce skills and may have unrealistic expectations; **families requesting restrictive services** instead of more individualized, community-based services; **exclusion of families from decision making** sometimes limits services and expectations; and **lack of boundaries by families**, who try to interfere with or control services instead of the person receiving them.

"I think what happens is that somebody calls up and says, 'My child has Down Syndrome. How do I get Medicaid?' and instead of them saying, 'Okay, let's figure this out—how old is your kid, blah, blah, blah,' they say, 'Oh, well, Down Syndrome doesn't get you Medicaid health insurance.' It's all how you ask for it. … They told one family that they wouldn't get a spot unless someone else's child died. I mean, really? You're just going to shovel guild on top of this person's experience as the parent of a child with a disability or autism? Really?"

"There's over 16,000 people in the state of North Carolina on the waiting list to receive Medicaid services. You know who I think about? The 16,000 that don't know about the services. … Every time I talk to parents and they have no plan; they don't know about what they're going to do about guardianship when they're gone. They have no future planning, let alone ABLE accounts and special needs trusts, and all of that. One mother said to me, 'I was not born knowing how to do this. I did not go to school to know how to do this, and it's a fulltime job! Just the lingo alone, never mind all of the services and providers.' And it's too much. It's overwhelming."

"I think the challenge that I probably see the most is trying to support the person in a way that they want to be supported, but also having to address the guardians' requests and concerns. It's not uncommon for the guardian to want more support and then that individual won't want more support than we think that person needs."

"We have some apartment complexes, which is a great way for somebody to step down if they're living in a group setting, to step into living in an apartment that's in a community and operated by us. We have people on site, so if someone has services, then they have more staff interaction. But people are afraid, families, especially our older families, they are afraid and you can't really get consent to help people make that next step. That sometimes holds people back from having more community-based services."

Finally, disability-related factors, such as **having high support needs**, **isolating themselves in the community**, and **requesting more restrictive services,** were barriers to inclusive, community-based services and supports.

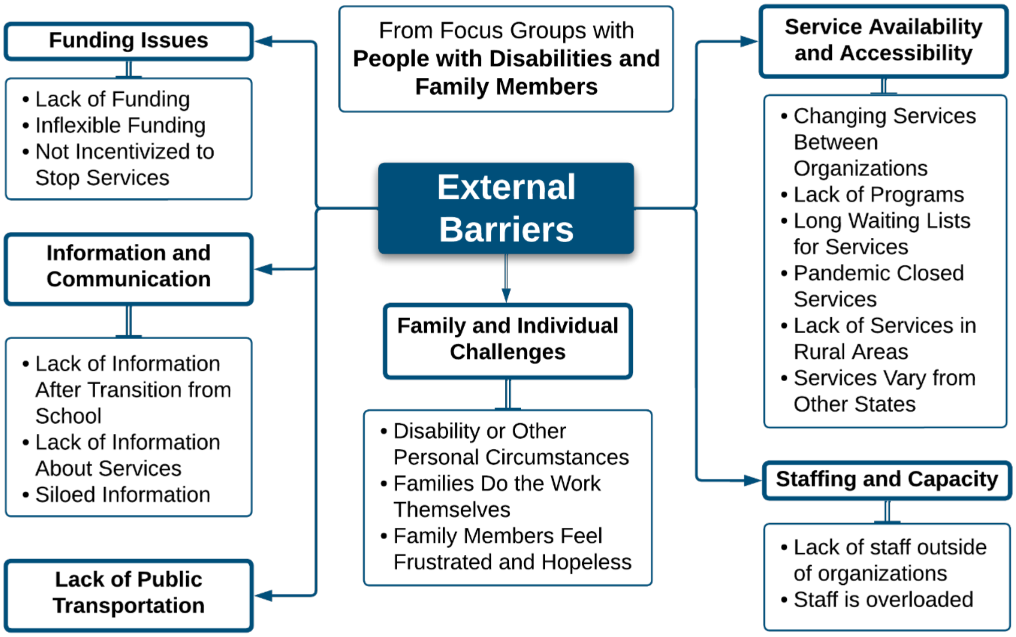
"We do have people that live in their own apartments in Charlotte that their families pay to rent the apartment for them and it's wonderful. But I can tell you after 34 years of experience, they're more lonely living in their own apartment in a complex with people they don't know compared to our folks in our 12 unit building where they feel comfortable talking to everyone and they're become friends with people. In the regular apartment building, we thought, 'oh, they'll make friends with people that live there.' But it doesn't usually happen as much as you want it to happen."

"Right now, in service delivery is really the message that folks only need the least amount of support. Integrated Employment is a great example. … Closing sheltered workshops, of course, those were wrong, illegal, terrible, but you just took this whole population of people, and some of them can get jobs out in the community, but a lot of them can't. Where are they? Where are their services? We serve a guy who is in his 50s in our supported employment program through Voc Rehab. But we can't find this guy a job because he's never had a job. And he misses his friends at the day program. Who are we to judge that type of service he should get?"

Perspectives of People Receiving Services and Family Members

People receiving services and/or their family members from each organization were also asked their perspectives about the community and societal barriers to individualized, community-based services during online focus groups. Their responses were grouped into six main categories: 1) Service Availability and Accessibility, 2) Staffing and Capacity, 3) Family and Individual Challenges, 4) Lack of Public Transportation, 5) Information and Communication, and 6) Funding Issues (see Figure 9).

Figure 9: External Barriers to Individualized, Inclusive Services Given by People Receiving Services and Family Members



Service availability and accessibility were common concerns for people receiving services and family members in focus groups. They often spoke of a scarcity of services or staffing for their loved ones, long waiting lists for existing programs or services (especially during and immediately after the pandemic), and the lack of community programs in the rural areas where they lived. One frustrated father spoke about his struggle to get his 23-year-old son services: *"He is currently receiving no real services to help him live in his community, other than what my wife and I are providing. It appears that the services he would require simply do not exist until he gets to the head of the line for the Innovations Waiver program, which currently takes about 12 years, unless he really crashes and burns and ends up homeless or in legal trouble."* A mother in the focus group shared a similar experience, saying, *"Pretty much somebody has to die to open spaces, which is really sad because then we have to create that living situation ourselves. Then you're back to this whole problem of trying to find the support staff to put in, and they're just not available. That's why so many of these guys are living with their parents—there's nowhere else."*

Participants pointed to the lack of funding for services and support staff as a big barrier to services being available. One mother shared her experience: *"There are people on those waitlists, and those waitlists are enormous. That's because they can't attract people because they're paid under minimum wage. I know because I'm doing it; it's not my main source of income, thank God. … There's nobody to do any of the work. There's no one to answer the phone. There's no one to figure out what the answer to your question."*

One family member shared how their son has switched services through multiple agencies over the years due to staff not showing up and not getting results, but explained that the problem is systemic: *"We've been through all of the agencies over the course of 36 years, so I don't think it's exclusively any one individual organization at fault."* Another family member lamented that there simply were not a lot of activities or programs to get involved with near them, so time in the community usually meant going to the mall. Participants also mentioned the lack of public transportation in rural areas and limitations on the hours of availability for public transportation. For example, one person receiving services talked about how he works at a concert venue and loves it but does not get out of work until late at night, after public transportation is running in the area, so he depends on family members for a ride home.

Family members expressed that they were often the ones to fill the needs of their loved ones when services fell short, leading to burnout, frustration, and hopelessness. One father said, *"People are frustrated and they don't feel like there's a solution. We provide a lot of feedback but there never seems to be a resolution or somebody that comes to the table and says, 'Okay, here's your path—Your daughter is 32, and these are the six things you need to do to make it happen.' I think most of us, if you told us what those six things were, we'd be all over it. It would get done. But nobody can tell us what those things are."* One mother talked about how she plays an active role in recruiting support staff for her son by tapping into the local university. *"I definitely have a hand in finding staff. I'll email the professors now and say, 'Hey, announce to* *your students that we need somebody.' Then, if one of the students emails me, I immediately just send them to [the provider organization]. Then she does the interviews and all that, then if they think they're a good fit for us, then the person comes here and we interview them. Then [my son] decides who he wants to hire. So, it's kind of a team effort*."

Parents also expressed frustration when trying to navigate the services system to find appropriate services for their loved ones. One parent said, *"What really frustrates me is every time I talk to these groups over the last seven years, they always say the same thing, 'Oh, we're so sorry this is happening. Let me send you some stuff to help you get started.' And then they send me six or eight attachments with 50 to 100 websites on it that looks like they've been cut and pasted by a 10-year-old. So now you give me 400 people to call, and I've got to go through the process of figuring out what the pieces are."* Participants of the focus groups also talked about how information and services are siloed in different systems, like the school system versus the disability system, and there was not a good transition between the two. One mother said, *"There's very little when school ends. It falls off like an avalanche when school ends and you're on your own to navigate the system. You really, really are. And if you are someone who came into the state, you know, somewhat late in the game and you have to figure it all out, it's absolutely undecipherable. And I think that there's not one agency that really is the source of information."*

Facilitators to Individualized, Community-Based Services

Executive leaders and frontline employees of the five participating organizations were asked in interviews and on a survey about what they perceived were the things that helped to provide individualized, community-based services to the people they support. People with IDD receiving supports from each organization in the study and their family members were also asked about facilitators in focus groups.

Facilitators discussed were analyzed and sorted into two main groups: “internal,” or having to do with elements within the organization, and “external,” or having to do with elements outside of the organization.

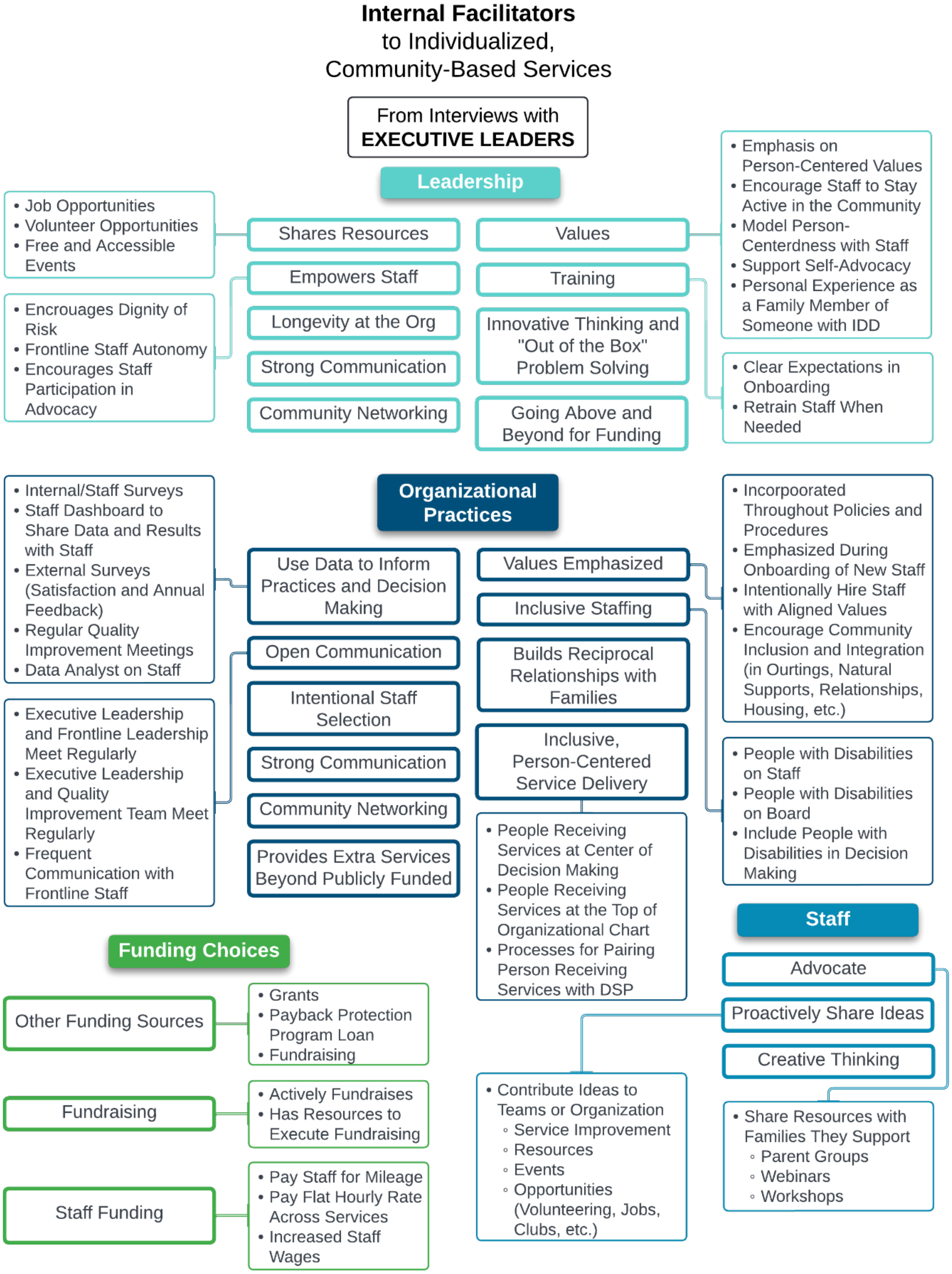
Internal Facilitators

Perspectives of Executive Leaders of Provider Agencies

Executive leaders of the participating organizations were interviewed for 1-2 hours via Zoom and asked a variety of questions related to their services to support community living and inclusion, including questions related to the facilitators of these services, such as, “*Can you describe any internal or organizational things that helped your organization faces when providing community-based services?*” Leaders were also asked questions related to funding for these services, how they support staff in delivering these services, and how the organization’s values guide tasks and decisions related to these services, in order to develop a deeper understanding of the facilitators related to delivering individualized, community-based services and supports. Internal facilitators discussed by executive leaders in interviews were grouped into four main categories: 1) Leadership, 2) Organizational Practices, 3) Funding Choices, and 4) Staff (see Figure 10).

Related to leadership, many factors were mentioned that leaders had done that had been helpful to providing individualized, community-based supports, including: **prioritizing person-centered values** by modeling them in their treatment of staff, encouraging active participation in the community, and supporting self-advocacy in the people they support; **training staff** with clear expectations during onboarding into the organization and retraining as needed; **innovative thinking** and “out of the box” problem solving; **going above and beyond for funding** by belonging to joint councils and committees and developing relationships with MCOs and government agents; **sharing resources** like job and volunteer opportunities and free events with staff so they could share them with the people they support; **empowering staff** to make decisions on their own in the field, encourage the goals of the people they support, and encourage participation in advocacy for the people they support; **longevity at the organization**, which gave leaders vision to know where they came from and where they want to go; **strong communication skills** with staff; and **community networking** with other organizations to build relationships and opportunities for the people they support.

Figure 10: Organizational Facilitators to Individualized, Inclusive Services Given by Executive Leaders of Service Providers for People with IDD



"On a personal note, my child has [a disability] and receives Medicaid services through this agency, so the bar is set very high because I walk the walk of a parent who has been doing this for 20 years. I truly just inherently understand what a difficult journey this is for the person with the diagnosis that needs the services, but also for the whole family."

"Since the 90s we were a self-determination model agency—so we started way back. It's ingrained in all of our documentation and all of our brochures and all of our job descriptions. We emphasize it constantly in all that we do."

"All of our leadership spends a lot of time networking and kind of being the face in our communities. … I can run a program, but if I don't engage and look outside of the program into the community, then I'm missing out on all the resources that could be natural supports. We can work smarter, not harder. We just opened our first group home in [a different state] and we talked a lot about that community, literally, what's around it? What are the people that are moving here going to like to do? Have you connected with the neighbors and the businesses and the local services?"

There were many organizational practices that executive leaders said helped to facilitate individualized, community-based supports, including: **emphasizing organizational values** repeatedly in onboarding of new staff and throughout organizational paperwork; **inclusive staffing practices** by hiring people with disabilities to be on staff and on the board to be included in organizational decision making; **building reciprocal relationships with families**; **ensuring inclusive, person-centered services** by having processes for pairing frontline staff with the person receiving services, placing people with disabilities at the top of their organizational charts, and ensuring that the people who are receiving services have the most say in their plans; **providing extra services above and beyond what is publicly funded** because the people they support would enjoy or benefit from them; **community networking to build relationships and opportunities** for the people they support; **fostering strong communication practices** throughout the organization; **intentionally selecting staff** whose values are aligned with the organization's; **maintaining open and frequent communication** among all staff; and **using data to inform practices and decision making**, including using data from internal and external surveys, having regular quality improvement meetings, and even having a data analyst on staff.

"It's something that's just ingrained in us that we're going to get out and we're going to do stuff. We're not going to be that organization that sits at home with the folks. And we start the interview process with the staff like, 'This is not a job where you are going to sit and be at home."

"We make sure we're out in the community. Our whole emphasis is: first of all, what do people want to do? So we ask them those questions: 'What is it they want to do? What are their dreams? What do they enjoy? What brings them joy?' We ask them those questions when we do their plans every year. And with an emphasis on community inclusion, we want to be out in the community. We don't want folks to be in a sheltered environment or in a sheltered workshop or

something. That's just always been our emphasis; that's just how we work—person first. And that's how we train all of our staff. So, when they come in the door, they know community is very important to us."

"We provide training to our staff to make sure that they understand the connections in their own communities and that the staff are really engaging with people. We try to match people to staff. It's not always perfect, but that's definitely something that we really try to do because if I'm paired with somebody that has the same interests as me, that's going to naturally prompt the activities that we're doing throughout the day. If I really like to exercise and I'm paired with somebody who likes to exercise, the staff is more apt to find exercise groups or community groups that like to get together and go to the gym. "

"The minute we stop trying to feel what the family is going through is when we fail. We've had staff that don't last because they're either burnt out, which we see a lot in this field, or they just don't get it. They went into the wrong kind of social work. … Everything for the family is emotional and visceral and real. We don't get to go home at five o'clock and not worry about the setting. So, to me, the way you provide community-based services, or any services, is to make sure that the participant and their family comes first. … It's all about communication and relationship building. That has to be the foundation."

Related to funding choices, executive staff said the things that facilitated individualized, community-based supports were **finding funding sources** other than Medicaid/Medicare like grants and payback protection loan programs; **fundraising** and getting sponsored from community organizations; and **creative staff funding**, like paying staff for mileage, paying a flat hourly rate across services, and a deliberate effort to increase staff wages.

"If [the person receiving services] doesn't have enough hours, we'll go to bat for them with the MCO. … Somebody's got to go to bat for them and say, 'We need more supported employment hours if this person is going to be successful in the community.'"

"We don't move people to other more intrusive locations just because they have more needs. We try to support them where they are. So, if they are living in their apartment, that's where the supports are going to be provided, regardless what the level of need is. That's what we try to do, and, in some cases, it requires requesting additional funding to be able to do that, and we've been successful in being able to get that."

"Mileage was a big thing. The staff really, really wanted, especially because we were pushing and pushing to get out and do different things. They were like, 'I can't afford to,' especially when gas was super high. They said, 'You're asking me to drive to all these places and do these activities, but I can't afford to do all that, and I have to use my car.' So, when we put mileage in place, that was really helpful and the staff really appreciated that. That was a couple of years in the making to get mileage and we're really happy about that. You can't expect people to drive their own vehicles on the salary that they're making. You can't afford to drive all over Asheville on $13 or $14 an hour."

> *"Because we're nonprofit, we can, of course, get the Medicaid and the state and country funding, but we also fundraise. We have a fundraising department and all of that money really enhances what we can do. So, although we rely mostly on government funding, our fundraising department raised $1 million last year, so that million dollars can go back into enhancing what we do. So, we don't just do government funded services; we have other programs that others might not do because they don't get that extra funding. We're happy to be able to do that and we have a great time doing it! When we have fundraising events, it's a time for all of us to get together and get the community involved."*

Perspectives of Employees of Provider Agencies

Popular employee responses on the Employee Survey reflected some of the same themes shared by executive leaders. Employees of participating service provider organizations were also asked questions about internal facilitators on the Employee Survey, including, "In your experience, which organizational factors help you to provide community-based services?" and given a list of seven common responses, as well as an *"Other"* option where they could write in their own response. The top responses selected by employees were "*clear communication channels*" (67.1%), "*supportive organizational culture*" and "*effective employee training*" (57.1%), and "*effective leadership*" (57.1%) (see Figure 11). Write in responses included: "*more of a sincere passion for those who have disabilities and not just for those who bring in money or financial assets to the company*," "*person-centered planning, empowering direct service staff to make suggestions and provide input regarding support plans*," and "*none of the above*."

Figure 11: Top Ranked Organizational Facilitators to Individualized, Community-Based Services from the Employee Survey

The survey also asked employees, "*Which of the following strategies or initiatives have you participated in at your organization to better support people with high support needs with their community-based services?"* and offered a list of four common responses, as well as an *"Other"* option where they could write in their own response. Most employees responded that "personalized support services" (30.5%) helped facilitate community-based supports best (see

Figure 12). Write in responses included: "*staff meetings that provide valuable information that other staff have learned about persons supporting*," "*weekly meetings with our community-based services to provide information and share ideas*," and "*specialized training one on one with the individual*."

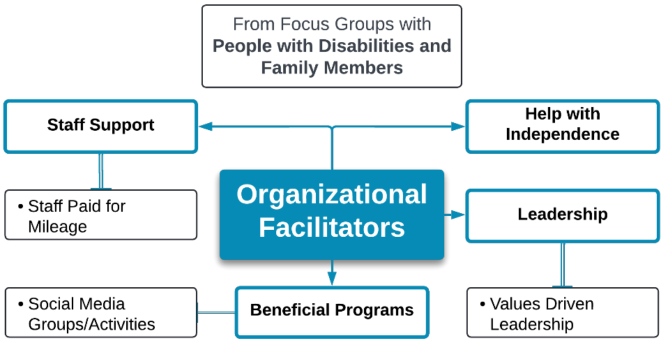
Figure 12: Top Ranked Strategies to Support People with High Support Needs from the Employee Survey

Executive leaders shared that working closely with the MCO to find more extensive services or additional funding and resources when needed and still working to deliver services in the community to match the person's needs and desires is important to delivering inclusive services to people with high support needs.

Perspectives of People Receiving Services and Family Members

People receiving services and/or their family members from each organization were also asked for their perspectives about the organizational facilitators to individualized, community-based services during online focus groups. Their responses were grouped into four main categories: Help with Independence, Leadership, Beneficial Programs, and Staff Support (see Figure 13).

Figure 13: Internal Facilitators to Individualized, Inclusive Services Given by People Receiving Services and Family Members



A few participants spoke positively about their services helping them work toward being more independent. One participant said*, "They try to help me be independent. I'm trying to live on my own one day."* Another participant, the mother of an adult with disabilities, spoke very positively about her son's experience with various programs offered by their provider. *"For two years, [my son] has been taking sing-along classes weekly and he loves it. It's really wonderful. They get together as a group on Zoom and they sing; it's just great. And they talk, it's all kind of social skills. It has been a huge, huge plus for him. There was a cooking class as well, where they do it virtually. And he does yoga classes too, which he really enjoys as a kind of wind down at the end of the day."*

In general, participants discussed services and employees in positive ways. One mother said, *"When [my son] first moved into his house, it was hard because it's pretty far out from Asheville—it's in Fletcher out in the country. The staff didn't get paid for miles, and so they didn't really want to just load him up in a car and take him to the park or take him to the Y. It was really prohibitive from that perspective, but now they're getting paid for mileage, so that's been great! Now it just feels like if there are limitations, I don't know about them."* Another parent said of the employees, *"The people involved at the management level have good hearts and good intentions."*

External Facilitators

Perspectives of Executive Leaders and Employees of Provider Agencies

Executive leaders of the participating organizations were asked questions related to the external facilitators to delivering individualized, community-based services during the interviews, including, *"Can you describe any external (community or societal) things that help your organization provide community-based services?"* Employees of participating service provider organizations were also asked questions about external facilitators on the Employee Survey, including, *"Please briefly describe any factors outside of your organization that have helped you to deliver community-based services."* External facilitators discussed by executive leaders in interviews and by employees on the survey were grouped into five main categories: 1) Leadership, 2) Employees, 3) Community, 4) Family Support, and 5) Organizational Values, Processes, and Practices (see Figure ###). Things that **Leaders** did to help individualized, community-based services reported by executive leaders and employees included: (from executives) engagement with outside organizations, networking and outreach, and (from employees) offering employee support. **Employee** factors included: (from executives) positive reputation building of the organization, (from employees) effective teams, and personal contributions. **Community** factors included: inclusive community and programs, (from executives) sense of belonging and acceptance, and (from employees) **Family Support**. And finally, **Organizational Values** included: (from executives) evaluating performance and satisfaction, sharing performance data, (from employees) organizational values, and training and networking opportunities (see Figure 14).

The Venn Diagram in Figure 14 is a summary of external facilitators discussed in interviews and on the survey. Figure 15 illustrates these external facilitators in greater detail, with themes that were shared in both the interviews with executive leaders and the responses from employees on the survey written down the center of the figure, and concepts shared in the interviews with executive leaders on the lefthand side, and concepts shared in the survey of employees on the righthand side of the figure.

Figure 14: Summary of External Facilitators to Individualized, Inclusive Services Given by Executive Leaders and Employees of Service Providers for People with IDD

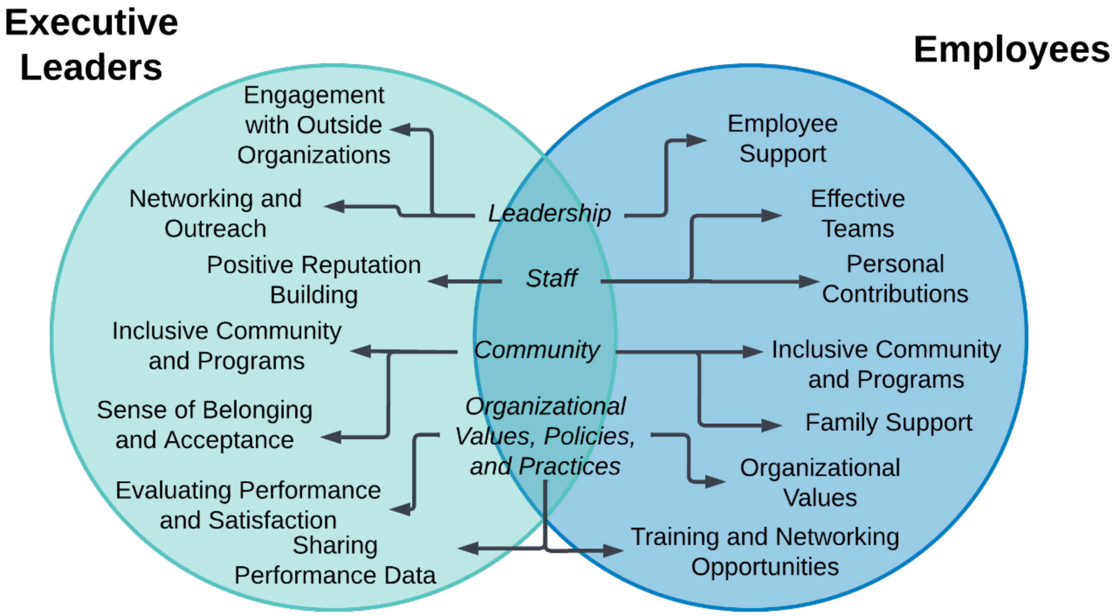
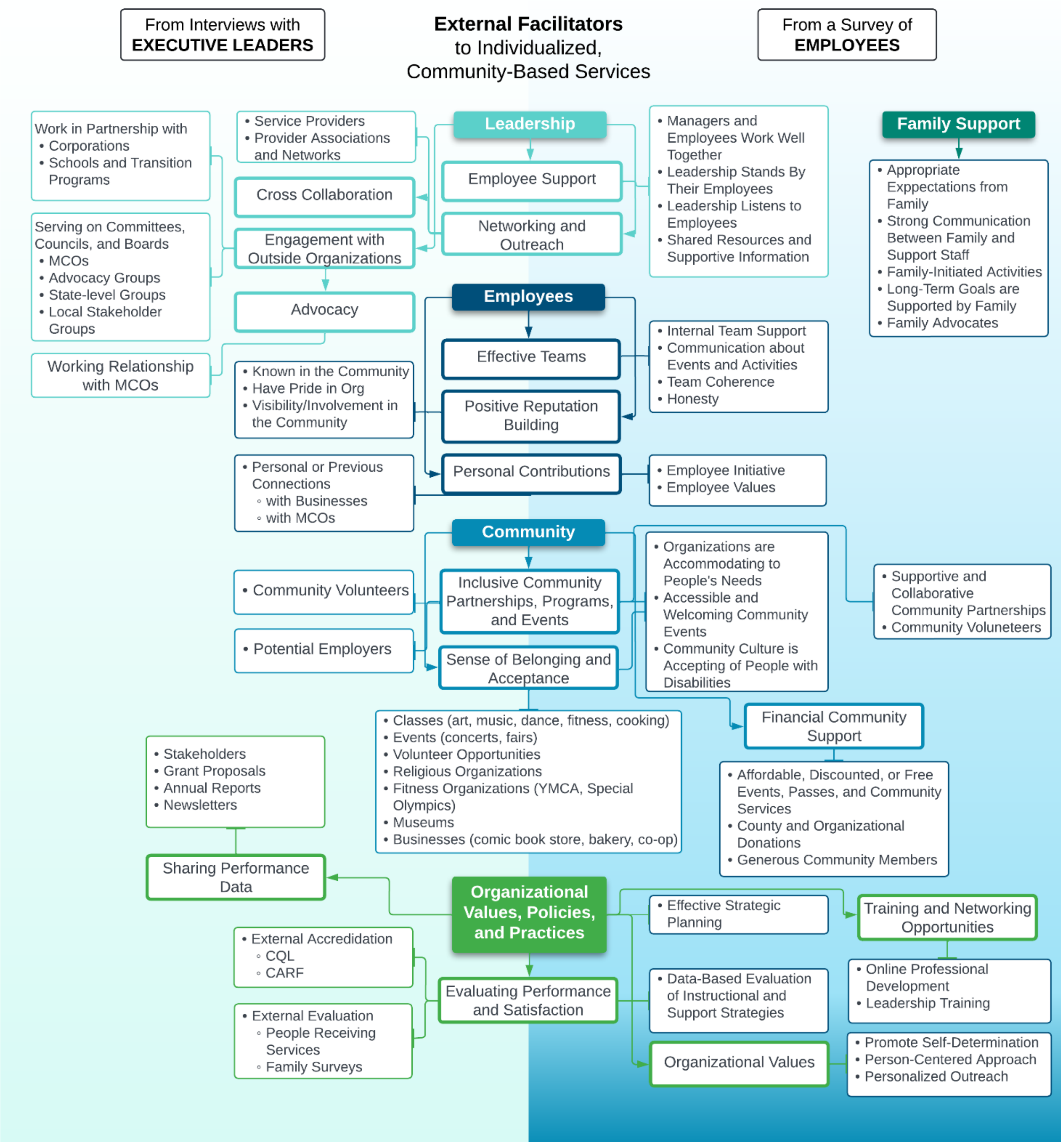


Figure 15: External Facilitators to Individualized, Inclusive Services Given by Executive Leaders and Employees of Service Providers for People with IDD



Related to things that leadership did externally to support individualized, community-based services, executive leaders and employees both discussed **employee support**, like managers and staff working well together, leadership standing by and listening to their employees, and everyone sharing resources and information with each other; and **networking and outreach** with other service providers and provider associations. Executive leaders also discussed their success with **engagement with outside organizations**, such as serving on committees, councils, and boards of MCOs, other stakeholder groups, and working with corporations and schools; **cross collaboration** with other provider and community organizations; and **advocacy** for the people they support through their working relationships with MCOs as helping to facilitate services.

"[Our leadership] serves on boards and even acts as the chair on a lot of different things. It's just so important to be at the table. … We serve in a lot of ways across the state, from the state level to provider groups. That's one of our goals — we always want to be a leader in the field. So, our leadership is on different boards or different decision making kind of groups throughout the state."

"We rely heavily on our managed care organization. I think that we partner well with them in addressing, or at least evaluating, different community-based opportunities out there. I think just having that partnership in that relationship with our managed care organization helps."

"We are very involved in a lot of the local advocacy groups, a lot of the councils and boards of various stakeholder groups that actually focus on involving our folks more and allowing our folks to be more involved in the community in addressing those barriers that are out there."

"We are open to trying new things and trying to figure out a way to make it happen. … We have this one individual who is very independent, she only gets a couple hours of support, and she really wanted to go to this concert that was more than two hours away. … We restructured her program so she could have staff in the evening and she went out to the concert two and a half hours away, stayed out 'til two in the morning, partying with her staff that she wanted to go with and it was the highlight of her month. Rather than saying, 'No you only get staff from 10 to 3,' we said 'Why can't we do that kind of stuff? What can't we be flexible in our scheduling and help with those kind of things and try to figure out how to make it happen?'"

Employee factors shared by executive leaders and employees included: **effective teams** that communicate about events and activities, are honest and support each other, and are cohesive overall; **positive reputation building** by making themselves known in the community, speak with pride about being a part of the organization, and being visible and involved in the community; and **personal contributions of employees** when they uphold the values of the organization and take initiative to be involved in the community.

"We've got a good reputation. I think it helps us get enhanced rates from [the MCO]. We also get a lot of referrals from staff — a lot of staff refer their friends and family to come work with us. … And I think for the most part the staff are really happy and they're promoting us out in the

community saying they're proud to say, 'I work for [our organization].' And we get a lot of feedback as well from community members that know our folks. They'll call and they'll talk to [leadership] and be like, 'Oh I saw [someone who receives your services] out today and he was so happy! He was doing this…' or 'Oh, I saw so and so and they were having a great time and their staff was amazing,' that kind of thing."

Things mentioned by executive leaders and employees that involved the community to help promote inclusive, community-based services included: **inclusive community partnerships, programs, and events** such as relationships with community volunteers and potential employers, and classes, events, museums and businesses that are welcoming and offer opportunities and relationships to people with disabilities; and a **sense of belonging and acceptance** at places in the community that are accommodating and accessible to people's needs and accepting of people with disabilities. Employees also mentioned **financial community support** was helpful, such as when there were affordable, discounted, or free events, passes, community services, and time and monetary donations from people in the community.

"We're all involved in the community. We always try to think, 'What would this person be doing if they didn't have a disability?' So, we always go there first. Instead of trying to create isolated things or doing typical things, we think about what non-disabled peers are doing instead of what a person with disabilities would be doing. That puts us out there more."

"We do a lot of community-based classes—that's really what our whole mission is, to be out in the community. So we partner with organizations to have classes for our folks."

"We're in this season where a lot of schools are doing transition fairs for a lot of their folks that are graduating, so we like to try and go out and be a part of that and to talk to people about, at least from our perspective, what some of the options are. We are partnering with a special needs group. They do these regular meetings with families on educational opportunities, and they've asked us to come alongside them and do this just to talk about [our organization] and service options. So, I think all those things that we're able to do to be a part of different groups and fairs and conferences, I think that helps connect us. … If I do that and my team and staff does that, that just helps to build our community resources."

"We have quite a few different relationships with different places that our folks go to a lot. So, not only the Y, but like there's a comic book store here that our folks love. They're super awesome. When you walk in the door, they've developed a whole little community there."

Regarding external organizational values, policies, and practices that were helpful, executives and employees talked about the importance of **evaluating performance and satisfaction**, such as with external accreditation programs and external evaluations from people receiving services and their families, as well as data-based evaluation of instructional and support strategies delivered. Executives also spoke about how **sharing their performance data** with stakeholders in annual reports, newsletters, and grant proposals, as well as using data to build effective strategic plans, was useful. Employees also thought that **training and networking opportunities**, such as online professional development and leadership training, and **organizational values** centered around self-determination, person-centered approaches, and personalized outreach helped to advance individualized, community-based services

"We do an annual satisfaction survey. We're also using Personal Outcomes Measures. We have one person on staff who's certified to be an interviewer, so we collect data through that mechanism. … we also use the National Core Indicators individual questions. We collect feedback during their annual review; we ask them questions about how they liked their services, what's important and what's not important. And then, of course, we have a complaint process."

"We take [data collected from people receiving services] and put it into our next quality assurance goals for the next year. We try to track and attain those goals."

"When we get survey data, our performance improvement team kind of manages that and they will send it over to leadership. … We get to our teams and say, 'Okay, here are our results. Do we have anything that's under the threshold of where we want to be? How can we impact that?' Sometimes the impact is us pulling together a focus group of families and/or staff, whatever the situation is, to see how we can improve this. If necessary, we create goals when we do annual planning."

"We put [data collected] into a rather complex dashboard that we have. We actually have a data analyst on staff. She takes data and puts it into a way that everyone can understand and that is sent out to all of our staff. We share some of that information with [the people we support] in more of an informal way. When we have parent meetings, we share that information with them as well. And it's posted online. We have a SharePoint portal for all the staff so people can look at it. It's reviewed by our quality team, it's reviewed by our leadership, and it's reviewed by our board. Our individuals have access to our SharePoint portal too."

Finally, employees mentioned family support, such as **families having appropriate expectations**, **strong communication between families and support professionals**, **family-initiated activities**, and **family members advocating** for their loved ones supported by individualized, community-based services.

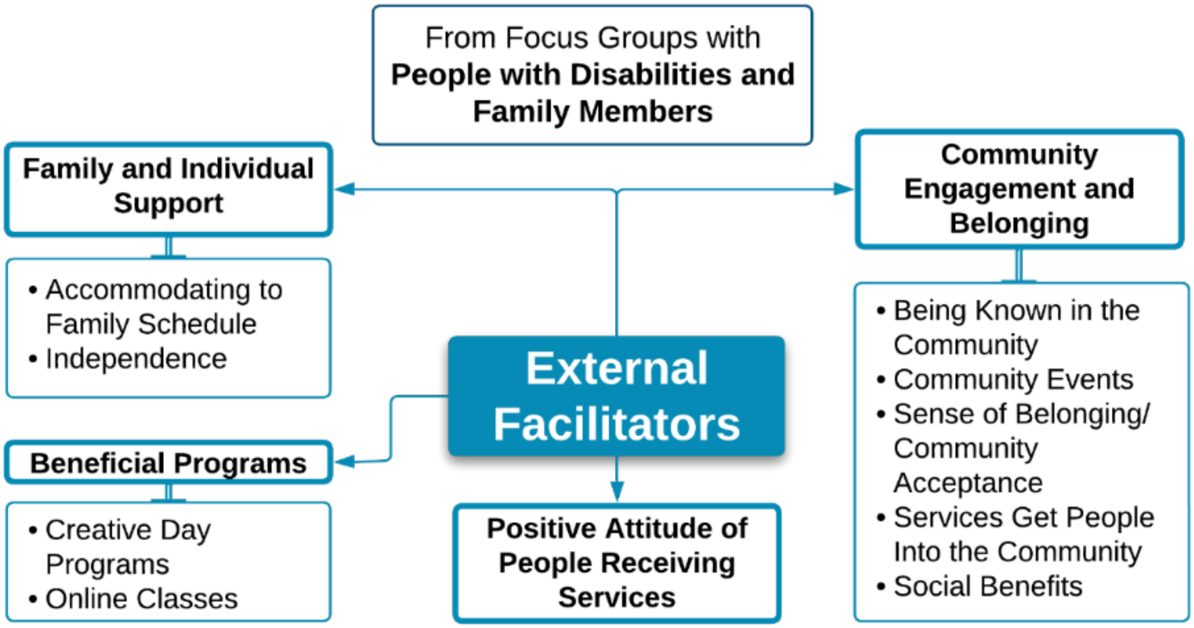
"If something's not right, I'll hear about it from the individual before the staff reach out. They have our phone numbers and we'll text or call because we're in the houses with the person so much. We'll say, 'Oh, how's it going with so and so?' or they will ask questions. They can provide feedback how they want. We have one lady who struggles with feedback and is really working on it. So one of her goals is that every day when staff leave, they say, "How did the day go?' and then that opens it up for her to give feedback to the staff and give direction on what worked and what didn't work."

Perspectives of People Receiving Services and Family Members

People receiving services and/or their family members from each organization were also asked for their perspectives about the external facilitators to individualized, community-based services during online focus groups. Their responses were grouped into four main categories: 1) Community Engagement and Belonging, 2) Positive Attitude of People Receiving Services, 3) Beneficial Programs, and 4) Family and Individual Support (see Figure 16).

Many people receiving services and their families mentioned community programs that stemmed from local churches, universities, parks and rec departments, and businesses that were positive experiences for them and their loved ones. *"I like going out in the community with my friends. I like meeting up places and hanging out and enjoying whatever we do. We go to the Y, the coffee shop, and other places and things like that,"* said one person receiving services. Another family talked about going to university sporting events: *"We live five minutes from a university and [my son] loves going to the men's basketball games. He gets a season ticket every year and goes. He only missed one game this year because we took him to the beach, and luckily we found it on ESPN Plus, and he was able to watch it while at the beach. … It's been really great for him because the seats they have are in the same place every time, and so you get to know the people around you, the other season pass holders. So everyone says, 'Hi' and recognizes us if we don't know them already, so that's been really nice."* Another person receiving services was proud to talk about his belonging to the Cape Verde College Jazz Band.

Figure 16: External Facilitators to Individualized, Inclusive Services Given by People Receiving Services and Family Members


From Focus Groups with **People with Disabilities and Family Members**

External Facilitators

Family and Individual Support
- Accommodating to Family Schedule
- Independence

Beneficial Programs
- Creative Day Programs
- Online Classes

Positive Attitude of People Receiving Services

Community Engagement and Belonging
- Being Known in the Community
- Community Events
- Sense of Belonging/ Community Acceptance
- Services Get People Into the Community
- Social Benefits

Many participants mentioned that their community YMCAs, libraries, recreational centers, and churches provide beneficial inclusive programs. One parent also spoke about the benefits of living in a small town when it comes to feeling included: *“Living in a rural area, small town has been great. I mean, so many people know him. I go places, and people are telling me stories. He loves our library and volunteers there. If I’m in the library by myself, all the librarians are always telling me stories about his volunteer day on Mondays and the things he said to them or the interactions they had, so that’s awesome.”*

Parents argued that even programs that were more geared toward people with disabilities offered many opportunities to be inclusive in the community. One parent said, *“Special Olympics has been great. His QP once said to me that Special Olympics doesn’t count for community networking because it’s not inclusive, but it’s totally inclusive. He’s in golf, and he goes to the golf course, and all these golfers come and chat with him and help him. And there are community partners that volunteer. And he goes in the pro shop and buys a snack, and chit chats with the person behind the counter. It’s totally community inclusive, but it happens to be Special Olympics golf.”*

All of the programs mentioned by people receiving services and their families helped people with disabilities be engaged and feel a sense of belonging in their communities, offering social benefits and opportunities to build independence. Positive attitudes of people receiving services and shared interests can also help people make connections and build relationships. One mother said, *“[My son] is a real friendly, happy kind of guy. He’s really charming and funny and cute and engaging and people are taken by that. … I always felt grateful for the fact that people who like working with people with disabilities really love [my son] because he is charming. I mean, he’s hard at times too, but he’s definitely got a lot going for him that he engages people.”* A participant receiving services shared a recent experience in the community: *“A few weeks ago I helped with the garden at the church. I kind of enjoyed that because myself, personally, I like to grow things in the garden. Sometimes, it feels like you know what you’re doing. My father taught me everything that I need to know. So [I said] ‘Tell me a little bit, and I know what to do to help you guys with the garden.’ So, they kind of bonded with me, and I bonded with them. They said, ‘Well, we hope to see you again!’”*

Model Organizations

Commonalities Among Organizations Providing Community Living Services

The five organizations participating in this case study submitted organizational files for a document analysis, where documents were compared to each other to look for commonalities and outstanding or exemplary elements. Because there are no established best practices or mandatory elements for organizational files in the disability field, common elements found through comparative analysis is the best way to find what organizations that are successfully providing individualized, community-based supports have in common and consider those elements as a starting standard for what should be included in the organizational files.

Also of note, while some elements may be considered exemplary on paper, there is no guarantee that these organizations are following these guidelines in their practices. However, research has found that organizations that have paperwork that supports and reinforces individualized, community-based principles in their policies are more likely to have them in practice than organizations that do not (Bailey & Gilden, 2018).

The chart below highlights the commonalities that were found in the paperwork reviewed from the five participating organizations (see Figure 17). Fifteen key sources of information were reviewed:

1. Vision Statement
2. Mission Statement
3. Organizational Philosophies
4. Strategic Planning Goals
5. Organizational Chart
6. Board of Directors Bylaws
7. Organizational Policies
8. Job Descriptions
9. Pay Scale Information
10. Onboarding Materials
11. Performance Review
12. Employee Handbook
13. Internal Evaluations
14. External Evaluations
15. Marketing Materials

In the chart, commonalities among all organizations and unique exemplary elements from specific organizations are listed for each source.

Figure 17: Commonalities and Unique Exemplary Elements of Model Provider Organizations

	Commonalities	**Unique Exemplary Elements**
Vision Statement	Key Words: empower/empowered/ empowering, active, involved, meaningful, goals, aspirations, dreams, inclusive/fully included, accessible, thrives, "achieve unique potential," "less limited"	Org A: Uses action words like "active" and "involved" where the person is doing an action Orgs D & E: Describe a world or community where people are included or can reach potential
	Referring to a vision for everyone- use words like "people" "everyone", "person" instead of "person with a disability"	
Mission Statement	Key Words: communities, support, advocacy, empower	Org B: Highlights "specialized knowledge and perseverance to navigate complex systems and find unique solutions." Org D: Focuses on providing hope in addition to quality of lives described in others
	Most organizations share common missions of supporting people with disabilities and promoting community integration in various ways	
	Advocacy, education, and community are central themes, ensuring people with disabilities and their families are informed and included	
	All have a multi-faceted approach (e.g., information, education, support, and advocacy; housing, employment, community services)	
	All have unique elements highlighting specific approaches, such as "specialized knowledge," "leadership in innovation," a focus on personal "dreams and goals," and a broader scope of service areas.	
Philosophies	Key Words: autonomy, inclusion, empowerment, diversity, respect, self-determination, supporting families, choice	Org A: Technology First approach that encourages the inclusion of technology as a natural support for people with disabilities. Operationalized philosophy in specific details, examples, and actions (how people and families are educated, where support is offered, opportunities provided, etc.) Org B: Full inclusion through comprehensive support for families and extensive advocacy Org C: Focuses on role in contributing to the community and establishing a proactive voice in the community Org D: Strong emphasis in ethics and innovation in services. Emphasis on data-driven leadership to encourage innovation
	All statements carry a transformative and normative message. Organizations reflect the need to expand services and follow organizational principles to ensure full participation and integration	
	All statements focus on respect and supporting people with disabilities to live meaningful lives in some way	

		Org E: Explicitly states concepts like “Recognize Disabilities, Emphasize Abilities” and “Cultivate Belonging” in their philosophies
Strategic Planning	Mix of internal and external goals focused on improving staff experience, engagement, and interpersonal relationships, customer experience, and community connections	Org C: Strategic pillars that guide organizational goals. Showed their process toward goals, activities, and timelines in a SWOT analysis Orgs C & E: Strategic plans were specific and actionable. Most plans included goals, tasks, timelines, and the person responsible
Organizational Chart	Directors on average were directly connected to about 6 programs or people next on the chart, but those programs/roles varied (HR, program supervisors/directors, billing/financial officers, compliance, technology, compliance, etc.)	Orgs B & C: Have their Board on their organizational charts Org B: “Persons and Families Supported” in the middle of a circular design that suggests that all positions and programs work or communicate together Org E: “Participants and Families” at the top of a hierarchical design and used an ‘upside down’ model that has the executive leadership of the org on the bottom of the chart
	Orgs A, D, and E include only people/roles in chart, while Orgs B and C include roles and programs	
	3 Orgs do not include people supported in their organizational charts; those that do include people supported also include families in the same space	
Policies	The area of focus for organizational policies ranged, including standards for boards of directors, organizational operations, and organizational staff. These documents are mostly performance and organizational procedure guides	Org A: Implemented a “Professional Behaviors & Boundaries (Respect to Person’s Supported)” policy that stresses an employee’s obligation to respect people's autonomy and self-determination, as well as diversity within people served and with employees. Includes policies about responsibility to mission of the organization, the need to maintain a diverse and representative board of directors, and the inclusion of a cultural competency and diversity plan Org B: Includes an “Open Door Communication” policy between employees Org C: “Corporate Compliance Plan” that enforces a code of ethical behavior within all employees and board members. It also has policies specifically related to “Quality of Care” by enforcing “Customers’ Rights” and abiding by the “Person Centered Plan" Org D: “Selection of Personal Staff” policy outlines that the people supported have the power to choose their own staff. Policies
	Some organizations have very structured and detailed policy documents and manuals	
	Several agencies included references to equal opportunity employment and in-depth expectations for respect for diverse identities and cultures of employees and people using supports.	

		related to the dignity and respect of people served are included, as well as a protective “Whistleblower Policy” to aid in appropriate treatment of staff and people supported. References ADA and accommodations policies for employees Org E: Includes an exhaustive set of specific policies related to the treatment, support, and human rights of people with disabilities (such as a right to dignity, privacy, and freedom from mental and physical abuse and exploitation, the right to self-determination, and the right to fair and equal treatment)
Board of Directors Bylaws	Bylaws contained legal information about background checks, no financial benefit, conflict of interest, no relation to executives, as well as roles and responsibilities of board members, operating budget, exit/removal procedures	Org B: Has strict qualifications for board members — must be a parent of a person with disabilities (age 26 and younger), person with disability, or person certified to work in special education, related services, or early intervention Org B & C: Reserve a percentage of positions on their boards for people with disabilities and/or family members Org D: References inclusive legislation that board members and meetings are expected to adhere to: ADA, NC Open Meetings Act, HIPAA Privacy and security rules and regulations, etc. E: Board must have at least one person with IDD (out of 13-15 board members) on board
	Most organizations included information about board composition, terms, and length/ limits, roles, and responsibilities and expectations of board members	
Job Descriptions	All organizations have jobs descriptions that mention the provision of services and support following a person-centered approach	Org A: Leadership position descriptions include a necessary level of knowledge and understanding of the principles of Servant Leadership. Hiring advertisements for DSP position emphasize person centered traits and professional development opportunities Org B: Describes the DSP role as supporting people to live a self-directed life, including securing and maintaining employment and involvement in the community and living in housing of their choice
	All organizations include general descriptions of duties, qualifications, requirements, and expectations.	
	Many job descriptions listed person centeredness, community integration, and prioritizing the rights of people with disabilities as core job responsibilities	

Pay Scale	$15-$17.50 per hour starting pay rate for DSP or $20-$22 (sleepover DSP at Org D); starting pay for executive directors/chief $75,000-$85,000 *Orgs A and B submitted limited pay scale information	Org D & E: Listed “Entry level salary” and “Salary cap,” giving the salary range instead of just the starting salary
Onboarding	Orientation includes information about the organization, context of work within the larger disability system and legislation/ regulations, overview of services, overview of benefits, resources, and policies, requirements for the job, needed training, role, and expectations	Org A: Includes Management Philosophy, and Administrative Policy and Procedures related to participatory management to create a diverse and welcoming workplace. Community inclusion is central in all documents as a pillar of the organization Org B: Onboarding presentation includes a list of person-centered resources to operationalize person centered supports Org D: All employees at all levels have orientation about Client Rights (including an Abuse, Neglect & Exploitation Attestation that requires an employee signature) and Individuals Rights training Org E: Comprehensive orientation emphasizes specific principles of inclusion such as Courtesy, Patience, and Dignity
	All organizations mention principles of inclusion and participation. Most organizations highlight the rights of people with disabilities. Some organizations include a “Code of Ethics”	
	Some organizations include materials and standards about cultural diversity and inclusion, equity and respect, ethics expectations, and the rights of people with disabilities	
Performance Review	All organizations have a robust and pre-set performance review plan, most include descriptions of strengths, areas for development, and plans and goals for the future	Org B: Includes an Annual Supervision Plan that assesses the employee’s development and knowledge related to inclusive services, rights, community inclusion, and cultural competency. Org C: Employees are asked to explain the alignment of their performance goals for the coming year with the Strategic, CQL, and QIT plans Org E: Frontline employees are assessed on if the employee “is learning to promote development and maintenance of other natural supports & community involvement for the participant”
	Most organizations focus on evaluating employee’s adherence to person centered practices that include community inclusion and participation	

Employee Handbook	Includes information related to code of conduct and expectations for employees. There was a range of depth of information included in each handbook, some included information about benefits, mileage, positions, performance appraisals, workplace expectations, organizational charts, resources, policies, and overarching organizational approaches. Documents ranged from 21 to 59 pages long	Org B: Includes a “Personal Beliefs and Partisan Political Activity” section that outlines appropriate and inappropriate activities for the workplace or use of work resources. Org B is very transparent about information security and confidentiality, appropriate use of organizational technology, and intellectual property rights Org C: Includes an overview of CQL’s Personal Outcome Measures (accreditation standards) and social media and internet activity procedures/expectations. Format varies, using outlines and FAQs, and lots of white space Org D: Included many unique sections, including “How to Use this Handbook,” “Wellness and Mental Health Days,” and “School Visitation Leave,” “Policies Related to People We Support” including “Inappropriate Behavior by the People We Support,” “Mistreatment of People We Support,” and “Reporting of Reasonable Suspicion/ Knowledge of a Crime Against a Person Supported”; “Policies Relating to the Use of Technology” including cellular phone use while driving and working, permission to record or livestreaming, and use of internet, email, voicemail, and social media related to their job; “Personal Beliefs” limitations and expectations Org E: Includes a “Complaints and Suggestions” section outlining procedures for employees to file complaints or suggestions to HR
Internal Evaluation	All employee surveys ask about a mix of topics such as satisfaction with organizational processes, pay, job responsibilities, support, access to needed resources, quality of services, relationships with coworkers, supervisors, and leadership team, climate and culture, etc. to understand employee experience, engagement, and contribution to their organization. Employee surveys range from 8-67 questions, including 0-16 open response questions Questions across surveys of all organizations asked about hard topics, like employee satisfaction with pay, areas of improvement	Org A: Asked employees to rate their experience over time to determine how people feel about the direction that the organization is going Org D: Asked questions about support for identifying and reporting issues when they arise Org E: Asked for recommendations on future training topics and “What can we do to make sure you remain a part of [our team]?”

	for the organization, if employees felt valued, and employee satisfaction with leadership *Org B did not submit internal evaluation information	They also assessed perspectives of employees about the quality of services provided
External Evaluation	Organizations that submitted external surveys focused on customer experiences with staff, services, choice, overall satisfaction with life, and their participation in the community. Some agencies also asked about parent/ family experiences to confirm results and impact of the organization on others' lives	Org C: Uses CQL's Personal Outcome Measures to evaluate the experience of people receiving supports Org E: The external evaluation asks if people have had all the support, they need to be more involved in their community. There is an external parent survey that asks about natural relationships and supports in the community
	Some organizations offered incentives for completing surveys *Orgs A and B did not submit external evaluation tools or results	
Marketing Materials	All marketing materials highlight the principles of person centeredness and values of the organizations	Org C & D: Have videos from the CEOs highlighting the community inclusion programs that encourage community involvement, personal growth, and natural supports, and a focus on self-determination, autonomy, and participation Org E: Comprehensive marketing strategy that targets advertisement of services, employee recruitment, and social media dissemination. Materials are developed following principles of inclusion and participation
	Organizations advertise their services in a variety of ways and strategies (e.g., on their websites, videos, social media, brochures, etc.), all related to conveying their efforts for community inclusion	

Limitations and Areas for Improvement for Organizational Paperwork

While there is no current “correct” or “standard” to determine “right” or “wrong” elements of organizational paperwork, some things were identified within various organizational documents that were not aligned with current trends in the field, evidence-based best practices in promoting self-determination, choice, and control for people with disabilities, and research in leading an engaged workforce, including:

Strategic Plan Goals: Most organizations did not have strategic planning goals ready to submit; strategic planning is a critical aspect of organizational growth and responsiveness. Strategic plans ensure that organizations have direction and vision for the future. Documenting and developing written strategic plans is also critical to ensure transparent decision making, and to enable employees and stakeholders to contribute to goals in meaningful ways. Ideally, each organization would have had future plans and goals written down so they can be readily shared among staff and with interested stakeholders on websites or in annual reports.

Board of Directors: Some organizations did not specify board composition or term length and limits of board members in their materials or bylaws; effective organizational governance requires that boards of directors have clear standards and expectations for board members to ensure healthy rotations. Further, disability sector organizations benefit from having people with lived experience, including people with disabilities and families in formal positions on their boards. Holding positions specifically for people with lived experience ensures that organizations are governed by people who are most impacted by their work.

Organizational Policies: Some organizations have very structured policies, documents, and manuals but do not include language related to their mission, values, or practices of community inclusion; previous studies have shown that including mission and value-driven language in all documents increases the likelihood of achieving those values.

Job Descriptions: Some job descriptions required physical abilities such as driving, lifting up to 50 pounds, hearing, standing, walking, climbing stairs, etc., which excludes many people with disabilities as candidates. Effective practices for organizations committed to hiring people with disabilities include reviewing job descriptions and considering accommodations that can be made or unnecessary requirements that can be removed to ensure inclusiveness in recruitment and hiring efforts.

Pay Scale Information: Some organizations did not have pay scale information to readily share; transparency in salary decisions and pay scale by position promotes objective and fair wages for employees.

Onboarding Materials: Some organizations do not mention person-centered, community-based, or inclusive philosophy, approach, or practices in onboarding paperwork. Best practices in onboarding include realistic job descriptions, clear expectations, and practices that exemplify the values of an organization.

Performance Review: Some organizations had no specific metrics related to community inclusion or participation in their performance reviews; to ensure that inclusion is a core component of roles and expectations related to the successful delivery of community-based services, performance standards and review processes should address inclusion.

Internal Evaluation: Some organizations did not include any open response questions on their surveys of employees; including open response questions in internal surveys allows employees to give specific details about their perspectives.

External Evaluation: Survey lengths and types varied greatly, with some surveys being very long and some being short and in plain language; best practice in survey design and stakeholder engagement indicates that organizations should use survey styles that match the purpose and audience of the survey. For external surveys of people with disabilities, families, and other community stakeholders, shorter, plain language surveys are more effective.

Unique Approaches by Model Organizations

The organizations that participated in this study were similar in that they all deliver at least some inclusive, community-based services, but they also have unique approaches to service delivery[1], including:

Partnering with large companies for discounts, donations, and fundraising: One organization partners with a large corporation to inexpensively rent space for its programs, which enables it to give scholarships with the money they save on rent. Another organization receives donations from community businesses in order to improve supports beyond what state and federal funding will cover.

Using technology to assist with service delivery: One organization uses technology to help monitor vitals and other health-related diagnostics from afar to help the people they support live more independently while still getting support when needed. Another organization is working toward remotely monitoring people receiving their services overnight instead of having a sleeping staff member with them. Another organization consults with national technology and independent living experts to prepare accommodations for the people they support.

Encouraging frontline management to be very involved: One organization has QPs that know as much as DSPs about the people they support and are very active in decision making on the ground level, which helps maintain quality services and constant communication between employees and family members.

Encouraging positive mental health for employees: One organization has a mental health therapist available to them to help manage the role of caregiving.

---

[1] This section names some unique approaches, but these approaches are not necessarily best practices.

Offering extra programs: One organization offers programs beyond what is publicly funded, such as cooking and exercise classes. Another organization partners with a pottery studio for classes and has a puppeteering group that creates a puppet show to perform in preschools to spread awareness about disabilities.

Integrating day programs into the community: one organization supports several people to volunteer in their communities, including Meals on Wheels and helping set up a community garden, where they interact with other community members.

Recommendations for Improvement

Employees, people receiving services, and the families of people receiving services shared many recommendations for improvement based on their experiences with the participating provider agencies. Employees gave feedback and perspectives on the OPPI and the Employee Survey and people receiving services and their families shared their recommendations during focus groups.

Perspectives of Employees

The Organizational Priorities and Practices Inventory (OPPI) is a tool designed to assess best practices in disability service agencies. The survey instrument holistically measures how organizations prioritize and implement evidence-based practices in order to promote efficiency and effectiveness and also positions the rights of people with IDD as a critical goal of organizational success.

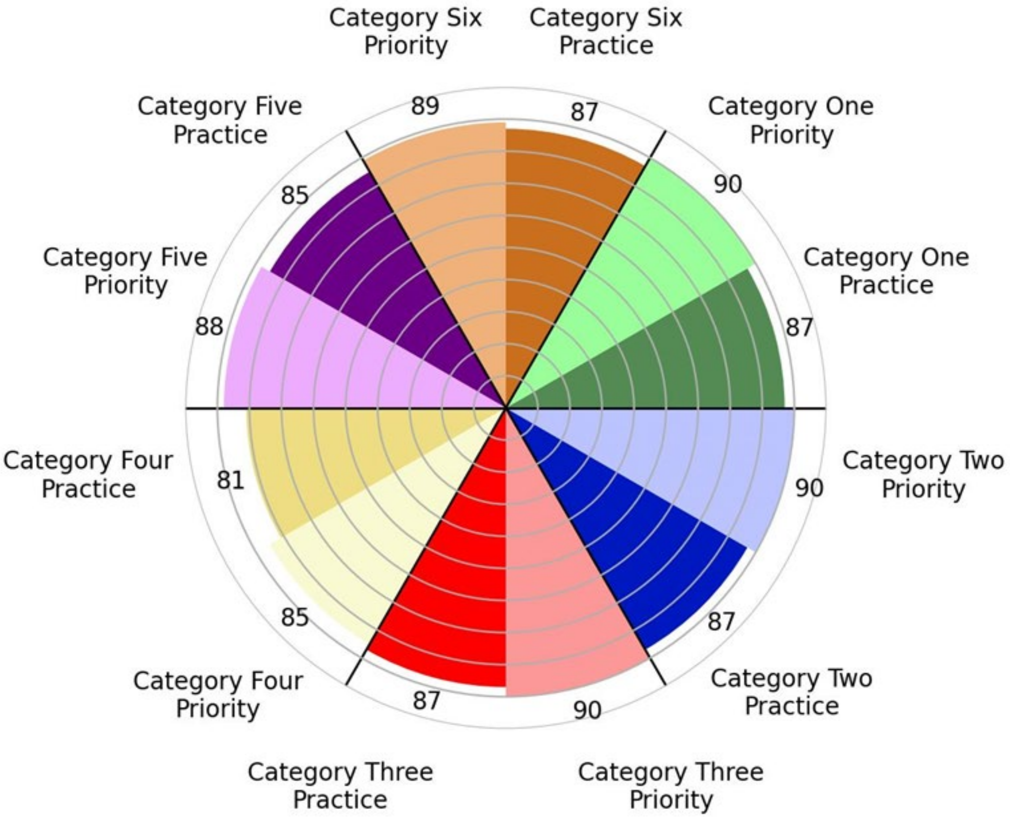
The OPPI was distributed to the five organizations participating in this study. In total 86 responses were collected. The table below shows the distribution of responses for each organization:

Organization	n	%
A	7	8.1%
B	11	12.8%
C	22	25.6%
D	25	29.1%
E	21	24.4%
Total	86	100.0%

The organizations participating in this study demonstrated a solid commitment to best practices related to human rights principles and effective organizational performance and management. Participants indicated high levels of both priority and practice across the six categories of effective practices of disability sector organizations (see Figure 18). In the domains of *Autonomy, Decision-Making, and Control for People with Disabilities*, *Community Living and Engagement for People with Disabilities*, and *Stakeholder Input into Management and Governance*, the average priorities were consistently high at 90%, with practices following closely at an average of 87%. Such alignment between the three categories shows that employees at these organizations highly prioritize human rights and quality of life principles, including the focus of this study, community inclusion, and participation. The small differences between priorities and practices indicate that organizations acknowledge current gaps between values and practices and, likely, strive for further alignment and implementation to strengthen quality of life of people with disabilities.

Figure 18: Summary of Participating Organization's OPPI Scores by Category

Category One	Autonomy, Decision Making, and Control for People with Disabilities	Priority	🟩
		Practice	🟩
Category Two	Community Living, Employment, and Engagement	Priority	🟦
		Practice	🟦
Category Three	Organizational Management and Governance	Priority	🟥
		Practice	🟥
Category Four	Staff Participation, Value, Impact, and Support	Priority	🟨
		Practice	🟨
Category Five	Leadership Strength and Development	Priority	🟪
		Practice	🟪
Category Six	Diversity, Equity, and Inclusion	Priority	🟧
		Practice	🟧



The category of *Staff participation, value, impact, and support* showed the most substantial gap between the average priority of 85% and the average practice of 81%. This gap, despite being small, was noticeable and indicated that while organizations acknowledge the importance of this area, there are still challenges in translating this priority into daily practices. The differences between priority and practice were similar in the *Leadership Strength* and *Skill Development* categories, as well as in the principles of *Diversity, Equity, and Inclusion (DEI)*. *Leadership Development* had an average priority of 88% and an average practice of 85%, while the *DEI* category had a slightly higher average priority of 89% and an average practice of 87%. Such high scores indicate a strong organizational focus in these areas.

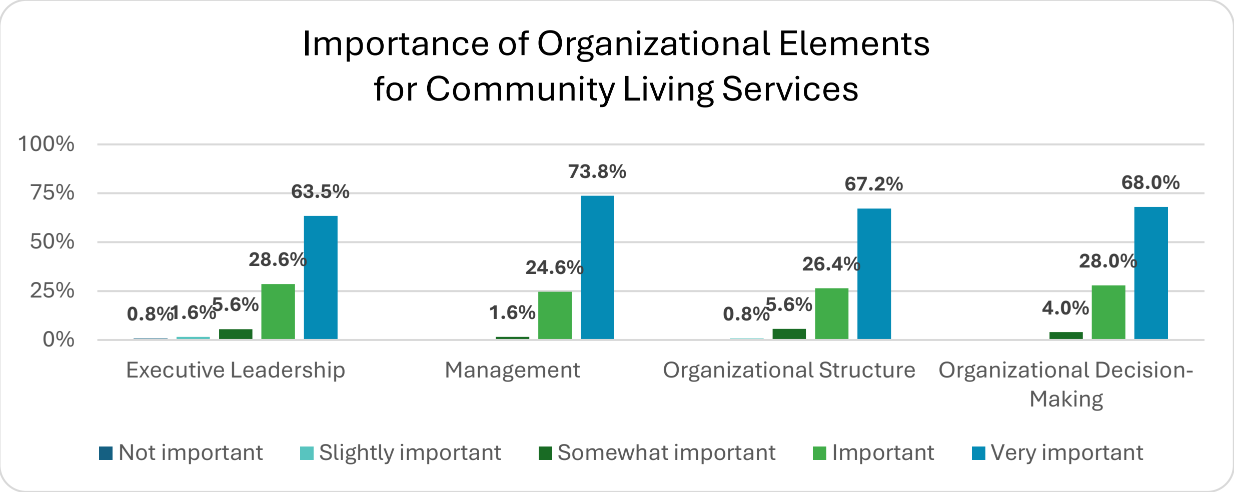
The organizations involved in this study outperformed in all areas compared to the average results of all other participants who have previously taken the OPPI, demonstrating their commitment to excellence. For instance, regarding principles of *Autonomy* and *Community living*, the participating North Carolina agencies' average priority rating was 4% higher, and the average practice rating was 10% higher than the national average. Also, in *Stakeholder Input*, the scores of the organizations in this study were 6% higher in priority and 9% higher in practice than the national averages. Moreover, these organizations more considerably prioritized staff participation principles, with a 14% higher average than the national data, while the practice score was only 2% higher. This highlights a potential area for further enhancement. However, the gap between priorities and practices for this category is remarkably closer (4%) than for the national data (8%), showing a promising path for improvement.

Building on the success of the North Carolina organizations in this study, there are areas that can be further improved. By narrowing the gaps between priorities and practices, particularly in the areas of *Staff Participation*, *Value*, *Impact*, and *Support*, these organizations can continue to set the standard for excellence. Introducing regular feedback mechanisms and recognition programs and providing more opportunities for professional growth can enhance staff value and support. Addressing these areas of improvement could help North Carolina's organizations inspire change and continue to lead in promoting human rights and achieving effective organizational performance that leads to community inclusion and participation.

Employee Survey

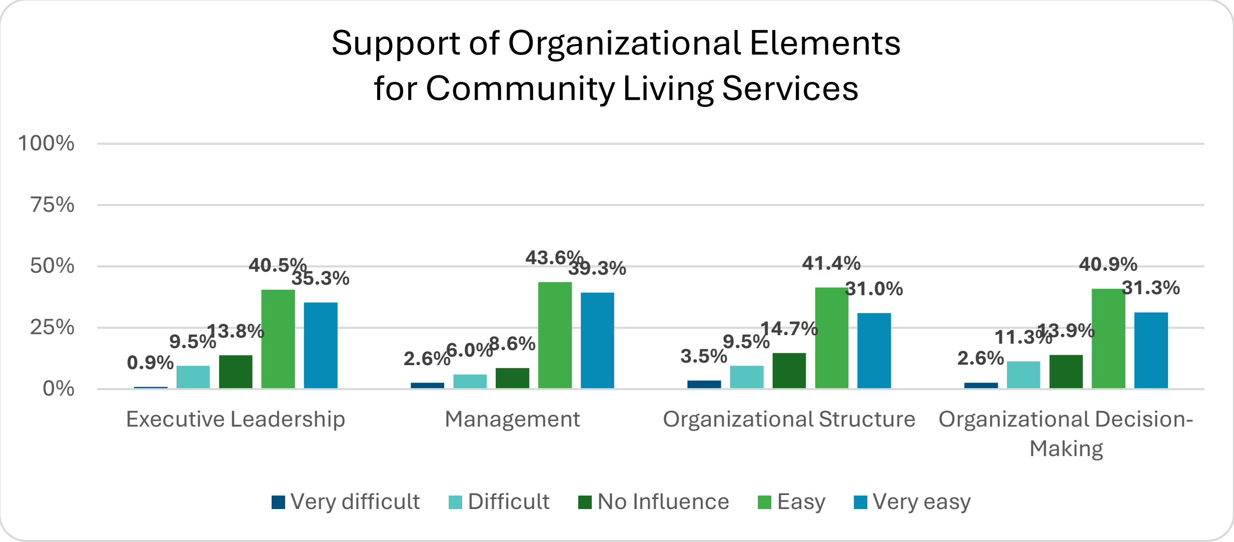
Employees of participating organizations were surveyed about their experiences with and perspectives about their organizations and the services they provide, including how different elements of their organization contribute to individual, community-based supports. In the survey, the employees were asked, *"How important are the following to your organization's delivery of successfully community-based services? Executive leadership; Management; Organizational Structure; Organization Decision-Making Processes"* and asked to rate their impact on a scale of "*Not Important*" to "*Very Important*." Most employees rated all of these elements as “*Very Important*,” with “*Management*” being rated higher than the rest (73.8%) (see Figure 19).

Figure 19: Importance of Organizational Elements for Community Living Services from the Employee Survey



Employees were also asked to, “Please rate how easy the following people or processes in your organization make the delivery of successful community-based services: Executive Leadership; Management; Organizational Structure; Organization Decision-Making Processes” on a scale from “Very Difficult” to “Very Easy.” Most employees rated all of these elements as “Easy,” with management getting rated at “Very Easy” (39.3%) and “Easy” (43.6%) the most (see Figure 20).

Figure 20: Support of Organizational Elements for Community Living Services from the Employee Survey



Employees were also asked a final open-ended question on the Employee Survey, "*Is there any other information or aspect of your organization related to community-based services that you would like to highlight or provide additional context about?*" Here are their final thoughts about how to best support individualized, community-based supports:

"I would like to add that taking the clients out into the community not only allows them to be included, this very needed support also allows our clients the chance to meet new friends as they visit different places that peak THEIR interests."

"Someone needs to take a hard look at those at the top who are stepping over a $5 bill to pick up a penny."

"I think the fact that employees receive mileage reimbursement really makes it more accessible for staff to go many places to support our individuals. I also think the regular team communication we have around available events is very supportive."

"[My organization does] a great job at communicating what events are happening in the community and allowing clients to choose which events they want to participate in."

"Community-based is important to our population. However, we find some prefer to live and socialize with their peers, which may be more group or facility-based."

"The passion... the true passion when it comes to people with disabilities who do not directly affect the organization's financial status. The desire to learn more about individuals and their disabilities."

"The distance with driving from one place to another limits how I can schedule."

"The majority of people we support are adults. Barriers are schedules and people have been conditioned that most things happen for them during "office hours." Most people of adult age have their social engagement during after work hours. It is not very typical to see people being supported socially in evening hours. Also, we must be able to pay people a liveable wage and to provide benefits. Provider agencies also need more resources so that additional trainings and continuing education can be provided. There are no conferences or learning opportunities like there use to be that created the sharing of ideas and comradery among people receiving services and providers."

"[My organization] is a non-profit which I think that is an important factor. Fiscal responsibility is a priority but also providing services that are needed but not always as profitable."

"[My organization] is great! I think with all the changing times that we have to get on one accord to keep up with all the processes and information we relay."

"Helps a lot of the people that need [our organization's] services to have better quality of life. We are like their family."

"One aspect worth highlighting is the importance of adaptability and flexibility in providing community-based services. Communities are dynamic and ever-changing and the needs and challenges they face can evolve rapidly. Therefore, the organization must be agile and responsive in order to effectively meet the needs of the community. By prioritizing adaptability and flexibility, the organization can better navigate the complexities of community-based service provision."

"Our main concern is staffing issues on my team. Although a raise was just given to staff from $12 to $15 an hour it is not enough wages to catch the attention of qualified workers to become staff here in many cases."

"I would like to see some online learning modules on LEAP and MET."

"Handbooks on the Relias Training would be very helpful or a printout of training."

"Our community resource specialist helps connect families with resources beyond that directly provided by our organization."

"Internal organizational structure makes it easier but the organizational structure of the government and insurance makes it very, very difficult to provide services."

Perspectives of People Receiving Services and Family Members

People receiving services and their family members who participated in the focus groups were asked, "*Are there areas where you feel more support or improvement is needed*?" and "*Is there anything else you'd like to add about your services that we haven't talk about*?" and given the opportunity to make recommendations about how to improve their services. People participating in the focus groups said they would like **more fun outings**, like to concerts, movies, and restaurants; **helpful resources**, like computer access and financial education workshops for people receiving services and their family members**; parent networking and support groups**, where families could share successes and resources; **more involvement with community groups** and to leverage partnerships with community businesses that would help advance employment and recreational opportunities; and **more routine surveys** or opportunities to provide feedback.

"I would really appreciate it if they offered some kind of workshop or was forthcoming with information about what to do. I mean, I'm 67 years old and I'm not gonna be here forever. I would really like to know that there's a plan in place for who's going to take over his finances."

"Some surveys that you get you can't really say much of anything in them."

Conclusion

This in-depth case study of five IDD service providers in North Carolina revealed many barriers and facilitators to inclusive, community-based supports, as well as common and exemplary practices of provider organizations. As the field continues to move away from congregate services toward more inclusive supports, service providers will greatly benefit from learning about existing examples and the specific things that successful organizations do to enable more inclusive services. While all organizations struggle with the similar lack of resources, programs, and steady employees, prioritizing the values of person-centered practices and self-determination throughout paperwork and practices, frequent and open communication among staff and with people receiving services, and forming collaborative partnerships with other community organizations were acknowledged across all participants of this study as ways to advance individual, community-based supports. Examining organizations that are striving to provide services that are not only compliant with current policy, but also following the trends and values of self-determination in the disability field, helps to illustrate concrete steps that organizations that are trying to transition to more individualized, inclusive services can take to deliver these services.

APPENDIX A: Demographics of Participating Organizations

Variable	n	%
Number of employees		
51-75 employees	1	20.00
151-175 employees	1	20.00
More Than 200 employees	3	60.00
Parttime employees		
1-10%	1	20.00
11-20%	0	0%
21-30%	0	0%
31-40%	2	40.00
41-50%	0	0%
51-60%	1	20.00
61-70%	0	0%
71-80%	1	20.00
81-90%	0	0%
91-100%	0	0%
Gender, % Female		
<50%	1	20.00
71-80%	2	40.00
81-90%	2	40.00
91-100%	0	0%
Gender, % Male		
10-19%	2	40.00
20-29%	2	40.00
30-39%	1	20.00
Gender, % Nonbinary		
>0.25-1%	1	20.00

>1-5%	2	40.00
Age, Under 25		
<10%	2	40.00
10-20%	2	40.00
30-40%	1	20.00
Age, 26-35		
10-20%	3	60.00
21-30%	2	40.00
Age, 36-45		
10-20%	2	40.00
21-30%	3	60.00
Age, 46-55		
1-10%	2	40.00
20-30%	2	40.00
31-40%	1	20.00
Age, 56 and above		
1-10%	3	60.00
40-60%	2	20.00
Race/Ethnicity of employees, Black or African American		
10-20%	1	20.00
50-60%	2	40.00
70-30%	1	20.00
Race/Ethnicity of employees, Asian		
>1-5%	3	60.00
Race/Ethnicity of employees, Hispanic or LatinX		
>1-5%	4	80.00
10-20%	1	20.00
Race/Ethnicity of employees, Native Hawaiian or Other		

>1-5%	1	20.00
40-50%	1	20.00
Race/Ethnicity of employees, Pacific Islander		
>1-5%	1	20.00
Race/Ethnicity of employees, White		
20-30%	4	80.00
60-70%	1	20.00
Geographical reach of services		
Regional/County	3	60.00
Multiple States	1	20.00
Statewide	1	20.00
Areas of Primary Services Delivery		
Mixed (urban, suburban, and rural)	4	80.00
Urban	1	20.00

Organization 1

Variable	
Number of Employees	More Than 200
Geographical Reach of Services	Multiple States
Areas of Primary Service Delivery	Mixed (urban, suburban, and rural)
Parttime Employees	1%-10%

Variable	%
Gender	
Female	74%
Male	24%
Nonbinary	2%
Age	
Under 25	15%
26-35	26%
36-45	30%
46-55	20%
56 and above	20%
Race/Ethnicity	
Black or African American	55%
Asian	-
Hispanic or Latinx	15%
Native Hawaiian or Other	-
Pacific Islander	-
White	30%

Organization 2

Variable	
Number of Employees	51-75
Geographical Reach of Services	Regional/County
Areas of Primary Service Delivery	Urban
Parttime Employees	31%-40%

Variable	%
Gender	
Female	80%
Male	20%
Nonbinary	-
Age	
Under 25	10%
26-35	26%
36-45	24%
46-55	22%
56 and above	18%
Race/Ethnicity	
Black or African American	58%
Asian	2%
Hispanic or LatinX	3%
Native Hawaiian or Other	-
Pacific Islander	-
White	37%

Organization 3

Variable	
Number of Employees	51-75
Geographical Reach of Services	Regional/County
Areas of Primary Service Delivery	Mixed (urban, suburban, and rural)
Parttime Employees	51%-60%

Variable	%
Gender	
Female	47%
Male	15%
Nonbinary	3%
Non-Disclosed	35%
Age	
Under 25	4%
26-35	15%
36-45	23%
46-55	14%
56 and above	8%
Non-Disclosed	36%
Race/Ethnicity	
Black or African American	-
Asian	-
Hispanic or Latinx	3%
Native Hawaiian or Other	-
Pacific Islander	-
White	62%
Non-Disclosed	35%

Organization 4

Variable	
Number of Employees	More than 200
Geographical Reach of Services	Statewide
Areas of Primary Service Delivery	Mixed (urban, suburban, and rural)
Parttime Employees	31%-40%

Variable	%
Gender	
Female	83%
Male	16.6%
Nonbinary	0.4%
Age	
Under 25	7%
26-35	18%
36-45	20%
46-55	26%
56 and above	29%
Race/Ethnicity	
Black or African American	70%
Asian	0.5%
Hispanic or Latinx	1%
Native Hawaiian or Other	1%
Pacific Islander	0.5%
White	24%

Organization 5

Variable	
Number of Employees	151-175
Geographical Reach of Services	Regional/County
Areas of Primary Service Delivery	Mixed (urban, suburban, and rural)
Parttime Employees	71%-80%

Variable	**%**
Gender	
Female	70%
Male	30%
Nonbinary	-
Age	
Under 25	33%
26-35	14%
36-45	13%
46-55	15%
56 and above	25%
Race/Ethnicity	
Black or African American	18%
Asian	4%
Hispanic or Latinx	4%
Native Hawaiian or Other	45%
Pacific Islander	-
White	29%

APPENDIX B: Executive Leadership Interviews

Seven executive leaders from five organizations participated in Executive Leadership Interviews. Interviews lasted between 1-2 hours and were conducted via Zoom videoconferencing.

Executive Leadership Interview Schedule

1. Can you provide an overview of the community-based services that your organization currently provides (including where people live, day supports, etc.)?
2. Can you describe how services and supports are decided for each person who receives services from your organization? (How are the types of community living services determined for each person? How much does the person receiving services participate in the process?)
3. Can you describe how someone with extensive needs (for example, more intensive behavioral or medical support needs) is supported in achieving community living?
4. Now I have a series of questions related to procedures that bring about successful community living services…
    a. Can you describe the most important internal or operational thing your organization does to achieve community inclusion? (Prompt if needed: Can you tell me a little more about that?)
    b. Can you describe the most important employee related thing your organization does to achieve community inclusion? (Prompt if needed: Can you tell me a little more about that?)
    c. Can you describe the most important leadership related thing your organization does to achieve community inclusion? (Prompt if needed: Can you tell me a little more about that?)
    d. Can you describe the most important use of funding your organization does to achieve community inclusion? (Prompt if needed: Can you tell me a little more about that?)
5. Is your organization doing anything unique that you don’t hear about other organizations doing to promote community living and inclusion?

For Organizations that still offer congregate services...

a. *We noticed in the services listed that you still provide congregate services like day supports or group homes. Can explain why?*
b. *Is there anything limiting you from only providing community based supports?*

6. Can you describe any internal (organizational) challenges your organization faces when providing community-based services? (Prompt if needed: These could be related to the staff, scheduling, funding, or other resources…)
7. Can you describe any external (community or societal) challenges your organization faces when providing community-based services? (Prompt if needed: Maybe related to public attitudes or perception, regulations or funding, building relationships, availability of housing/transportation/employment opportunities, the economy, etc.)

8. Are there any areas of need or improvement that have been identified within your organization regarding community-based services?
9. Can you describe any internal (organizational) things that help your organization provide community-based services? (Prompt if needed: These could be related to the staff, scheduling, funding, or other resources…)
10. Can you describe any external (community or societal) things that help your organization provide community-based services? (Prompt if needed: Maybe related to attitudes or public perception, regulations, funding, court decisions, building relationships, availability of housing/transportation/employment opportunities, the economy, etc.)
11. How does your organization develop and foster relationships with other organizations in the community to enhance community-based services?
12. Can you describe an example of a successful community partnership?
13. How do leadership, management, and governance practices contribute to these community connections?
14. Many organizations say they have difficulty providing community-based services given the regulations, service options, funding options, and policies from Local Management Entity-Managed Care Organizations (LME-MCOs). How do you make the funding work to provide these services?
15. Can you describe the organizational structures and decision-making processes that facilitate community-based services?
16. How do the organization’s values reflected in your vision and mission statements influence and guide everyday tasks and decisions within your organization?
17. How do these values affect your delivery of community-based services?
18. How do frontline staff, managers, and executives communicate, provide feedback, and support one another in your organization?
19. How do those communication methods impact community-based services?
20. How do people receiving community-based services provide feedback on their experiences with community services?
21. How does your organization routinely evaluate its progress related to employee and customer satisfaction with community-based services?
22. How is that evaluation information shared or utilized within your organization?
23. How is that evaluation information shared or utilized with the people you support and their families?

APPENDIX C: Employee Survey

Employee Survey Participant Demographics

Variable	n	%
Organization's Name		
The Charles Lea Center	16	11.43
FIRSTwnc	17	12.14
InReach	30	21.43
Monarch	45	32.14
Triangle Disability & Autism Services	32	22.86
Age		
26-35	19	13.67
36-45	32	23.02
46-55	39	28.06
56 and above	39	28.06
Under 25	10	7.19
Race/Ethnicity		
American Indian or Alaska Native	1	0.72
Asian	2	1.45
Black or African American	44	31.88
Hispanic or LatinX	4	2.90
Native Hawaiian or Other Pacific Islander	2	1.45
White	85	61.59
Years at Current Organization		
Less than 1 year	34	27.64
1 to 5 years	44	35.77
6 to 10 years	13	10.57
11 to 15 years	12	9.76
16 to 20 years	11	8.94
21 to 25 years	5	4.07
25 to 30 years	2	1.63
More than 30 years	2	1.63
Years Worked in the Disabilities Field		
Less than 1 year	13	9.49
1 to 5 years	35	25.55
6 to 10 years	18	13.14
11 to 15 years	12	8.76
16 to 20 years	27	19.71
21 to 25 years	9	6.57
25 to 30 years	10	7.30
30 to 35 years	6	4.38

More than 35 years	7	5.11
Position		
Director Level	9	6.52
Executive Level	5	3.62
Frontline Level	50	36.23
Manager Level	37	26.81
Other (Please Describe)	37	26.81

Employee Survey Questions

The purpose of this study is to better understand the strategies, structures, and practices that advance community living opportunities for people with intellectual and developmental disabilities. Your organization has been selected to participate in the study because it delivers community-based services in North Carolina. If you choose to participate, you will be asked to complete this survey as well as another survey called the Organizational Priorities and Practices Inventory (OPPI). Completing this survey will take about 15 minutes. Completing the OPPI will also take about 15 minutes. There are no foreseen risks for participating in this research. The main benefit to you from this research is contributing to advancing needed information to the field and ultimately advancing community living opportunities for people with intellectual and developmental disabilities. If you decide to participate, there will be no additional cost to you. Taking part or not in this research study is your decision. You can decide to participate and then change your mind at any point. If you have any questions about the purpose, procedures, or any other issues related to this research study, you may contact the Principal Investigator, Monica Mesa Alvarez, at mmesa@natleadership.org or Cory Gilden at cgilden@natleadership.org.		Yes, I agree to participate in this study
Demographic Information Please tell us a little more about yourself to help with our analysis of the survey results. *Your responses will remain confidential and will be de-identified.*		
1	Gender	Male Female Non-Binary/Third Gender Prefer Not to Say

2	Age	Under 25 26-35 36-45 46-55 56 and Above
3	Race/Ethnicity	American Indian or Alaska Native Asian Black or African American Hispanic or LatinX Native Hawaiian or Other Pacific Islander White
4	How many years have you been at your organization?	Less than 1 Year [Range of 2-29 Years] More than 30 years
5	How many years have you worked in the disabilities field?	Less than 1 Year [Range of 2-49 Years] More than 50 years
6	What is the name of your organization?	[Open Response]
7	Which position most describes your current role?	Executive Level Director Level Manager Level Frontline Level Other (Please Describe)
8	In your experience, which of the following organizational challenges have you faced when providing community-based services? *Select all that apply.*	Limited Resources Staffing Issues Scheduling Issues Communication Issues Toxic Organizational Culture Lack of Employee Training Poor Leadership Other (Please Describe)
9	Please briefly describe any challenges or areas of need outside of your organization that you have experienced when trying to provide community-based services.	[Open Response]
10	In your experience, which organizational factors help you to provide community-based services *Select all that apply*	Adequate Resources Adequate Staffing Appropriate Scheduling Clear Communication Channels Supportive Organizational Culture

		Regular Team Meetings or Meetings with Supervisors Effective Employee Training Effective Leadership Other (Please Describe)
11	Please briefly describe any factors outside of your organization that have helped you to deliver community-based services.	[Open Response]
12	Which of the following strategies or initiatives have you participated in at your organization to better support people with high support needs with their community-based services? *Select all that apply.*	Personalized Support Services Specialized Training Increasing Accessibility Collaborative Partnerships with Community Organizations Other (Please Describe)
13	How do people who receive services from your organization provide feedback about their community-based services? *Select all that apply*	Routine Surveys or Questionnaires Sporadic Surveys or Questionnaires Direct Communication with Staff Social Media or Listserv Family or Caregiver Input Other (Please Describe)
14	How important are the following to your organization's delivery of successful community-based services? -Executive Leadership -Management -Organizational Structure -Organization Decision-Making Processes	Not Important Slightly Important Somewhat Important Important Very Important
15	Please rate how easy the following people or processes in your organization make the delivery of successful community-based services: -Executive Leadership -Management -Organizational Structure -Organization Decision-Making Processes	Very Difficult Difficult No Influence Easy Very Easy
16	Is there any other information or aspect of your organization related to community-based services that you would like to highlight or provide additional context about?	[Open Response]

APPENDIX D: Organizational Priorities and Practices Inventory (OPPI)

The Organizational Priorities and Practices Inventory (OPPI) is a tool designed to assess best practices in disability service agencies. The survey instrument holistically measures how organizations prioritize and implement evidence-based effective practices in order to promote efficiency and effectiveness and also position the rights of people with IDD as a critical goal of organizational success. Survey results illustrate how organizational procedures prioritize and strive toward six principles related to best practices in the disabilities field: (1) Autonomy, choice, and control for people with disabilities; (2) Community living, employment, and engagement; (3) Organizational management and governance; (4) Staff participation, value, impact, and support; (5) Leadership strength and skill development; and (6) Diversity, equity, and inclusion.

A strength of the OPPI is its multidimensional approach. It evaluates best practices at three essential levels: individual, organizational, and professional (Schalock et al., 2017). At the individual level, the OPPI measures whether organizations follow practices that reflect values of dignity, respect, equality, empowerment, self-determination, non-discrimination, and inclusion Verdugo et al., 2005). At the organization level, the OPPI evaluates how current practices enable justice, beneficence, and autonomy in the workplace. Lastly, at the professional level, the OPPI examines how practices involve a balanced approach to professional development and performance management.

The OPPI was distributed to the five organizations invited to participate in this study. In total 86 responses were collected. The table below shows the distribution of responses for each organization:

Organization	n	%
A	7	8.1%
B	11	12.8%
C	22	25.6%
D	25	29.1%
E	21	24.4%
Total	86	100.0%

For more OPPI results from this study, please see the supplemental report at https://www.natleadership.org/reports.html.

APPENDIX E: Focus Groups

About Focus Group Participants

One focus group was held for each organization. Focus groups took place on March 19, March 27, April 2, April 9, and May 16 of 2024. Focus groups lasted between 16 and 68 minutes. Twelve people participated in the virtual focus groups, including six people with disabilities receiving services and six family members of people receiving services. Six people receiving services who could not attend the focus groups also submitted their responses to the focus group questions via email. Participants in the focus groups and their loved ones received many services from the participating provider organizations, including employment support, personal assistance, counseling, respite, supported living, transportation, community networking, group home residential services, and community living services. Participants have been receiving services between 2 and 35 years. Participants were not specifically asked for their diagnoses, but some disclosed diagnoses of people receiving services represented in the focus groups included ADHD, generalized anxiety disorder, autism, and seizures.

Focus Groups with People Receiving Services and Family Members Questions

1. Can you describe the types of services and levels of support you receive from [SERVICE PROVIDER]?
2. How long have you been receiving services from [SERVICE PROVIDER]?
3. What is going well to make sure you are a part of your community?
4. What gets in the way of you belonging to your community?
5. Are there areas where you feel more support or improvement is needed?
6. Outside of what [SERVICE PROVIDER NAME] does, what community factors contribute to you feeling like you are a part of your community?
7. Are there any community resources that have been particularly helpful?
8. How does your organization communicate important information on services or opportunities to connect to your communities with you?
9. Do you feel like you get enough information about your or your family members' services and supports?
10. Are there ways for you or people receiving services to share feedback about services?
11. How can [SERVICE PROVIDER NAME] and other organizations that offer these services improve the feedback process?
12. Is there anything else you'd like to add about your services that we haven't talk about?

APPENDIX F: Research Methods

A case study is "a research approach that is used to generate an in-depth, multi-faceted understanding of a complex issue in its real-life context" (Crowe et al., 2011). This project was a case study of five organizations that provide community living services that support people with disabilities to be included in their communities. This research explored common barriers, facilitators, and organizational elements that help or hinder individual, community-based supports for people with IDD. Data was collected from four sources: organizational documents, interviews with executive leaders, surveys from employees, and focus groups with people receiving services and family members of people receiving services.

This research was performed with approval from the Institutional Review Board of the University of Delaware (approval no. 2130598-1) and informed consent was obtained from all participants written or verbally before participation.

Recruitment

Purposeful sampling was used to recruit organizations for this study that satisfied the following selection criteria: 1) The organization delivers direct services and supports to people with intellectual and developmental disabilities in North Carolina, 2) The organization is CQL accredited, and 3) The organization delivers individualized, community-based services and supports. Organizations were recommended for recruitment by staff from CQL, the NCCDD, and by expert consultants who work with provider organizations in North Carolina.

Document Analysis

Reflexive and Codebook Thematic Analysis was used to develop coding and themes for the document analysis (Braun & Clarke, 2019). A reflexive thematic analysis, or latent projective content analysis, approach was used to analyze most organizational documents, where codes and themes were not predefined, but instead emerged from comparison of the sources (Braun & Clarke, 2019; Kleinheksel et al., 2020). Codebook thematic analysis, or manifest content analysis, was used to analyze vision and mission statements, values and philosophy statements, and organizational charts, where a codebook was developed before coding and used to analyze content (Braun & Clarke, 2006; Kleinheksel et al., 2020).

Executive Interviews

Interviews with executive leaders were conducted after collecting organizational files for the document analysis. Researchers asked executive leadership follow-up questions related to findings from the document analysis to triangulate data and to verify the authenticity (i.e., if the document is genuine and not forged), credibility (i.e., free from error and from reliable sources), representativeness (i.e., how typical a document is), and meaning (i.e., significance of content and the context in which it was created) of the written materials (Kridel, 2015). Triangulating data compares different types of data from various sources to confirm findings across data sets to find consistency and develop a deeper understanding of the topic (Morgan, 2022). Triangulation reduces researcher bias and increases trustworthiness of results (Bowen, 2009; Morgan, 2022).

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 within 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.

Employee Surveys

Employees participated in two surveys after the executive interviews were conducted, one developed specifically for this project that was reviewed by field experts prior to distribution, and the Organizational Priorities and Practices Inventory, a holistic organizational evaluation tool created and validated by the National Leadership Consortium for disability focused organizations nationwide. Both surveys were emailed to executive leaders who were interviewed along with email content explaining the surveys, providing links to the surveys, and giving the survey deadline. Executive leaders confirmed via email once the surveys were sent to all their employees.

Employee surveys were analyzed using descriptive statistics to produce total or mean scores of responses.

Focus Groups

One focus group was conducted for each organization at a time when executive leaders thought would work best for the people they support. Information about the focus groups and links to register were emailed to executive leaders who were interviewed, who distributed the information to the people receiving services from their organizations. People receiving services were also invited to submit responses to the focus group questions via email if they were unable to attend the virtual focus groups. People receiving services and family members were incentivized to participate in the focus groups by being entered in a drawing to win one of two $25 Amazon eGift cards per focus group.

Focus group data were analyzed using Thematic Analysis to code the data and identify themes (Barun & Clarke, 2006; 2021). The online qualitative platform Dedoose (www.dedoose.com) was used to facilitate analyses. Final themes and related content were organized into thematic maps.

APPENDIX G: What are the Biggest Barriers to Inclusive Services? Infographic

What are the Biggest Barriers to Inclusive Services?

In the Summer of 2024, leaders of five organizations in North Carolina that offer individualized, inclusive supports to people with IDD were interviewed, their frontline workers filled out surveys, and the people getting services and spoke in focus groups about their experiences with community based-services. ***Here's what they said about the biggest barriers to inclusive services:***

STAFFING ISSUES

- Low **Wages**
- High **Turnover**
- Need More **Training**

63% of frontline workers said **Staffing Issues** were a challenge to providing community-based services

NOT ENOUGH RESOURCES

- Not Enough **Money**
- Not Enough Public or Provider **Transportation**
- Not Enough Safe, Affordable **Housing**

33% of frontline workers said **Limited Resources** were a challenge to providing community-based services

NOT ENOUGH PROGRAMS

- **Long Waiting Lists** for Services
- Not Enough Services in **Rural Areas**
- Not Enough **Staff**

NOT ENOUGH COMMUNICATION

- About Available **Services**
- About **How to Navigate** the DDA and Medical Systems,
- **Within Organizations** between different levels of professionals

26% of frontline workers said **Communication Barriers** were a challenge to providing community-based services

This infographic shows results from a 2024 case study by the National Leadership Consortium about how to advance individualized, inclusive services, funded by the North Carolina Council on Developmental Disabilities. More key findings can be found at ***www.natleadership.org/reports***.

NCCDD North Carolina Council on Developmental Disabilities

NATIONAL LEADERSHIP CONSORTIUM ON DEVELOPMENTAL DISABILITIES

APPENDIX H: What Makes Inclusive Services Happen? Infographic

What Makes Inclusive Services Happen?

In the Summer of 2024, leaders of five organizations in North Carolina that offer individualized, inclusive supports to people with IDD were interviewed, their frontline workers filled out surveys, and the people getting services and their families spoke in focus groups about their experiences with community-based services. ***Here's what they said about what makes inclusive services happen:***

PRIORITIZING COMMUNITY ENGAGEMENT

- in **Organizational Advertising and Paperwork**
- when **Hiring** people
- in **Plans**, and
- in **how money is spent**

57% of frontline workers said **Effective Employee Training** helps them provide community-based services

OPEN COMMUNICATION OFTEN

- between **Frontline Workers and Managers**
- between **FrontlineWorkers and People Receiving Services and Their Families**, and
- between **Leaders and Community Organizations**

67% of frontline workers said **Clear Communication** channels helps them provide community-based services

PARTNERSHIPS WITH OTHER ORGANIZATIONS

- With **Managed Care Organizations and Government Groups**
- With **Community Organizations**
- With **Disability Organizations and Advocacy Groups**

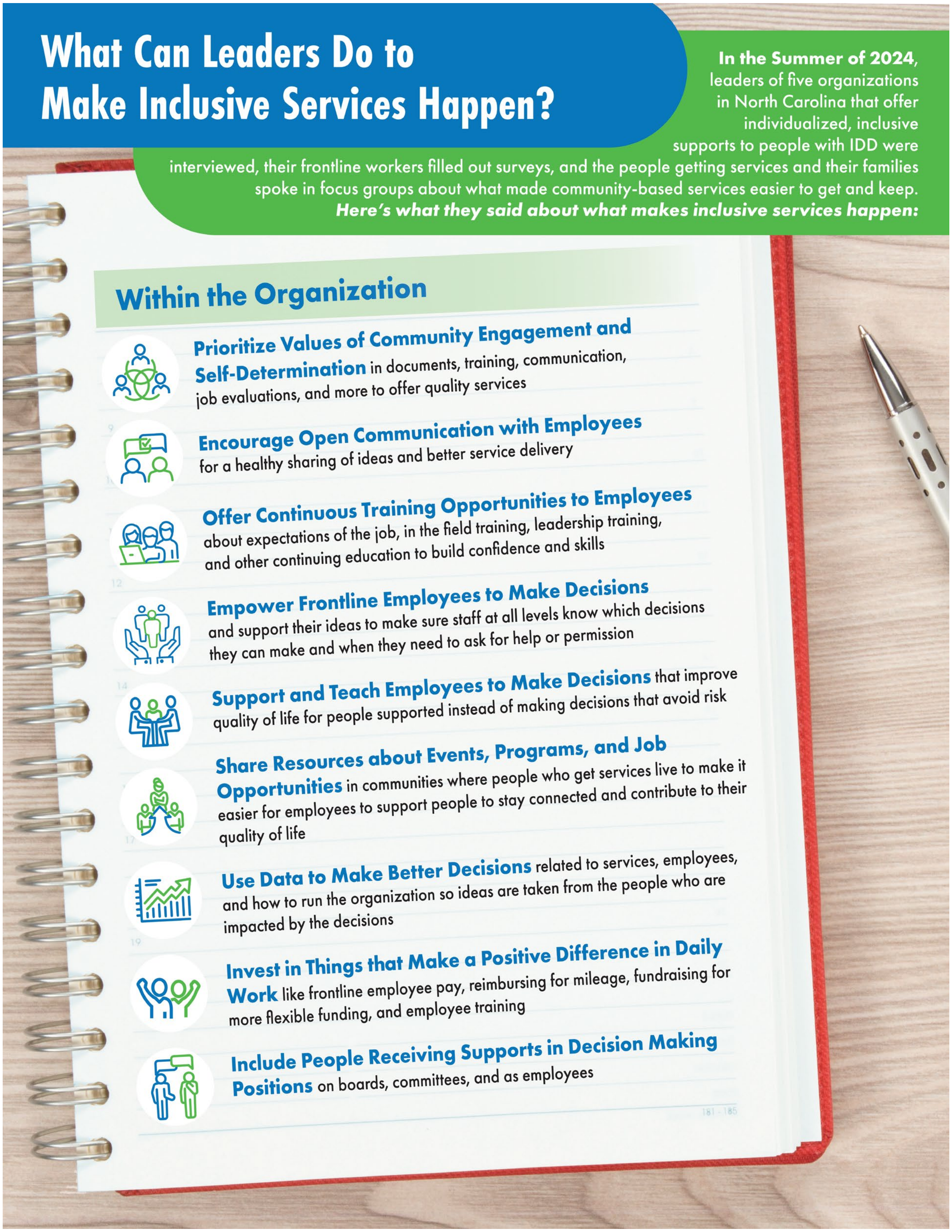
50% of frontline workers said **Collaborative Partnerships with Community Organizations** helps them provide community-based services to people with high support needs

This infographic shows results from a 2024 case study by the National Leadership Consortium about how to advance individualized, community-based services, funded by the North Carolina Council on Developmental Disabilities. More key findings can be found at ***www.natleadership.org/reports***.

NATIONAL LEADERSHIP CONSORTIUM ON DEVELOPMENTAL DISABILITIES

NCCDD North Carolina Council on Developmental Disabilities

APPENDIX I: What Can Leaders Do to Make Inclusive Services Happen? Infographic

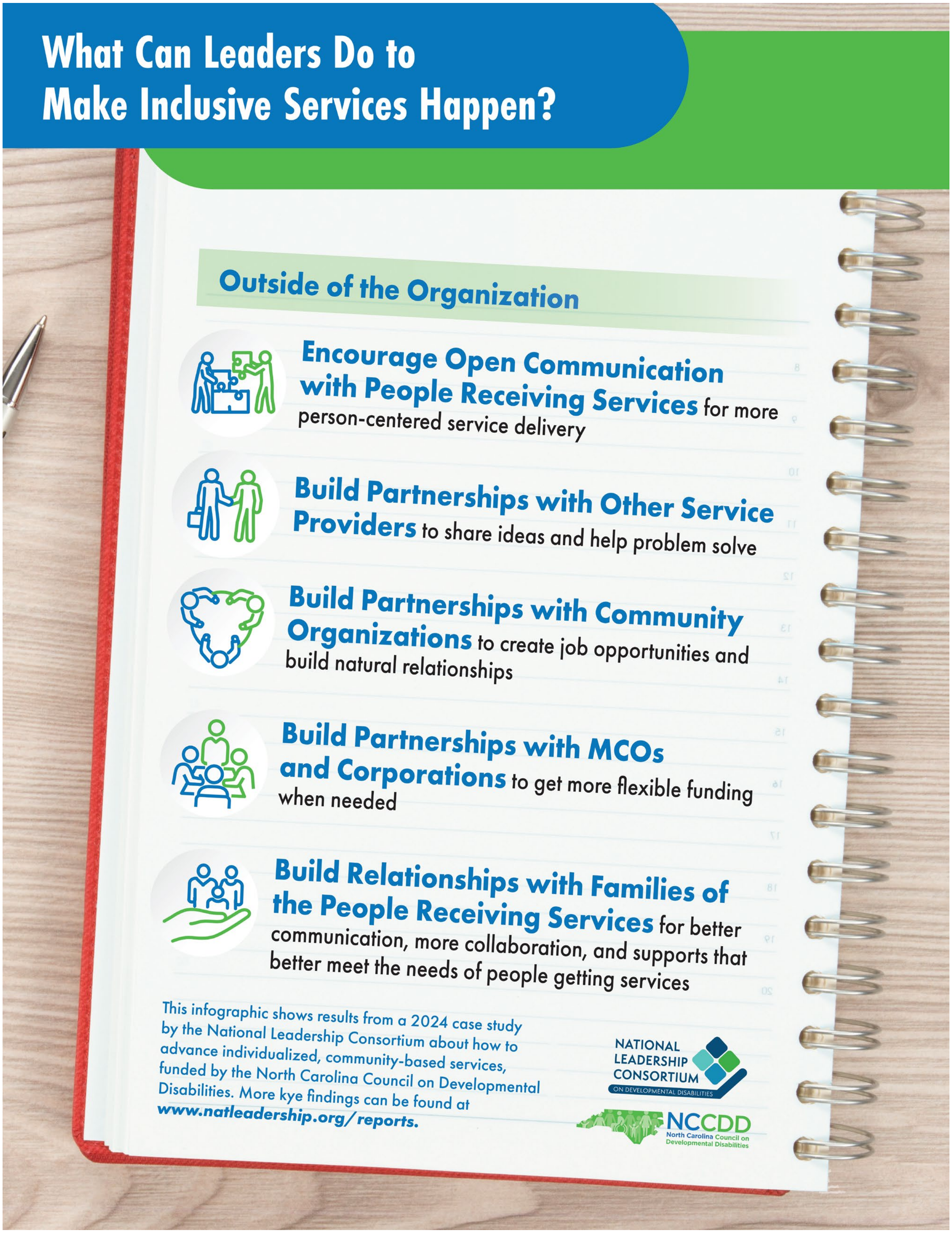


What Can Leaders Do to Make Inclusive Services Happen?

In the Summer of 2024, leaders of five organizations in North Carolina that offer individualized, inclusive supports to people with IDD were interviewed, their frontline workers filled out surveys, and the people getting services and their families spoke in focus groups about what made community-based services easier to get and keep. ***Here's what they said about what makes inclusive services happen:***

Within the Organization

- **Prioritize Values of Community Engagement and Self-Determination** in documents, training, communication, job evaluations, and more to offer quality services
- **Encourage Open Communication with Employees** for a healthy sharing of ideas and better service delivery
- **Offer Continuous Training Opportunities to Employees** about expectations of the job, in the field training, leadership training, and other continuing education to build confidence and skills
- **Empower Frontline Employees to Make Decisions** and support their ideas to make sure staff at all levels know which decisions they can make and when they need to ask for help or permission
- **Support and Teach Employees to Make Decisions** that improve quality of life for people supported instead of making decisions that avoid risk
- **Share Resources about Events, Programs, and Job Opportunities** in communities where people who get services live to make it easier for employees to support people to stay connected and contribute to their quality of life
- **Use Data to Make Better Decisions** related to services, employees, and how to run the organization so ideas are taken from the people who are impacted by the decisions
- **Invest in Things that Make a Positive Difference in Daily Work** like frontline employee pay, reimbursing for mileage, fundraising for more flexible funding, and employee training
- **Include People Receiving Supports in Decision Making Positions** on boards, committees, and as employees



What Can Leaders Do to Make Inclusive Services Happen?

Outside of the Organization

Encourage Open Communication with People Receiving Services for more person-centered service delivery

Build Partnerships with Other Service Providers to share ideas and help problem solve

Build Partnerships with Community Organizations to create job opportunities and build natural relationships

Build Partnerships with MCOs and Corporations to get more flexible funding when needed

Build Relationships with Families of the People Receiving Services for better communication, more collaboration, and supports that better meet the needs of people getting services

This infographic shows results from a 2024 case study by the National Leadership Consortium about how to advance individualized, community-based services, funded by the North Carolina Council on Developmental Disabilities. More kye findings can be found at ***www.natleadership.org/reports.***

NATIONAL LEADERSHIP CONSORTIUM ON DEVELOPMENTAL DISABILITIES

NCCDD North Carolina Council on Developmental Disabilities

APPENDIX J: References

Bailey, C., & Gilden, C. (2018). *Barriers and catalysts to self-directed services and supports for adults with disabilities: Results of the 2018 I/DD Provider Survey on Self-Directed Supports and Services*. National Leadership Consortium on Developmental Disabilities. https://www.natleadership.org/pdfs/Final_IDD_Provider_Survey_on_Self-Directed_Services_and_Supports_Report.pdf

Bown, G. A. (2009). Document analysis as a qualitative research method. *Qualitative Research Journal, 9*(2), 27-40.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health, 4*, 589-597. https://doi.org/10.1080/2159676X.2019.1628806

Braun, V., & Clarke, V. (2021). Toward good practice in thematic analysis: Avoiding common problems and be(com)ing a knowing researcher. *International Journal of Transgender Health, 1*, 1-6. https://doi.org/10.1080/26895269.2022.2129597

Crowe, S., Cresswell, K., Robertson, A., Huby, G., Avery, A., & Sheikh, A. (2011). A case study approach. *BMC Medical Research Methodology, 11*, 100. https://doi.org/10.1186/1471-2288-11-100

Kleinheksel, A. J., Rockich-Winston, N., Tawfik, H., & Wyatt, T. R. (2020). Demystifying content analysis. *American Journal of Pharmaceutical Education, 84*(1), 7113. https://doi.org/10.568/ajpe7113

Kridel, C. (2015). The biographical and documentary milieu. In M. F. He, B. D. Schultz, & W. H. Schubert (Eds.), *The Sage guide to curriculum in education* (pp. 311-318). Sage.

Morgan, H. (2024). Using Triangulation and Crystallization to Make Qualitative Studies Trustworthy and Rigorous. *The Qualitative Report*, *29*(7), 1844-1856. https://doi.org/10.46743/2160-3715/2024.6071

Verdugo, M., Schalock, R., Keith, K., & Stancliffe, R. (2005). Quality of life and its measurement: Important principles and guidelines. *Journal of Intellectual Disability Research*, 49. 707-717. DOI: 10.1111/j.1365-2788.2005.00739.x.

Schalock, R. L., Gomez, L. E., Verdugo, M. A., & Claes, C. (2017). Evidence and evidence-based practices: Are we there yet?. *Intellectual and Developmental Disabilities*, 55(2), 112-119.