Nebraska Council on Developmental Disabilities

Five-Year Needs Assessment Report

2025

NCDD
Nebraska Council on Developmental Disabilities

UNIVERSITY OF NEBRASKA MEDICAL CENTER℠
MUNROE-MEYER INSTITUTE

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PURPOSE

The Nebraska Council on Developmental Disabilities (NCDD) engages in advocacy, capacity building, and systemic change activities that assure that individuals with developmental disabilities and their families participate in the design and have access to the needed community services, individualized support, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life. To stay focused on its mission, the NCDD conducts a needs assessment every five years to identify ways to make a positive difference in the lives of individuals with developmental disabilities and their families. This report presents the results of the 2025 Needs Assessment, which will guide the NCDD's future activities.

METHODOLOGY

PROCESS

The University of Nebraska Medical Center's Munroe-Meyer Institute (MMI) was contracted to implement the needs assessment in partnership with the Council. Three key informant groups were identified: individuals with development disabilities (self-advocates), their family members or guardians, and community providers. Data were collected through surveys, interviews, and focus groups during Spring 2025 through Summer 2025, with surveys collected from June 10-July 14, 2025.

NEEDS ASSESSMENT SURVEY

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) identifies key areas of emphasis that serve as a national framework for supporting individuals with developmental disabilities and their families. These emphasis areas, including *quality assurance, education and early intervention, childcare, health, employment, housing, transportation, recreation, and family supports (informal and formal),* guided the structure of this statewide needs assessment. In addition to the federally defined priorities, the Nebraska Council on Developmental Disabilities planning committee identified several state-specific areas for further exploration. These included eligibility criteria for services, serving underserved communities, assistive technology, waiting lists, and the adequacy of waiver services.

Family members, guardians, service providers, and other community members concerned with services for individuals with developmental disabilities were asked to rate items on a 5-point scale (from *not at all important* to *very important*). *Not applicable* was an option. In addition to rating the questions, respondents were asked to select two top priorities from the areas of emphasis. Self-advocate survey participants answered a series of questions using a smiley face (*yes*) or sad face (*no*). The Council collaborated with the MMI evaluation team to review the survey questions, provide feedback, and ensure content was clear, accessible, and aligned with its priorities.

Surveys were available in both English and Spanish, and an audio narration option was available for both surveys. The survey was broadly distributed through targeted email lists and requests to agencies to facilitate multi-modal dissemination, including text and social media posts. A concerted effort was made to reach minority populations. MMI evaluation staff partnered with key parent groups and a self-advocate group, who helped recruit participants for the 2025 Needs Assessment surveys or focus groups.

FOCUS GROUPS AND INTERVIEWS

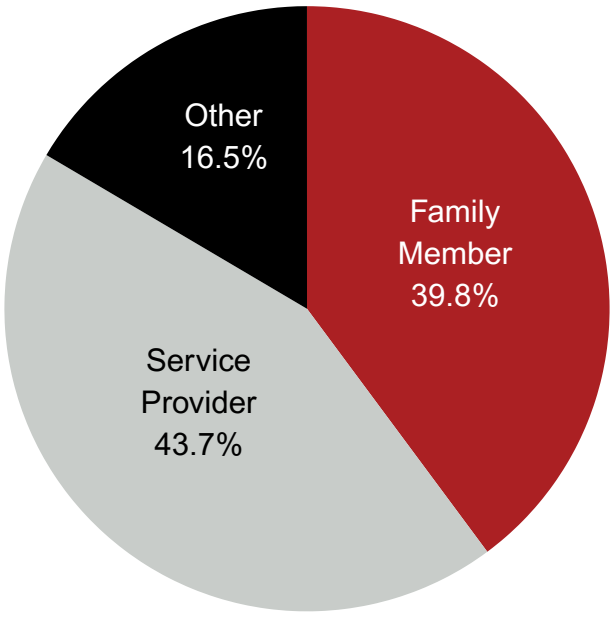
The second phase of the assessment process included the completion of interviews and focus groups. Participants either volunteered to be interviewed when they completed the survey or agreed to participate in a focus group after being identified through a partnering group. The interviewees represented a cross-section of family members, service providers, other community members, and individuals with disabilities. Due to the low number of responses to the Spanish survey, a focus group with parents and guardians who speak Spanish was prioritized.

EVALUATION FINDINGS

DESCRIPTION OF SURVEY, FOCUS GROUP RESPONDENTS

The goal of the survey distribution was to have a broad representation including geographic distribution, language, and ethnic diversity. A total of 236 individuals completed the Developmental Disabilities Needs Assessment survey. A small percentage of respondents (2.5%) completed the Spanish survey. Most respondents were service providers (43.6%) or family members (39.8%). Of the 184 who provided their race, the majority were Caucasian (85.1%) and some were two or more races (5.5%), Black (2.8%), or other (1.7%). Several respondents indicated their race as unknown/preferred not to answer (4.9%). A small number of respondents (7.1%) were of Hispanic origin. Respondents lived in a mix of urban [50,000] (61.4%), rural [<2,500] (19.6%), and urban cluster [2,500 - 49,999] (19.0%) settings. The majority were female (88.0%), with fewer male respondents (12.0%).

Roles of Survey Respondents



A total of 102 individuals completed the Self-Advocate survey. A small percentage of respondents (2.9%) completed the Spanish survey. Of the 102 who provided their race, the majority were Caucasian (73.6%), and some were two or more races (12.7%), Black (7.8%), or Asian (1.0%). Several respondents indicated their race as unknown/preferred not to answer (4.9%). A small number of respondents (9.8%) identified as Hispanic. Respondents lived in a mix of urban (58.9%), rural (20.5%), and urban cluster (20.6%), and more were female (63.8%) than male (36.2%).

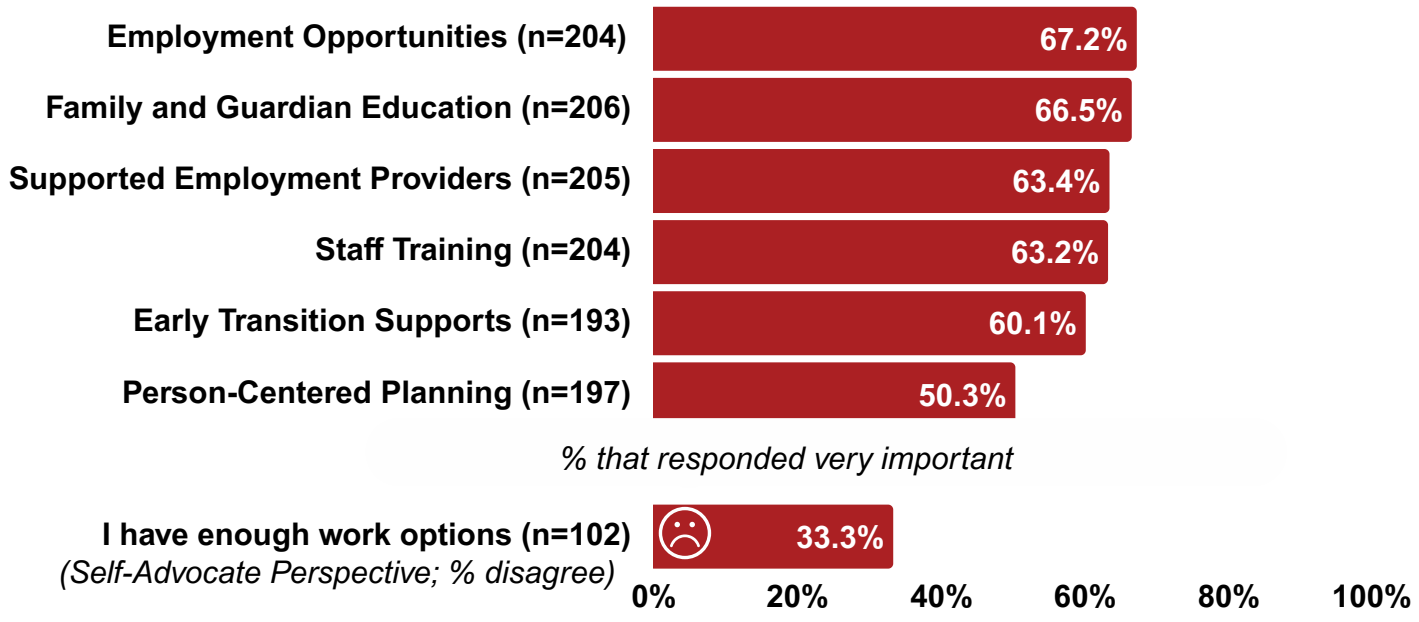
Four focus groups were held, with a total of 16 participants. Two groups were comprised of self-advocates, totaling 8 participants. One group consisted of Spanish-speaking parents/family members in a metropolitan area, with 4 participants. The other group included parents/family members, self-advocates, and professionals from both rural and urban settings, totaling 4 participants. Twenty-four interviews were conducted with a variety of participants, including parents, professionals, and other community members. The participants resided in urban and rural areas of the state.

Survey results are presented in the subsequent Survey Results sections of this report. The percentages reported represent the percentage of participants who responded *very important* to the Needs Assessment questions. For the Self-Advocate results, the percent represents those who responded *disagree* by selecting a sad face (no). Focus group, interview, and open-ended survey responses were analyzed and themed. Compiled results are represented in the subsequent Experiences sections of this report.

EMPLOYMENT
SURVEY RESULTS

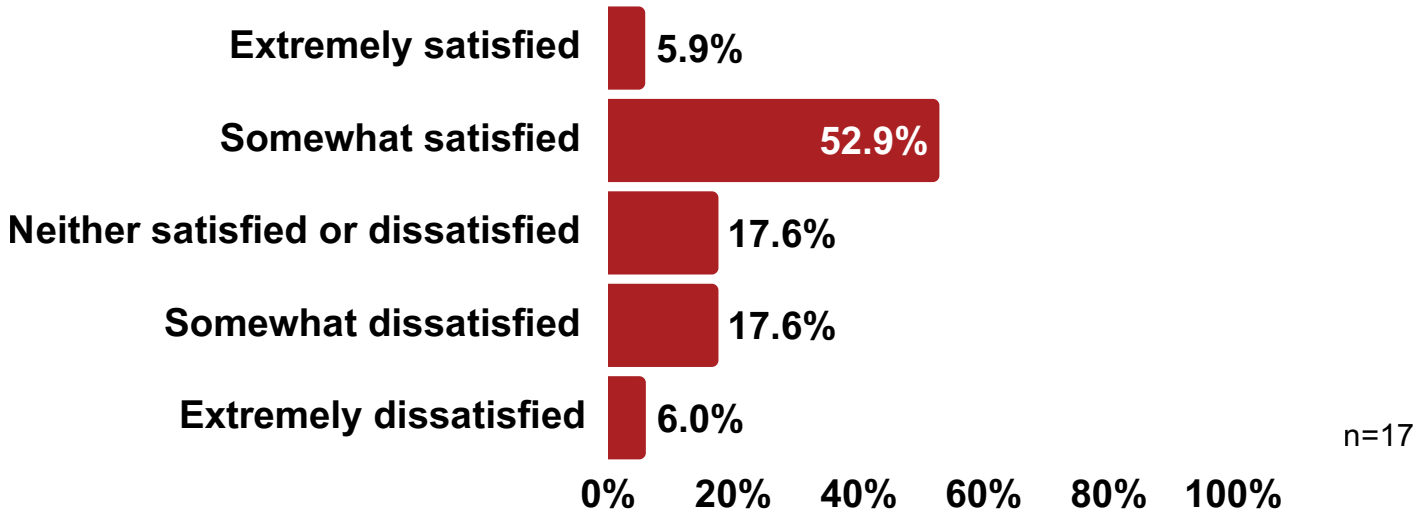
Information was gathered on employment supports and opportunities for individuals with developmental disabilities. Findings highlight the importance of creating inclusive, person-centered systems that prepare youth early, support families, and expand meaningful job options.

- **Employment Opportunities:** Nearly seven in ten respondents (67.2%) emphasized the need to increase job opportunities for individuals with developmental disabilities, reflecting widespread concern about limited access to meaningful work.
- **Family and Guardian Education:** About two out of three (66.5%) highlighted the need to provide education and resources to families and guardians so they can make informed decisions and effectively support employment choices.
- **Supported Employment Providers:** Almost two-thirds (63.4%) identified the need to recruit, retain, and train supported employment providers on best practices, ensuring stability and quality in supported employment services.
- **Staff Training:** Many respondents (63.2%) prioritized equipping staff with training to improve communication with individuals who have intellectual and developmental disabilities.
- **Early Transition Supports:** Over half (60.1%) valued reaching youth earlier through Individualized Education Plans (IEPs) that focus on competitive, integrated employment outcomes. This approach helps set strong expectations for adulthood.
- **Person-Centered Planning:** Employment services planned and led by the individual were emphasized by 50.3%, reflecting the importance of centering choice and control in the planning process.
- **Self-Advocate Perspectives:** One-third (33.3%) said they **wish they had more work options**, underscoring the gap between current opportunities and the desire for meaningful, integrated employment.



EMPLOYMENT
SURVEY RESULTS

Families were asked whether their family member with a developmental disability can access **Supported Employment Services** and, if so, how satisfied they are with those services. Among those who receive them, 58.8% reported being satisfied or extremely satisfied. However, this finding reflects a relatively small group (n=17), roughly 8% of those who answered the employment section of the survey. While more than half of this group value the support provided, the limited response rate suggests caution in interpretation and highlights the need to improve access so more families can benefit from high-quality, effective supported employment services.



EMPLOYMENT EXPERIENCES

The following section summarizes key findings gathered through focus groups, interviews, and survey comments related to employment. These perspectives emphasize both the value of meaningful work and the barriers individuals face in accessing and maintaining job opportunities. The figure presents themes for each group, as well as shared themes across groups.

Participants emphasized the need for employment services that are inclusive and meaningful. Opportunities were especially limited in rural areas, where options often involved only entry-level jobs. In urban communities, access to competitive employment was often tied to waiver status or eligibility, creating inequities. Transportation and workplace supports were persistent barriers, and families noted challenges finding opportunities that match individual strengths and interests.

> ***A kind and understanding boss would help me.***
> - Self Advocate, Focus Group

Shared Themes

Focus Group Themes

Interview Themes

Survey Themes

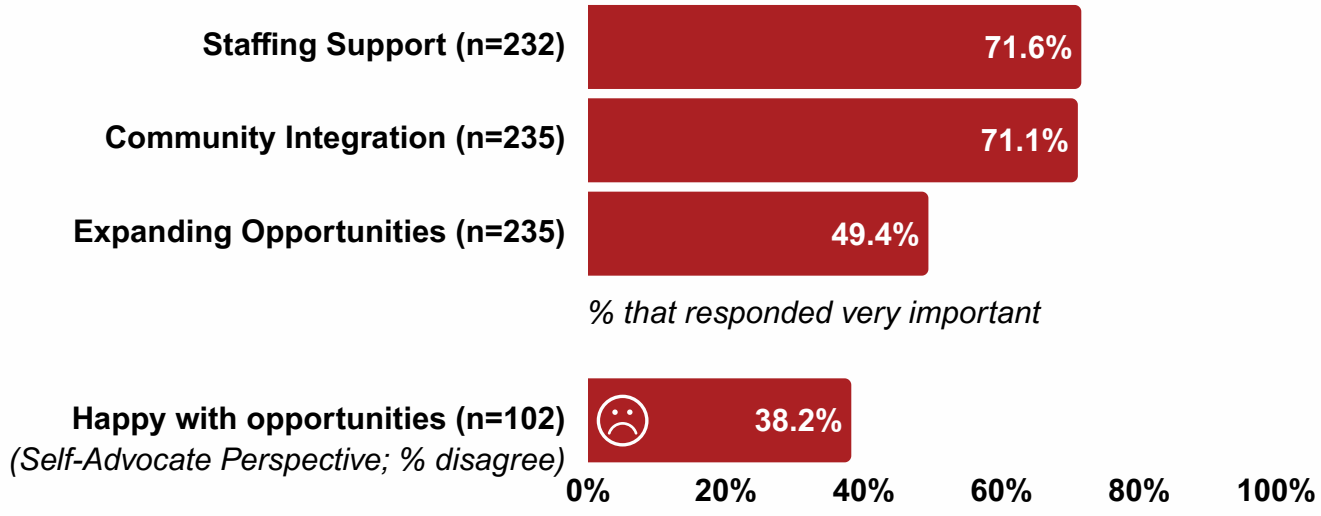
> ***VR is not necessarily the best option… it fits the box or you get nothing.***
> - Parent, Survey Comment

Findings consistently highlight the value of meaningful employment and the systemic barriers to achieving it. Survey data emphasized the need to expand job opportunities, strengthen supported employment services, and provide training for staff and families. Qualitative feedback echoed these themes, underscoring gaps between available opportunities and individual aspirations for integrated, person-centered employment.

RECREATION AND COMMUNITY ACTIVITIES
SURVEY RESULTS

Information was gathered on the availability of recreational, leisure, and social activities in local communities for individuals with developmental disabilities. Respondents highlighted several priorities as very important to improve access and satisfaction with these opportunities.

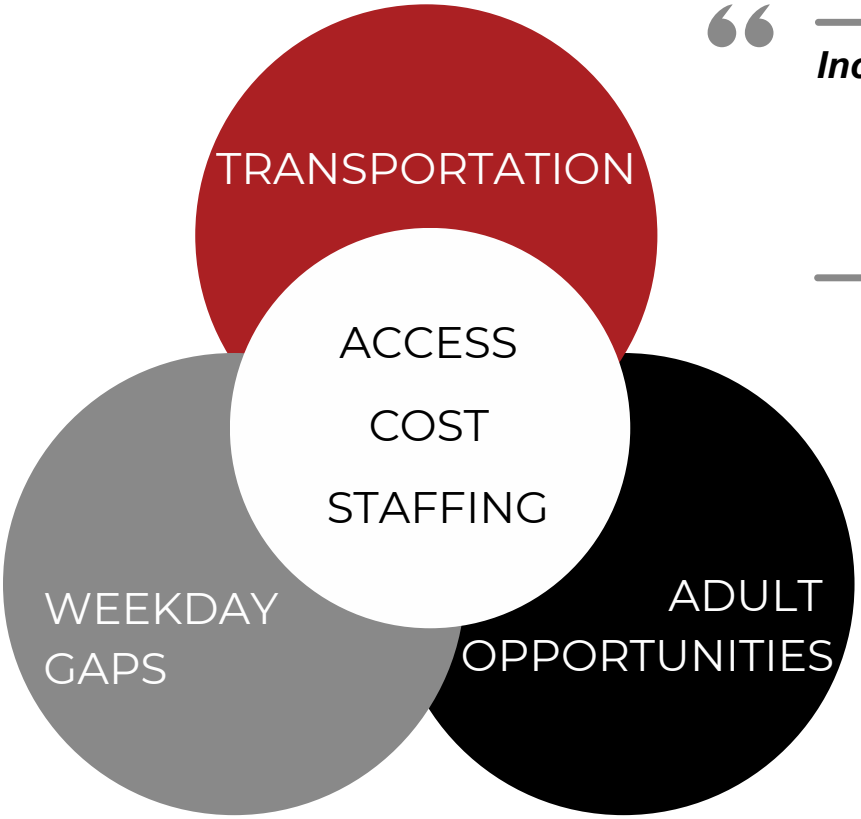
- **Staffing Support:** A large majority (71.6%) emphasized the importance of raising pay rates for staff, recognizing that higher wages could help recruit and retain staff to support more individuals in participating in community activities.
- **Community Integration:** Similarly, 71.1% of respondents stressed the need for access to integrated community activities, underscoring the importance of inclusion alongside peers without disabilities.
- **Expanding Opportunities:** Nearly half of respondents (49.4%) indicated that increasing the number of recreation opportunities in their area is very important.
- **Self-Advocate Perspectives:** Some self-advocates (38.2%) reported **dissatisfaction with the number of recreational opportunities** currently available in their communities, reflecting a gap between need and availability.



RECREATION AND COMMUNITY ACTIVITIES EXPERIENCES

The following section summarizes key findings gathered through focus groups, interviews, and survey comments related to recreation. These perspectives highlight both opportunities and barriers to inclusive, meaningful leisure and social activities for individuals with disabilities. The figure presents themes for each group, as well as shared themes across groups.

Participants consistently highlighted the need for more inclusive and meaningful community opportunities. Recreational and leisure activities were especially limited in rural areas, where options were often restricted to basic outings, such as shopping or dining. Even in urban areas, self-advocates and families noted that access was often dependent on waiver status, creating inequity. One self-advocate explained, “I think for myself it would be like transportation is a big issue,” emphasizing the persistent barrier of getting to activities. Collectively, these voices underscore the need for intentional, inclusive programming that fosters belonging and reduces inequities.



> ***Inclusive recreation activities are important—nothing separate is equal!***
> ***- Survey Comment***

Shared Themes

Focus Group Themes

Interview Themes

Survey Themes

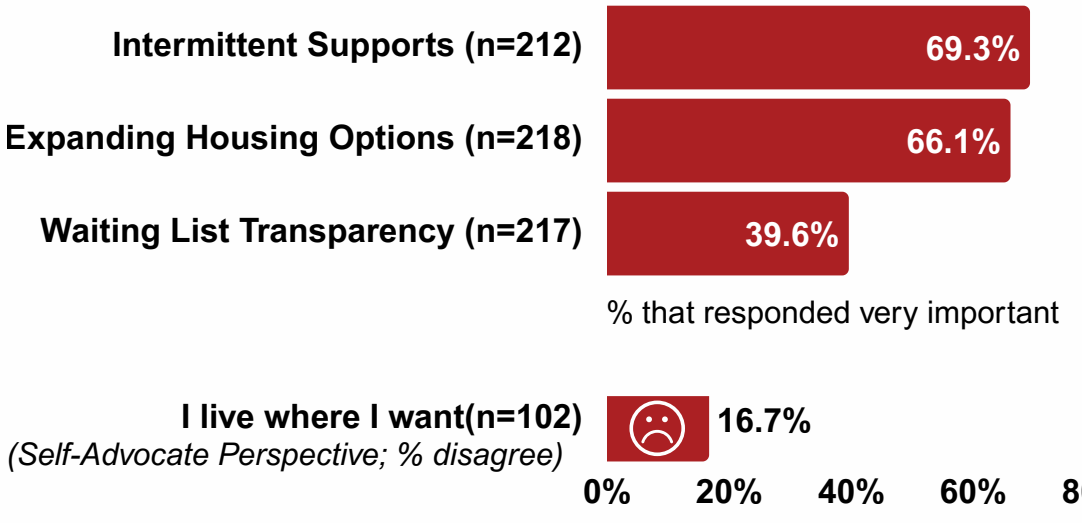
> ***The biggest barrier was that there’s tons of activities for people with disabilities if you’re on a waiver. If you’re not on a waiver, there’s nothing for you.***
> - Self-Advocate, Focus Group

Overall, findings highlight that expanding opportunities, addressing transportation barriers, and stabilizing the workforce through competitive pay are critical to making recreation more inclusive. Both quantitative and qualitative data underscore that without these improvements, individuals with developmental disabilities remain limited in their ability to participate fully in community life.

HOUSING
SURVEY RESULTS

Information was gathered on assistance programs designed to help individuals and families afford stable, safe, and suitable housing, as well as on intermittent waiver supports that can be provided on an as-needed basis rather than continuously. Findings highlight both the urgency of addressing housing shortages and the importance of flexible supports for individuals with developmental disabilities who do not require 24/7 residential care.

- **Intermittent Supports:** The majority (69.3%) identified supporting individuals who could live independently with intermittent waiver supports as a very important focus. This would expand opportunities for those who do not require 24-hour care but still need periodic assistance to maintain independence.
- **Expanding Housing Options:** Two-thirds of respondents (66.1%) emphasized the importance of creating more housing options or renovation programs to increase the amount of accessible, affordable units for individuals with developmental disabilities. These strategies could ease the shortage of suitable housing and reduce waitlist pressures.
- **Waiting List Transparency:** Nearly two in five respondents (39.6%) said it is very important to know how many individuals with disabilities are currently on waiting lists for housing help. This reflects a strong need for transparent tracking systems that allow families, advocates, and policymakers to understand the scope of the problem.
- **Self-Advocate Perspectives:** Some self-advocates (16.7%) reported that **they do not currently live where they want** within their community, underscoring the disconnect between personal preferences and available housing options.



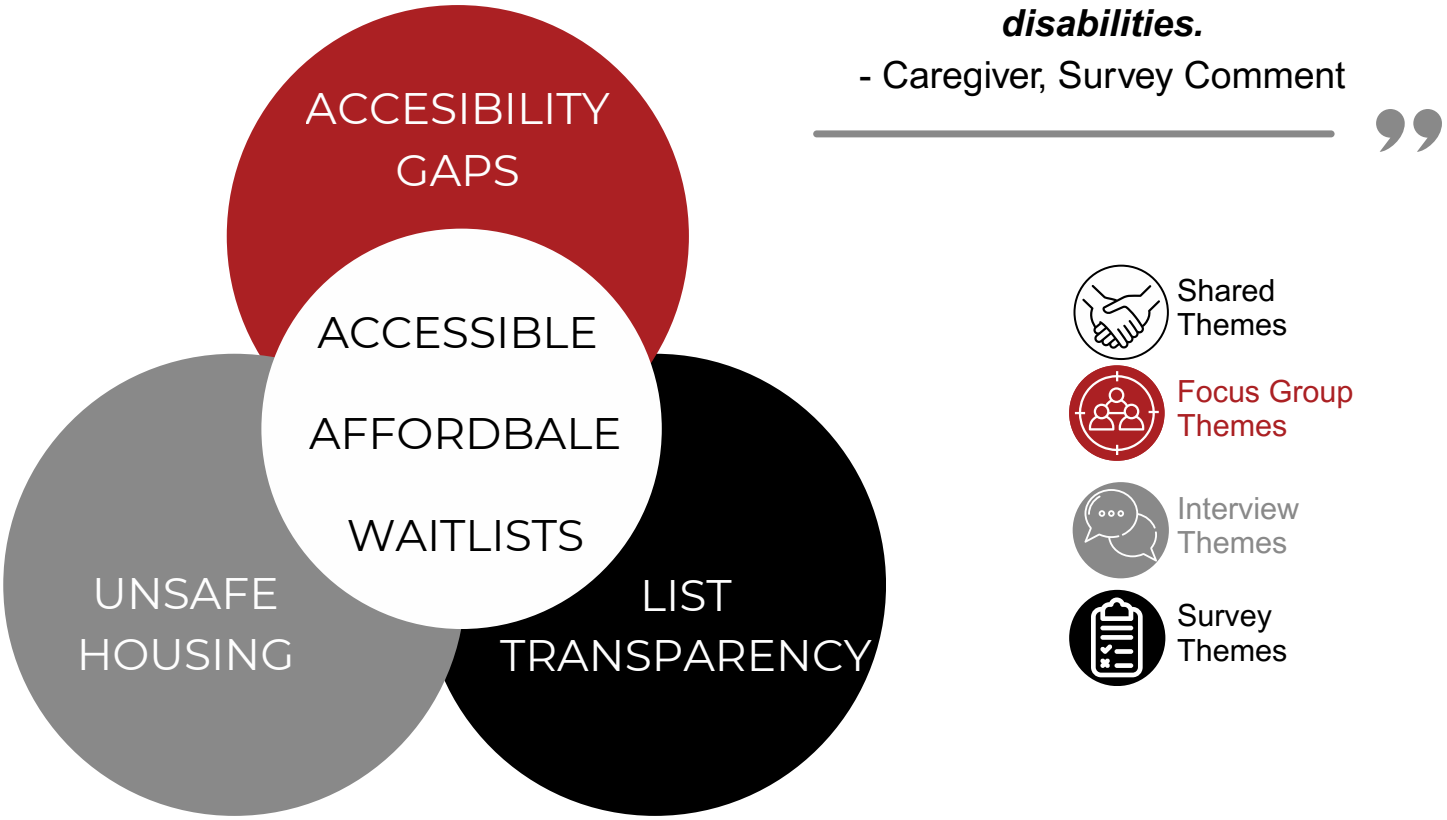
HOUSING EXPERIENCES

The following section summarizes key findings gathered through focus groups, interviews, and survey comments related to housing. The data reflect ongoing needs and challenges around safe, affordable, and accessible housing options that support independent living. The figure presents themes for each group, as well as shared themes across groups.

Housing was described as one of the most urgent and unmet needs. Self-advocates and families pointed to the lack of wheelchair-accessible apartments and stressed that supports must be in place from the first day of independent living. Parents in interviews described navigating housing as overwhelming and confusing. Families also noted “the very long waiting lists” and lack of affordable and safe housing as substantial barriers to securing housing. Collectively, the data show that a lack of housing undermines independence, stability, and quality of life.

> ***There is a very long waiting list to find housing.***
> - Parent, Interview

> ***Nebraska lacks affordable, accessible housing... voucher classes are not geared for people with disabilities.***
> - Caregiver, Survey Comment



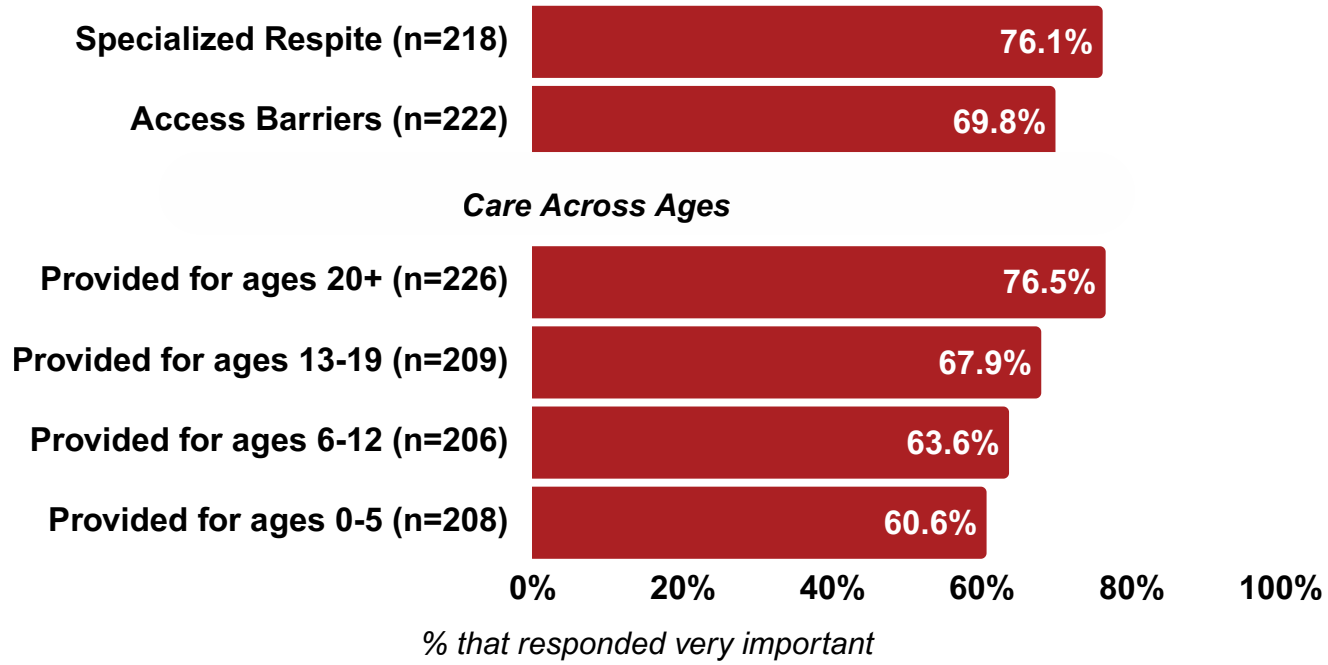
Survey responses and qualitative input both emphasized the shortage of affordable, accessible housing and the importance of flexible supports. Families and self-advocates underscored the disconnect between personal preferences and available housing, noting that some do not live where they want. Closing gaps will require both new housing development and policies that promote independence through intermittent supports.

CHILD CARE AND RESPITE SERVICES
SURVEY RESULTS

Respite care offers a brief break for the primary caregiver, allowing them time to rest or attend to other responsibilities while someone they trust steps in to provide assistance. Information gathered shows that both respite and childcare are highly valued supports for families of individuals with developmental disabilities, yet current systems fall short of meeting demand.

- **Specialized Respite:** More than three-quarters of respondents (76.1%) emphasized the need for respite care options tailored for individuals with complex medical needs and/or severe behavioral needs. Families often struggle to find providers who are trained and comfortable addressing these higher levels of care.
- **Access Barriers:** Over two-thirds of respondents (69.8%) indicated it is very important to address the challenges that limit access to respite care, including low pay for staff, not enough available services, and insufficient training for providers. These barriers prevent many families from securing consistent, reliable support.

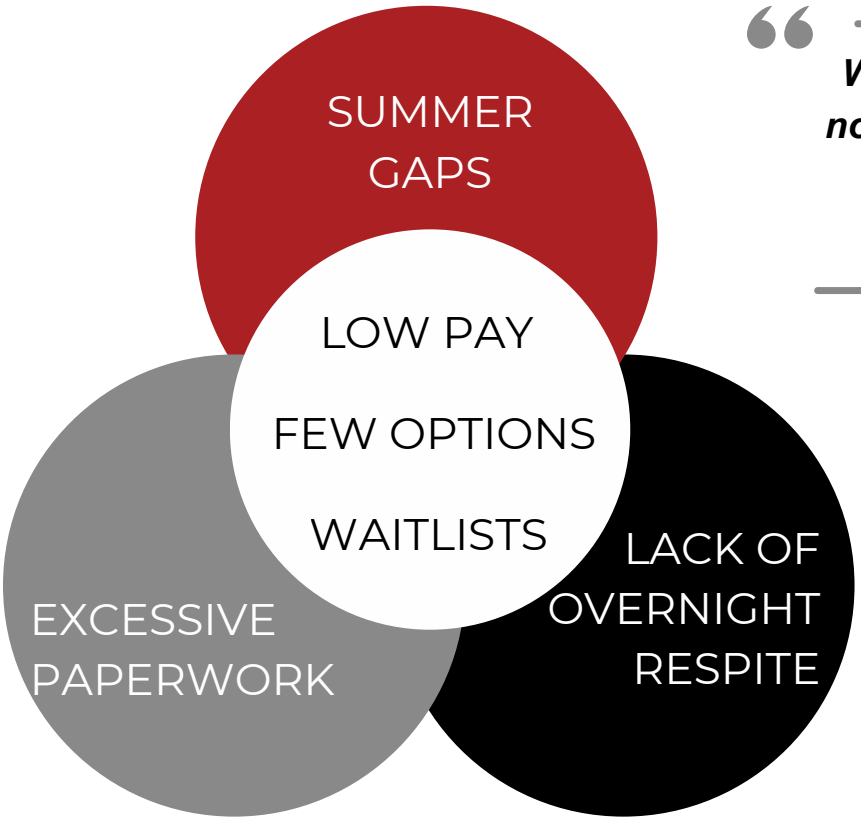
- **Child Care Across Ages:** Respondents also emphasized the importance of providing developmentally appropriate care across various age groups. Priorities included care for adults **20+ years** (76.5%) and for children **13–19 years** (67.9%), **6–12 years** (63.6%), and ages **0–5 years** (60.6%). These results underscore the need for childcare and respite systems that adapt across the lifespan, from early childhood through adulthood.



CHILD CARE AND RESPITE SERVICES EXPERIENCES

The following section summarizes key findings gathered through focus groups, interviews, and survey comments related to childcare. These insights illustrate the challenges families face in finding reliable, affordable, and inclusive care, as well as the impact of limited options on family well-being. The figure presents themes from each group, as well as shared themes across groups.

Childcare and respite were consistently identified as critical but difficult to access. In interviews, family members described paperwork that discouraged providers. Self-advocates and family members participating in the focus groups emphasized the lack of summer programs, especially for teens. Survey comments highlighted the exhaustion parents face when respite is unavailable, especially for children with complex medical needs. Collectively, these findings show that respite is not a luxury but a vital service for family well-being.



> ***We are exhausted… we have not had respite in years due to medical needs.***
> - Parent, Survey Comment

Shared Themes
Focus Group Themes
Interview Themes
Survey Themes

> ***It's a high-turnover field. We're not paying them for the jobs we ask them to do.***
> - Parent, Survey Comment

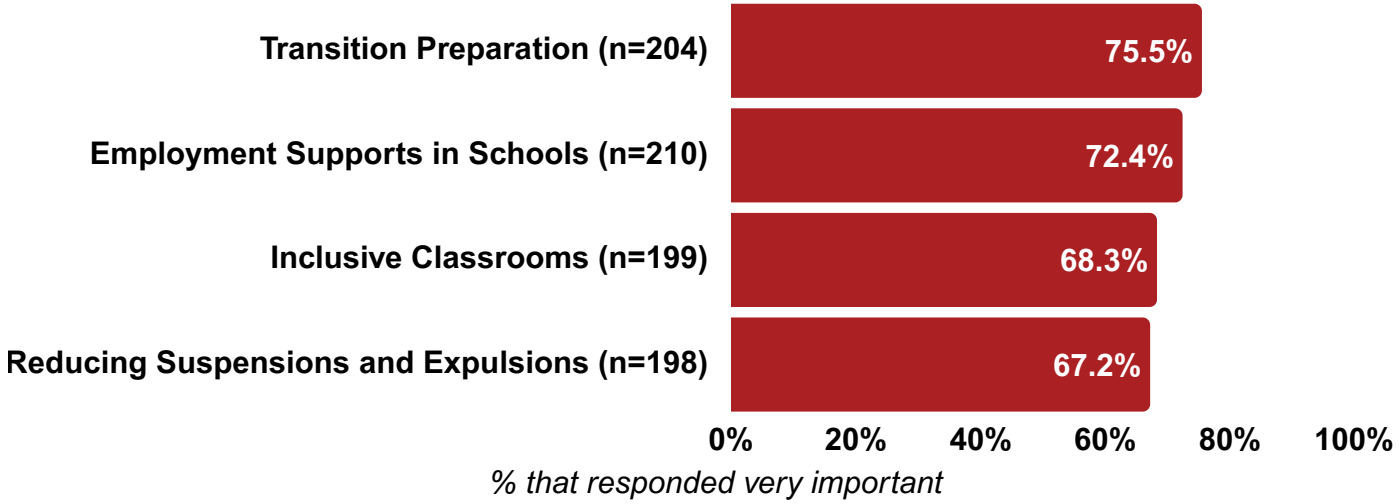
The survey and qualitative feedback consistently stress that respite and childcare are highly valued yet inaccessible support services. Families identified barriers such as low wages, limited availability, and inadequate training, while also noting the need for specialized care for individuals with complex needs. Together, the findings point to an urgent need for system changes to expand and sustain these essential services across the lifespan.

EDUCATION AND EARLY INTERVENTION
SURVEY RESULTS

Information was gathered on education systems and early intervention services that support children and youth with developmental disabilities. Respondents underscored the importance of strengthening both early childhood practices and secondary education preparation to ensure inclusion, stability, and smooth transitions into adulthood.

- **Transition Preparation:** The highest need identified was improving secondary teacher preparation to better collaborate with adult service agencies (75.5%). Respondents emphasized that successful transitions require coordination between schools, families, and community providers so students can move confidently into adult life, employment, and postsecondary opportunities.
- **Employment Supports in Schools:** Nearly three-quarters of respondents (72.4%) identified recruiting, retaining, and training supported employment providers on best practices as very important. This reflects a strong need for schools to connect students with high-quality employment supports that prepare them for adulthood.
- **Inclusive Classrooms:** A majority (68.3%) reported that it is very important to support inclusive classrooms at all grade levels. Respondents pointed to the need for practices and resources that promote equitable learning environments where students with and without disabilities learn together.

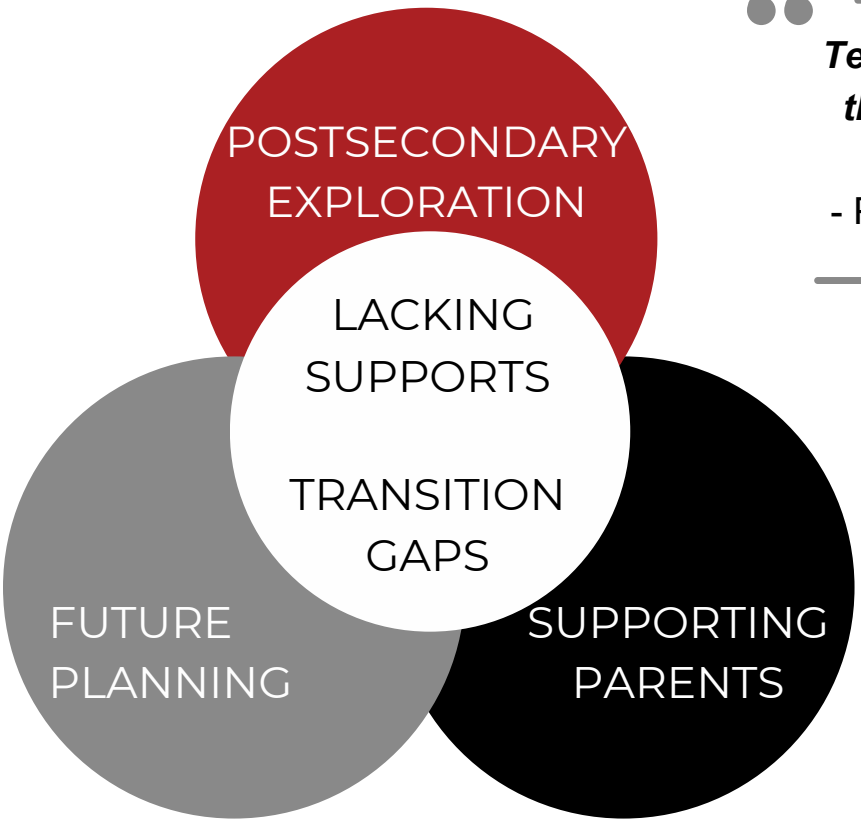
- **Reducing Suspensions and Expulsions:** Over two-thirds (67.2%) stressed the importance of stopping suspensions and expulsions in early childhood settings through staff training and awareness. Families emphasized that exclusionary discipline undermines inclusion and long-term success for children with developmental disabilities.



EDUCATION AND EARLY INTERVENTION EXPERIENCES

The following section summarizes key findings gathered through focus groups, interviews, and survey comments related to education. Participants shared insights on access to inclusive learning opportunities, support for diverse needs, and planning for transition into adulthood. The figure presents themes for each group, as well as shared themes across groups.

Education was consistently described as a vital pathway to independence, but one that was not always accessible. Self-advocates shared experiences of exclusion, such as being left out of college tours. Parents in interviews reported that planning for the future often fell entirely on families, with little guidance from schools. Responses emphasized that parents were often unaware of IEPs, 504 plans, or other available resources because schools failed to share information. Overall, the data illustrate that education systems are not consistently preparing youth with disabilities for long-term success.



> ***Teachers provide resources... they themselves don't even know what is out there.***
> - Parent, Spanish Focus Group

Shared Themes

Focus Group Themes

Interview Themes

Survey Themes

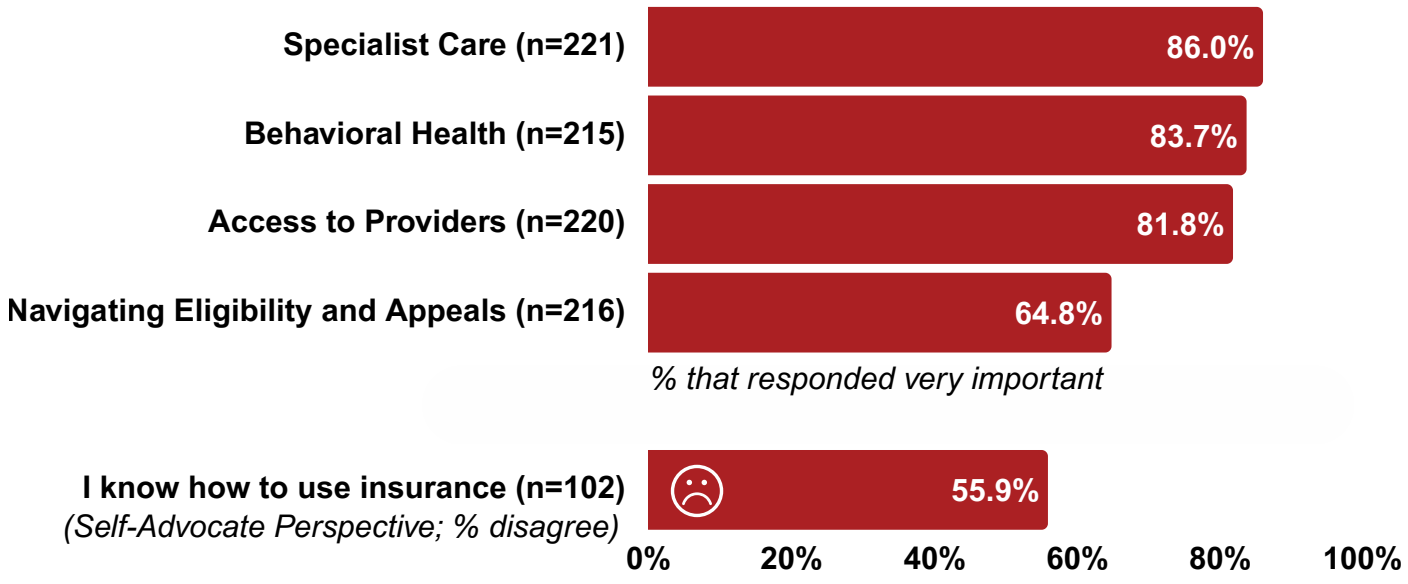
> ***It was up to us to figure things out after high school. Nobody explained what was next.***
> - Parent, Interview

Results point to a need for stronger inclusion, consistent quality across districts, and better transition planning. Respondents emphasized improving teacher preparation and preventing exclusionary discipline, and families stressed the importance of coordinated supports as children age. Taken together, the findings underscore the need for lifelong educational equity and smooth pathways into adulthood.

HEALTH AND HEALTHCARE
SURVEY RESULTS

Respondents were surveyed about health and healthcare needs for individuals with developmental disabilities. As part of the survey, Medicaid was defined for participants as the largest public health insurance program for people with disabilities, offering free or low-cost coverage for eligible low-income adults, children, older adults, and people with disabilities. Respondents stressed the need for greater provider participation in Medicaid, stronger behavioral health systems, expanded access to specialists, and more support in navigating eligibility and appeals to ensure individuals with developmental disabilities receive consistent, comprehensive care.

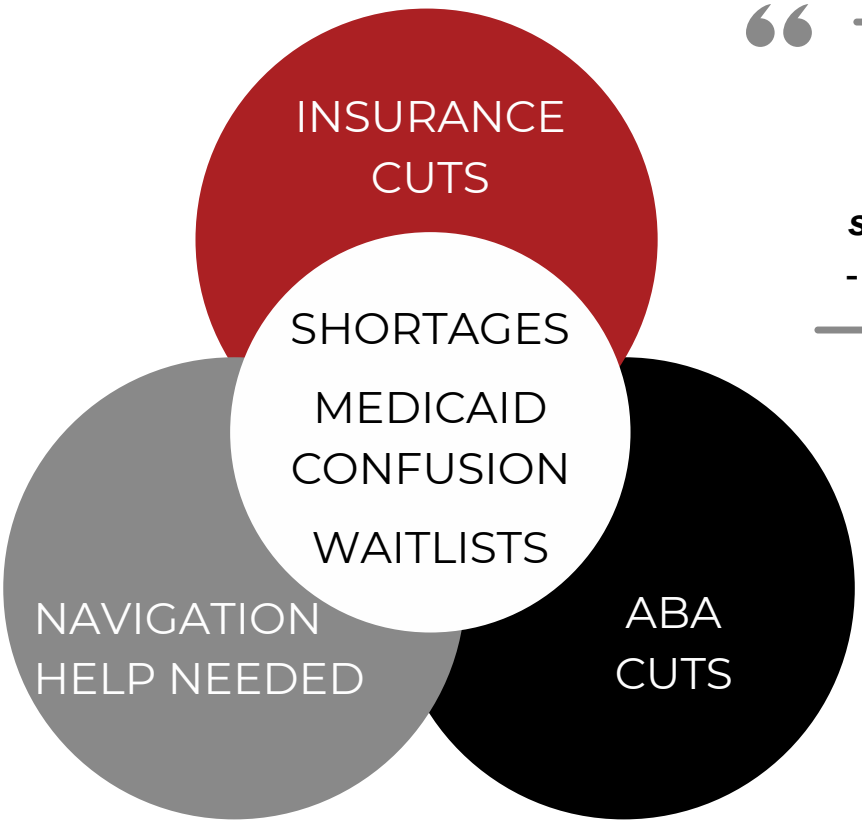
- **Specialist Care:** Increasing access to specialists (such as dentists) who accept Medicaid was emphasized as very important (86.0%). The limited availability of these providers often leaves families without access to critical care.
- **Behavioral Health:** Improving behavioral health services for youth with disabilities emerged as a top need (83.7%), with families and professionals highlighting gaps in funding and access to tailored supports.
- **Access to Providers:** Expanding the number of healthcare providers who accept Medicaid was identified as a critical need (81.8%) to ensure individuals can consistently receive routine and specialized care.
- **Navigating Eligibility and Appeals:** Monitoring Medicaid eligibility denials and providing support throughout the appeals process was considered very important (64.8%) to reduce stress and ensure continuity of coverage.
- **Self-Advocate Perspectives:** Many self-advocates (55.9%) reported **they do not know how to work with their insurance or Medicaid** and need training or help, underscoring the importance of practical guidance and support.



HEALTH AND HEALTHCARE EXPERIENCES

The following section summarizes key findings gathered through focus groups, interviews, and survey comments related to health and healthcare. These perspectives shed light on access to medical services, coordination of care, and navigation of complex healthcare systems. The figure presents themes for each group, as well as shared themes across groups.

Accessing healthcare was described as stressful and inconsistent. Families and self-advocates cited shortages in dental, behavioral health, and specialty care providers. Focus group participants felt providers listened, but reimbursement cuts left them without options. Parents described the paperwork burden as “way too much for parents to navigate,” while survey respondents underscored systemic issues such as reduced ABA funding and lack of Medicaid case workers. The findings highlight that navigating healthcare is not just a logistical challenge but a major source of stress for families.



> ***The process for Medicaid and social security is incredibly hard...it’s very stressing for me as a parent.***
> - Parent, Spanish Focus Group

Shared Themes

Focus Group Themes

Interview Themes

Survey Themes

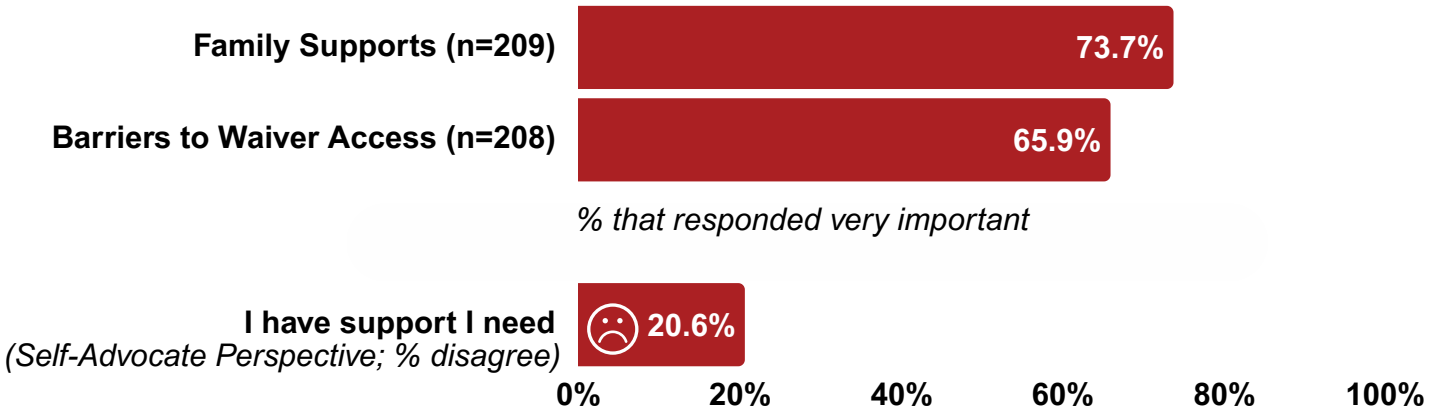
> ***Finding a dentist or eye doctor who accepts Medicaid is very difficult.***
> - Parent, Interview

Quantitative and qualitative data strongly align in highlighting urgent healthcare challenges. Families and self-advocates described barriers in accessing providers, specialists, and behavioral health services, while also needing more help navigating Medicaid. These combined perspectives underscore the need for system-wide improvements to ensure consistent and equitable care.

INFORMAL AND FORMAL SUPPORTS
SURVEY RESULTS

Information was gathered on both informal supports (such as family, friends, and community networks) and formal supports (such as waiver services and professional caregiving). The findings highlight persistent barriers and unmet needs that limit access to reliable support systems for individuals with developmental disabilities and their families.

- **Family Supports:** Addressing the lack of family supports, such as respite services and other waiver-based programs, was identified as a critical focus (73.7%). Families consistently noted that current systems fall short in providing the necessary resources to sustain their caregiving roles.
- **Barriers to Waiver Access:** Removing barriers to accessing developmental disability waiver services was also seen as very important (65.9%). Families pointed to obstacles such as language, transportation, cultural differences, and immigration status, which make it difficult to qualify for or navigate needed supports.
- **Self-Advocate Perspectives:** Some self-advocates (20.6%) shared **they do not have someone to support them when they need help.** This highlights the isolation individuals may experience when both informal and formal support systems are unavailable or inconsistent.



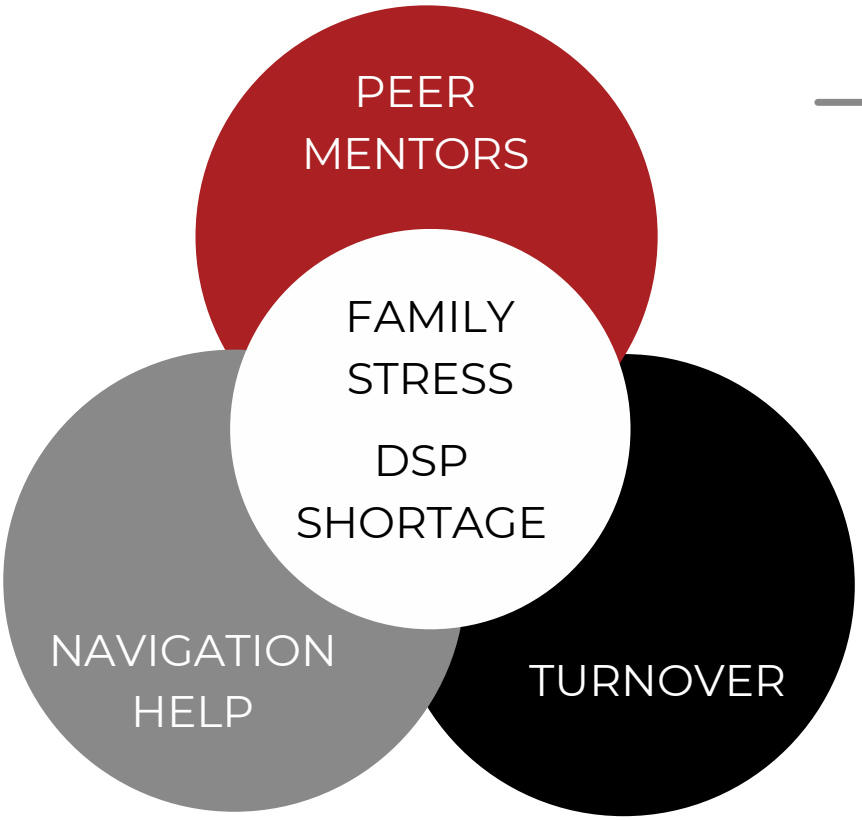
INFORMAL AND FORMAL SUPPORTS EXPERIENCES

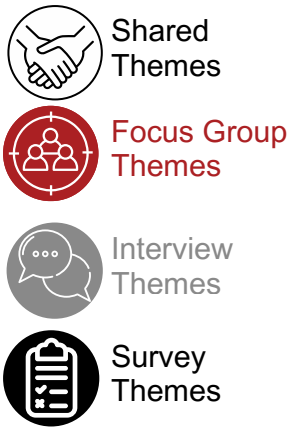
The following section summarizes key findings gathered through focus groups, interviews, and survey comments related to informal and formal supports. These findings highlight the importance of family, peer, and professional supports, as well as the challenges created by workforce shortages and turnover. The figure presents themes for each group, as well as shared themes across groups.

Supports were consistently described as insufficient, with workforce shortages creating instability. Families reported feeling overwhelmed when they had to cover service gaps themselves. Parents described the need for guides to help them navigate complicated systems. Self-advocates valued peer mentors and informal supports, but noted they were not enough. Families pointed out that "providers are not paid enough to retain them." Together, these findings highlight the critical role of both formal and informal supports and the urgent need for workforce investment.

> ***Providers are not paid enough to retain them.***
> - Parent, Interview

> ***If you can make more money at McDonald's than supporting someone...this is the problem.***
> - Survey Comment



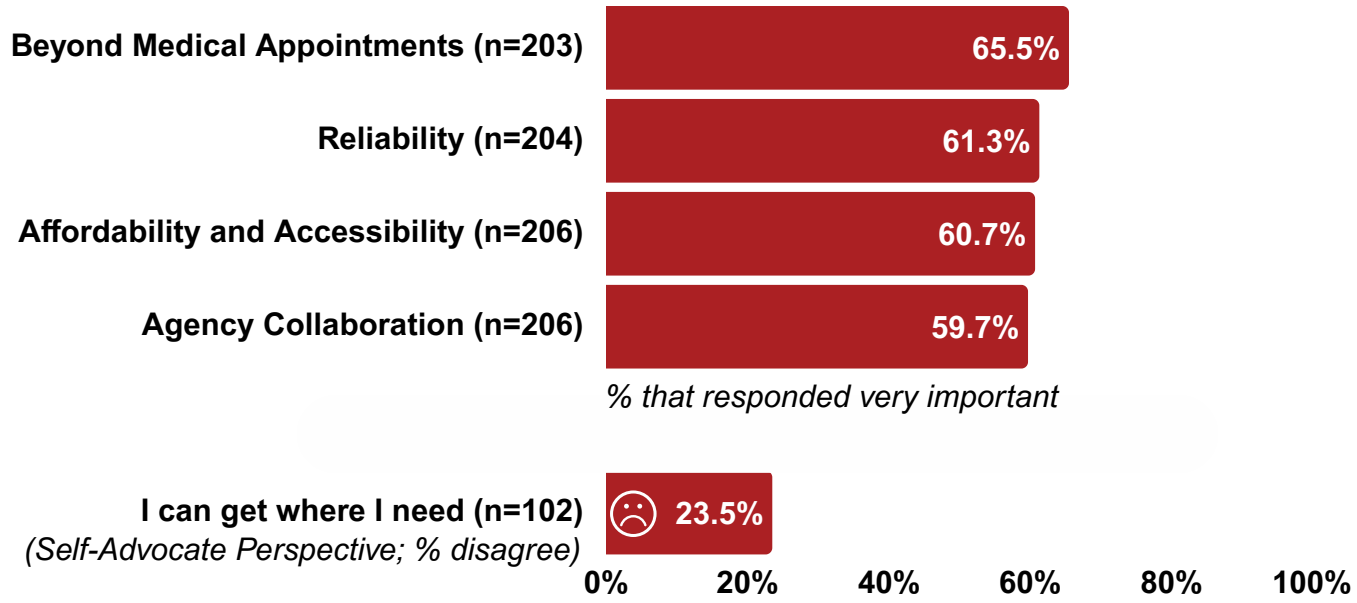


Findings across methods indicate that both informal and formal supports often fall short of meeting the needs of families and individuals. Survey respondents prioritized reducing barriers to waiver access and expanding family supports, while self-advocates emphasized the isolation that results when supports are unavailable. These results reinforce that reliable support systems are foundational to independence and quality of life.

TRANSPORTATION
SURVEY RESULTS

Information was gathered on transportation systems and their role in supporting individuals with developmental disabilities. Access to reliable, affordable, and inclusive transportation is essential for health, independence, and community participation, yet significant gaps remain.

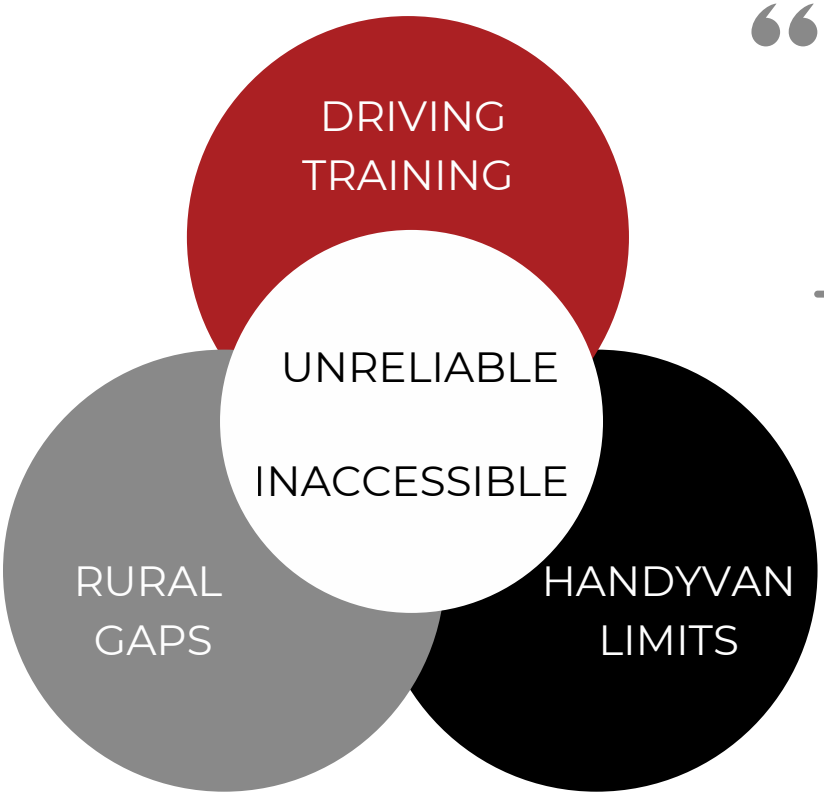
- **Beyond Medical Appointments:** Access to transportation for work, school, and community activities, not just medical needs, was viewed as very important (65.5%). Expanding options in these areas is essential to foster independence and inclusion.
- **Reliability:** Addressing transportation challenges to ensure consistent and dependable options was identified as an important issue (61.3%). Families and individuals often described canceled rides or limited schedules that disrupted daily life.
- **Affordability and Accessibility:** The need for more affordable, accessible, and higher-quality transportation options was highlighted as critical (60.7%), reflecting concerns about cost and limited availability.
- **Agency Collaboration:** Over half of the participants (59.7%) emphasized the importance of improving collaboration among Nebraska agencies on transportation issues. Stronger coordination could expand coverage, reduce duplication of efforts, and create more consistent access to services.
- **Self-Advocate Perspectives:** Nearly one-quarter (23.5%) reported **they do not have a way to get where they need to go**. This highlights the direct impact of transportation barriers on daily life and the lost opportunities for full participation in work, school, and community activities.



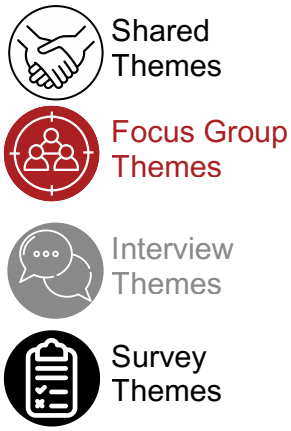
TRANSPORTATION EXPERIENCES

The following section summarizes key findings gathered through focus groups, interviews, and survey comments related to transportation. These findings highlight the crucial role of reliable and accessible transportation in facilitating community participation and employment. The figure presents themes for each group, as well as shared themes across groups.

Transportation emerged as one of the most significant barriers across all groups. Self-advocates expressed that learning to drive and using public transit were important steps toward independence, yet safety and accessibility concerns made this difficult. Families, particularly in rural areas, discussed the absence of reliable transportation options, which force long trips or reliance on others. A parent explained, “Transportation is so costly,” while another shared, “The bus system can be difficult to navigate for someone with a developmental disability.” Collectively, these perspectives underscore transportation as a gatekeeper issue that limits access to healthcare, recreation, employment, and community participation.



> ***We have thousands of adults who need transportation… we have 8 HandyVans.***
> - Professional, Survey Comment



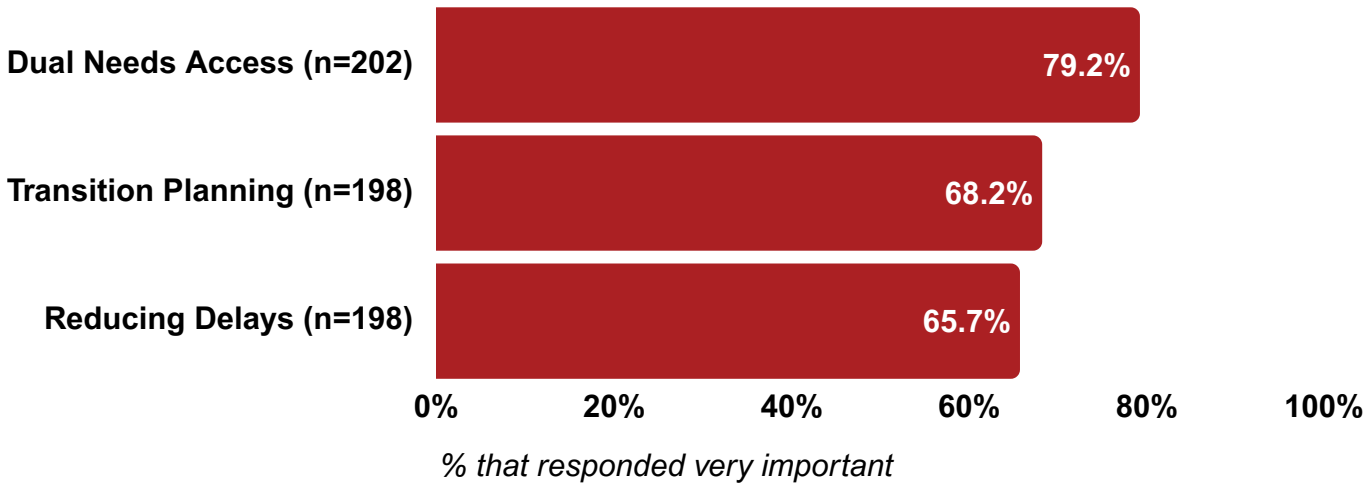
> ***You have to call a week in advance, and sometimes wait an hour just to see if you’re going to get one.***
> - Parent, Survey Comment

Across surveys and focus groups, transportation emerged as a persistent barrier to independence, particularly in rural areas. While some self-advocates reported having reliable access, many families described affordability and reliability issues that limited their daily lives. Findings consistently emphasize the need for affordable, accessible, and coordinated transportation systems that extend beyond medical trips to support work, education, and community life.

CRITERIA FOR ELIGIBILITY OF SERVICES
SURVEY RESULTS

Information was gathered on eligibility requirements and access to developmental disability and related services. Families, professionals, and self-advocates highlighted the importance of smoother, more equitable pathways to supports that reduce delays and gaps during transitions.

- **Dual Needs Access:** Making it easier for individuals with both developmental disabilities and mental or behavioral health needs to access services was emphasized by 79.2%. Participants noted that current systems are often fragmented and difficult to navigate.
- **Transition Planning:** Improved planning as individuals move from school into employment or waiver services was identified by 68.2%, underscoring the importance of coordinated preparation for adulthood.
- **Reducing Delays:** Avoiding delays in accessing Nebraska VR employment services or waiver day program services when students finish school was prioritized by 65.7%. Timely support was described as essential to prevent service gaps and loss of skills.



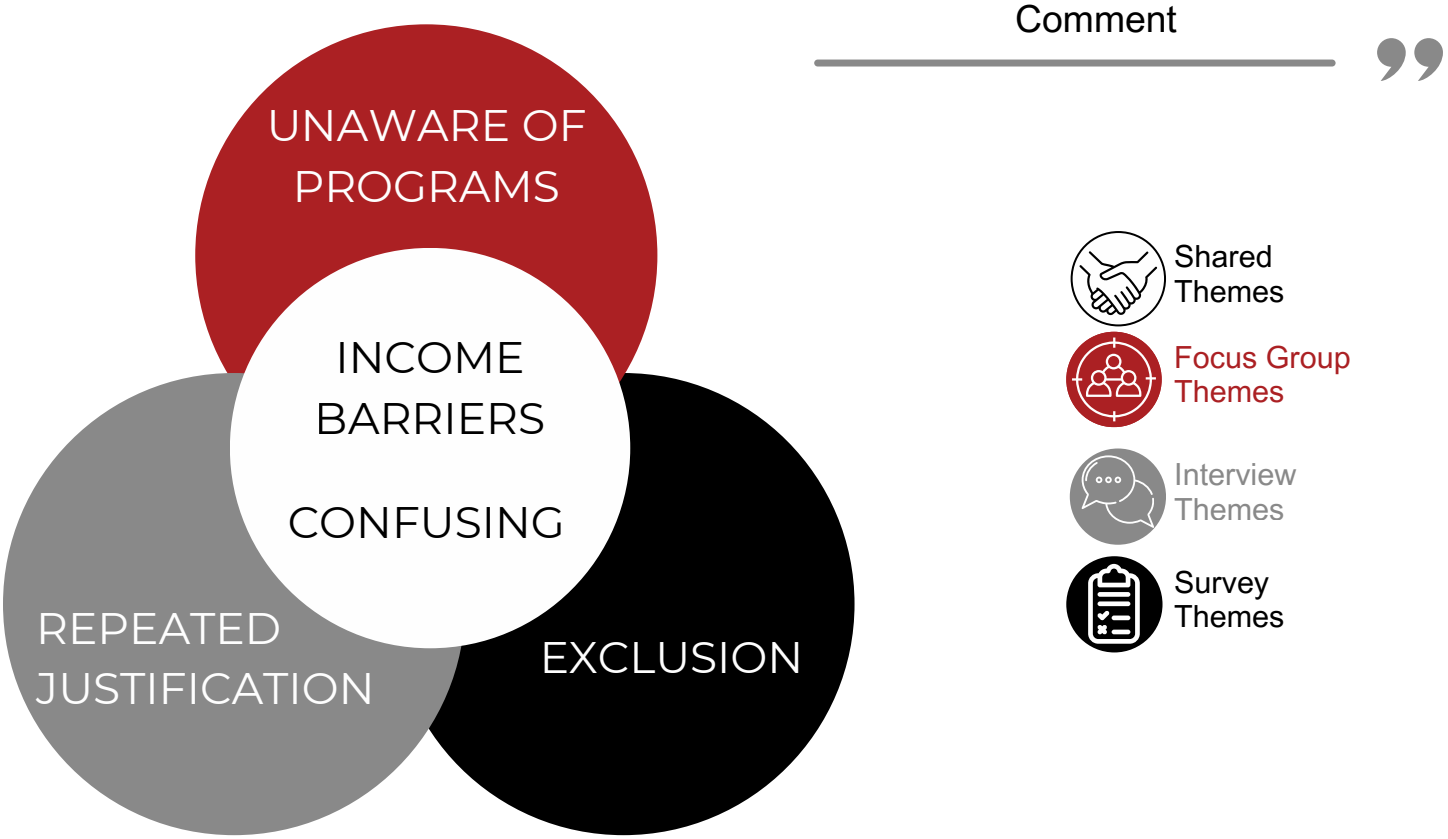
CRITERIA FOR ELIGIBILITY OF SERVICES
EXPERIENCES

The following section summarizes key findings gathered through focus groups, interviews, and survey comments related to service eligibility. Participants described barriers related to complex rules, repetitive requirements, and inequities in access. The figure presents themes for each group, as well as shared themes across groups.

Service eligibility rules were described as confusing, repetitive, and unfair. Families often did not know about the existing programs until years later. Parents in interviews expressed frustration at being required to re-justify services for long-term conditions. One parent explained, “Once qualified, there’s no reason they should have to justify every 30 days.” Others pointed out that income-based cutoffs excluded families who still had significant needs. Overall, these perspectives show that eligibility processes are a major barrier to equitable access to services.

> ***We shouldn’t have to work less to qualify for Medicaid.***
> - Parent, Spanish Focus Group

> ***Income cutoffs left us without help, even though we still had needs.***
> - Family Member, Survey Comment

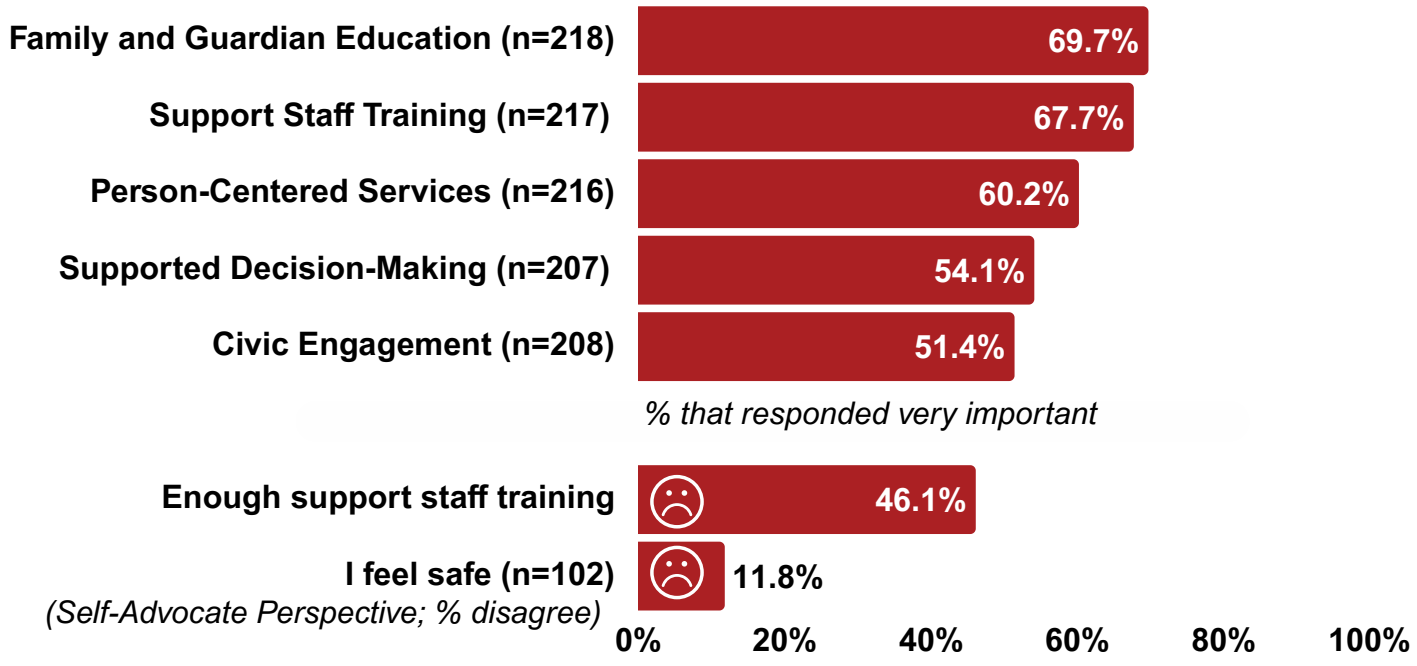


Survey results showed strong concern for smoother, more equitable service access, particularly for individuals with dual needs and during school-to-adult transitions. Families and self-advocates described challenges with delays and inconsistent planning. Together, the findings point to the need for coordinated, streamlined eligibility processes that reduce barriers and prevent service gaps.

QUALITY ASSURANCE
SURVEY RESULTS

Information was gathered on quality assurance and self-determination, focusing on how individuals with intellectual and developmental disabilities are supported to make choices and participate fully in their communities. A guardian was defined for participants as having the legal right to make decisions for a person with a disability who cannot make important decisions on their own.

- **Family and Guardian Education:** A majority of respondents (69.7%) highlighted the importance of providing education and support so guardians and families can better understand available options and resources.
- **Support Staff Training:** Approximately two-thirds (67.7%) emphasized the need to increase staff knowledge and skills to improve communication with individuals with intellectual and developmental disabilities**.**
- **Person-Centered Services:** Many participants (60.2%) prioritized having services that are led by the individual receiving them. This reflects strong support for person-centered planning approaches that place the person's goals and preferences at the center of decision-making.
- **Supported Decision-Making:** Just over half (54.1%) stressed the importance of helping individuals with intellectual and developmental disabilities make their own choices through Supported Decision-Making, rather than relying solely on guardianship.
- **Civic Engagement:** Slightly more than half (51.4%) underscored the value of increasing opportunities for civic participation, including voting and engaging with policymakers.
- **Self-Advocate Perspectives:** Some individuals shared that their **support staff does not have enough training to understand them** (46.1%), and a smaller group reported **they do not feel safe** (11.8%). These perspectives underscore the importance of stronger staff preparation and creating environments that promote both dignity and safety.



QUALITY ASSURANCE EXPERIENCES

The following section summarizes key findings gathered through focus groups, interviews, and survey comments related to quality assurance and self-determination. Perspectives reflect concerns about oversight, accountability, and inclusion of individuals in decisions that affect their lives. The figure presents themes for each group, as well as shared themes across groups.

Families and individuals expressed concerns about oversight and accountability in services. Self-advocates described wanting a stronger voice in school and service planning. Parents highlighted that “They’re not having families and people with disabilities at the table to discuss the barriers,” while providers noted the tension that occurs when guardians have control. Self-advocates described wanting a stronger voice in school and service planning. Taken together, these findings show that people with disabilities want to be included in decisions that affect their lives, but often are not.

> ***People with disabilities want to be included in decisions that affect their lives, but often are not.***
> -Self-Advocate, Interview

> ***Sometimes the guardians like to take over… and it’s not really the individual’s input.***
> -Interview, Service Coordinator

Shared Themes

Focus Group Themes

Interview Themes

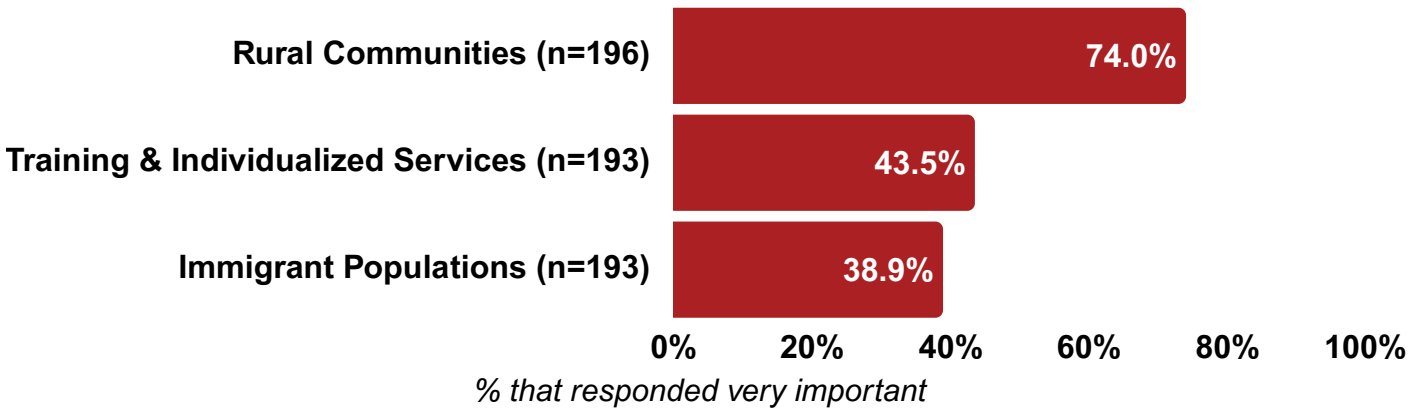
Survey Themes

Survey and qualitative findings both underscore the importance of dignity, choice, and safety. Respondents emphasized the need for stronger staff training, expanded family education, and increased opportunities for supported decision-making. Self-advocates also raised concerns about safety and communication with staff, pointing to the need for systemic improvements that promote self-determination and protection.

REACHING UNDERSERVED COMMUNITIES
SURVEY RESULTS

Information was gathered on how to better reach underserved communities, including immigrant families, rural areas, and culturally diverse populations. The findings point to the importance of tailoring supports, expanding outreach, and addressing gaps in access.

- **Rural Communities:** Nearly three-quarters (74.0%) emphasized the importance of addressing unmet needs in rural areas, reflecting concerns that developmental disability supports are often limited or unavailable outside urban centers.
- **Cultural Training and Individualized Services**: A need for providers to receive more cultural training and to create individualized services was emphasized by 43.5%, pointing to the importance of tailoring supports to families' unique backgrounds and circumstances.
- **Immigrant Populations:** Intentional outreach to immigrant populations was prioritized by 38.9% to ensure families are aware of and connected to developmental disability services.

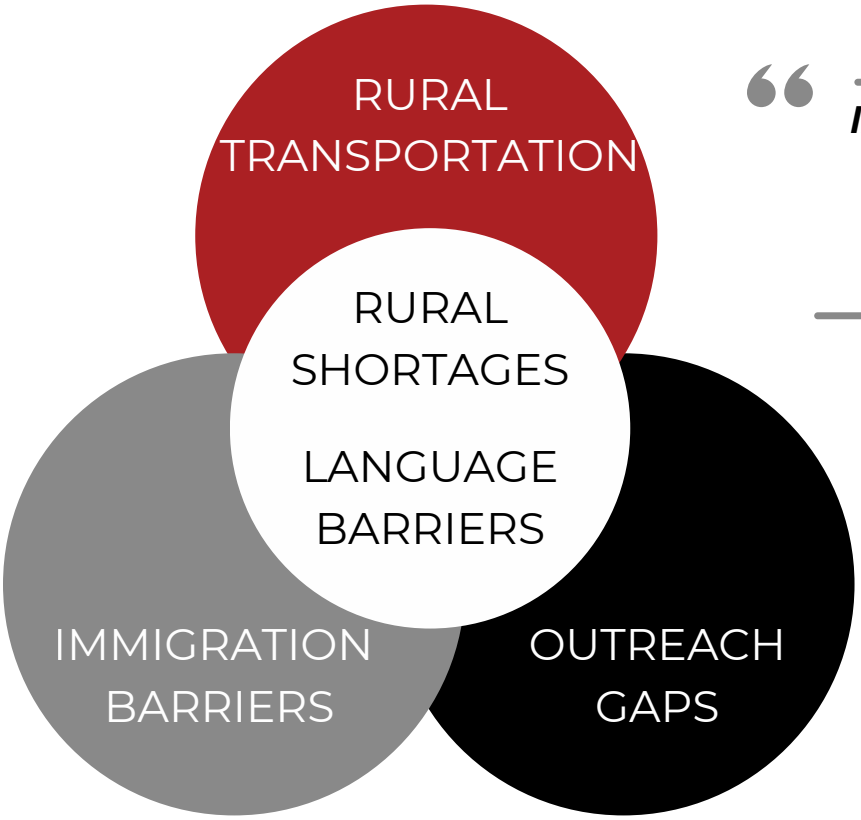


REACHING UNDERSERVED COMMUNITIES EXPERIENCES

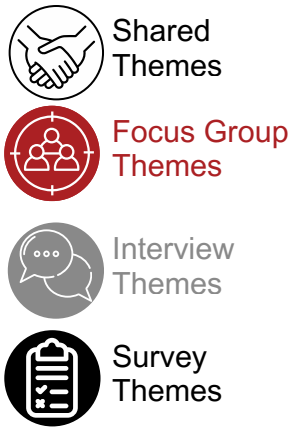
The following section summarizes key findings gathered through focus groups, interviews, and survey comments related to reaching underserved communities. These findings underscore the disproportionate barriers faced by rural, immigrant, and minority populations. The figure presents themes for each group, as well as shared themes across groups.

Underserved groups, including rural and immigrant families, faced disproportionate barriers. Self-advocates described transportation gaps in rural communities as especially isolating. Parents noted that immigration status prevents many families from qualifying for services. Families explained, “All resources are limited in rural areas… families drive hours for care.” These findings underscore that inequities are greatest for those least able to access services.

> ***Transportation gaps in rural communities are especially isolating.***
> - Self-Advocate, Focus Group



> ***Immigration status prevents many families from qualifying for services.***
> - Parent, Interview

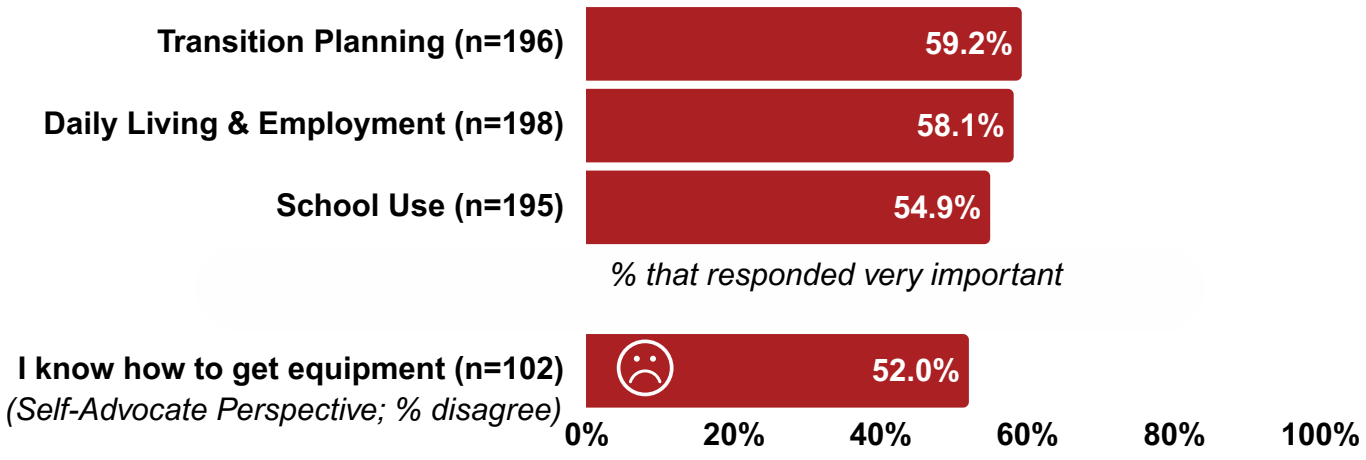


Findings consistently highlight disparities in access for rural, immigrant, and culturally diverse populations. Families described language, affordability, and availability barriers, particularly for older children and those with complex needs. Both quantitative and qualitative data emphasize the importance of tailored outreach, culturally responsive supports, and intentional system design to reach all communities.

ASSISTIVE TECHNOLOGY
SURVEY RESULTS

Information was gathered on the role of assistive technology (AT) in supporting individuals with developmental disabilities across school, daily life, and employment. Findings emphasized the importance of improving understanding, access, and planning for AT to increase independence and long-term success.

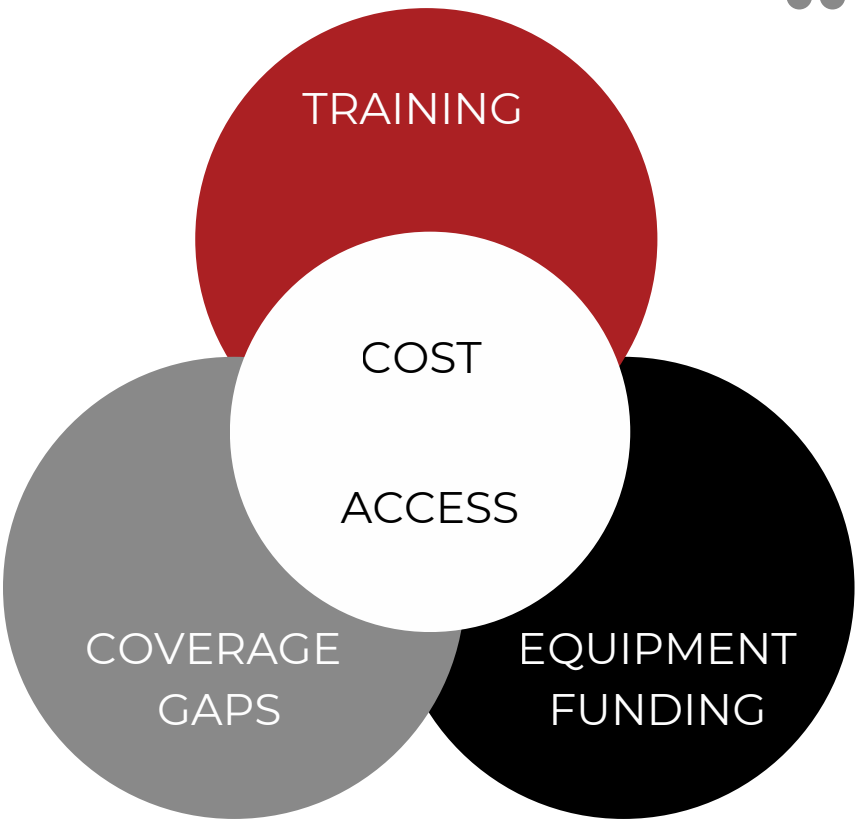
- **Transition Planning:** Improving transition planning for assistive technology as students move from school to adulthood was emphasized by 59.2%, ensuring supports remain consistent across life stages.
- **Daily Living and Employment:** Supporting the use of assistive technology to promote independence in daily living, health maintenance, and employment was prioritized by 58.1%.
- **School Use:** Over half (54.9%) said it is very important to help schools understand how assistive technology can be used to support learning.
- **Self-Advocate Perspectives:** 52.0% reported **they do not know how to get equipment** (assistive technology or durable medical equipment), underscoring the need for clearer guidance and training on access.



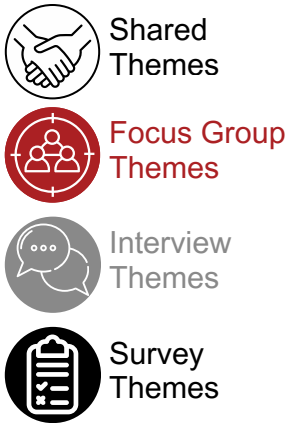
ASSISTIVE TECHNOLOGY EXPERIENCES

The following section summarizes key findings gathered through focus groups, interviews, and survey comments related to assistive technology. These perspectives highlight both the essential role of assistive technology in promoting independence and the barriers created by costs, training gaps, and lack of access. The figure presents themes for each group, as well as shared themes across groups.

Assistive technology was identified as essential but often inaccessible. Families reported that costs and coverage gaps left them without needed equipment. Self-advocates noted the need for training to use devices effectively, saying, “Training is not provided—families don’t know how to use the devices.” Collectively, participants described assistive technology access as critical to safety and independence, yet systemically underfunded.



> ***The state does not provide enough options for adaptive equipment… this is a critical need.***
> - Parent Interview



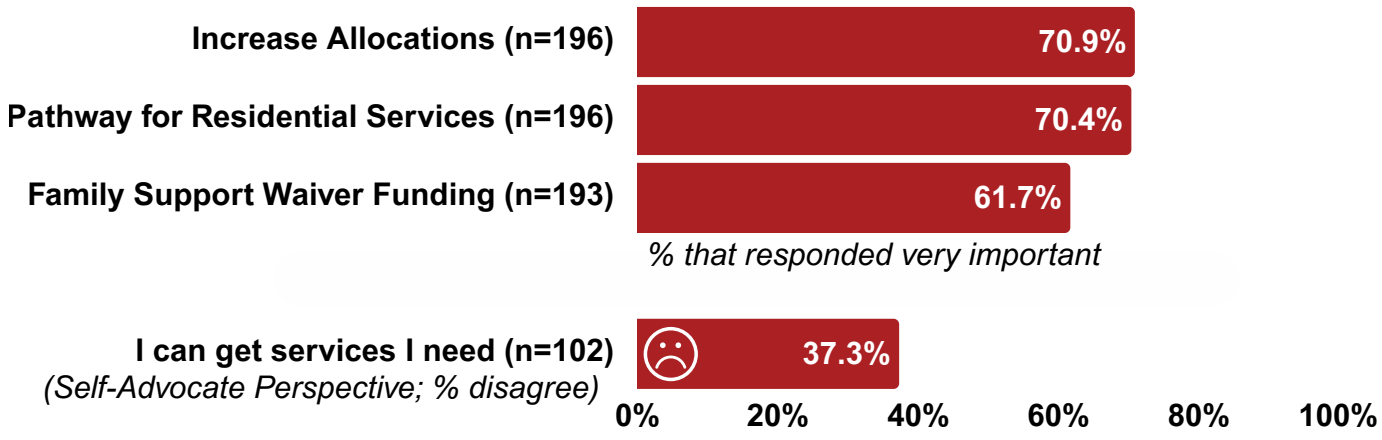
Survey and qualitative findings align in emphasizing the importance of understanding, access, and continuity of assistive technology supports. Families and self-advocates described confusion about obtaining equipment and inconsistent planning for transitions. These results highlight the need for more clear guidance, stronger planning, and greater integration of assistive technology across education, daily life, and employment.

WAITING LISTS
SURVEY RESULTS

As part of the survey, participants were provided the following definition: Home and Community-Based Services are provided through the Medicaid program. These critical services help people with Intellectual and Developmental Disabilities (I/DD) live full and independent lives in their communities, with support in activities of daily living, meal preparation, employment support, medication management, and more. Information gathered in this area highlighted the urgent need to reduce waiting lists and ensure funding adequately meets individual and family needs.

- **Increase Allocations:** Increasing funding allocations for Home and Community-Based Services Developmental Disabilities Waivers was identified as very important by 70.9%.
- **Pathway for Residential Services:** Ensuring that the Developmental Disabilities Department's assessment provides a clear pathway to residential services when needed was emphasized by 70.4%.
- **Family Support Waiver Funding:** Guaranteeing that allocations for the family support waiver are sufficient to meet all family needs was prioritized by more than half (61.7%).

- **Self-Advocate Perspectives:** More than one-third (37.3%) reported that they cannot access the services they need due to waiver waiting lists, underscoring the impact of delays and shortages on their daily lives.

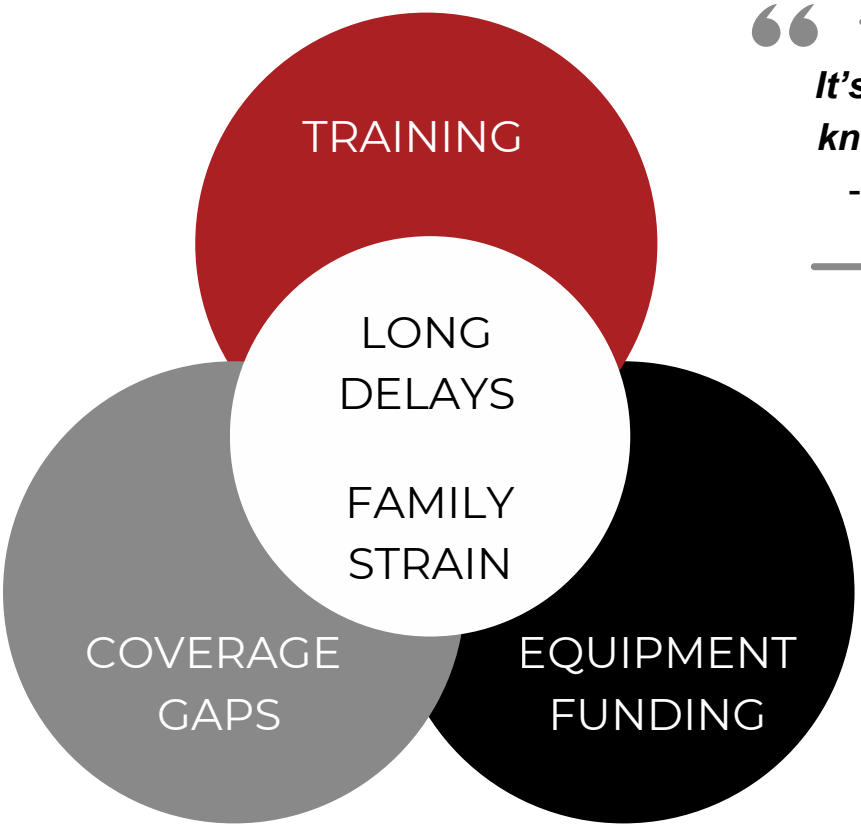


In 2024, Governor Jim Pillen and the Nebraska Department of Health and Human Services launched an initiative to eliminate the state's developmental disabilities waitlist by June 2025. The Division of Developmental Disabilities replaced the previous one-size-fits-all model with a tiered system that allocates supports based on assessed need. Over 3,000 individuals have since received services, most through new family support waivers providing up to $10,000 annually for children living at home or with access to Medicaid health services based on level of care rather than parental income. This approach has reduced costs and expanded access; however, advocates continue to express concern about provider capacity and the adequacy of lower-level supports. Others caution that adults may face limited opportunities to obtain residential services, such as group home or Shared Living Provider placements.

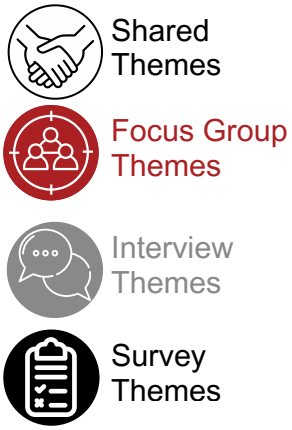
WAITING LISTS EXPERIENCES

The following section summarizes key findings gathered through focus groups, interviews, and survey comments related to waiting lists. Families and self-advocates highlighted the stress and inequities resulting from prolonged delays in accessing services. The figure presents themes for each group, as well as shared themes across groups.

Waiting lists were universally criticized as too long and discouraging. Self-advocates highlighted how extended waits disrupt transitions after high school, while parents described delays so discouraging that some families chose not to apply at all. Participants also emphasized the need for improved training for families on how to navigate the system and for staff to provide accurate and timely guidance. Collectively, these findings demonstrate that waitlists undermine trust in the system and limit timely access to essential services.



> ***It's hard to even begin when you know you'll be waiting for years.***
> - Parent, Spanish Focus Group



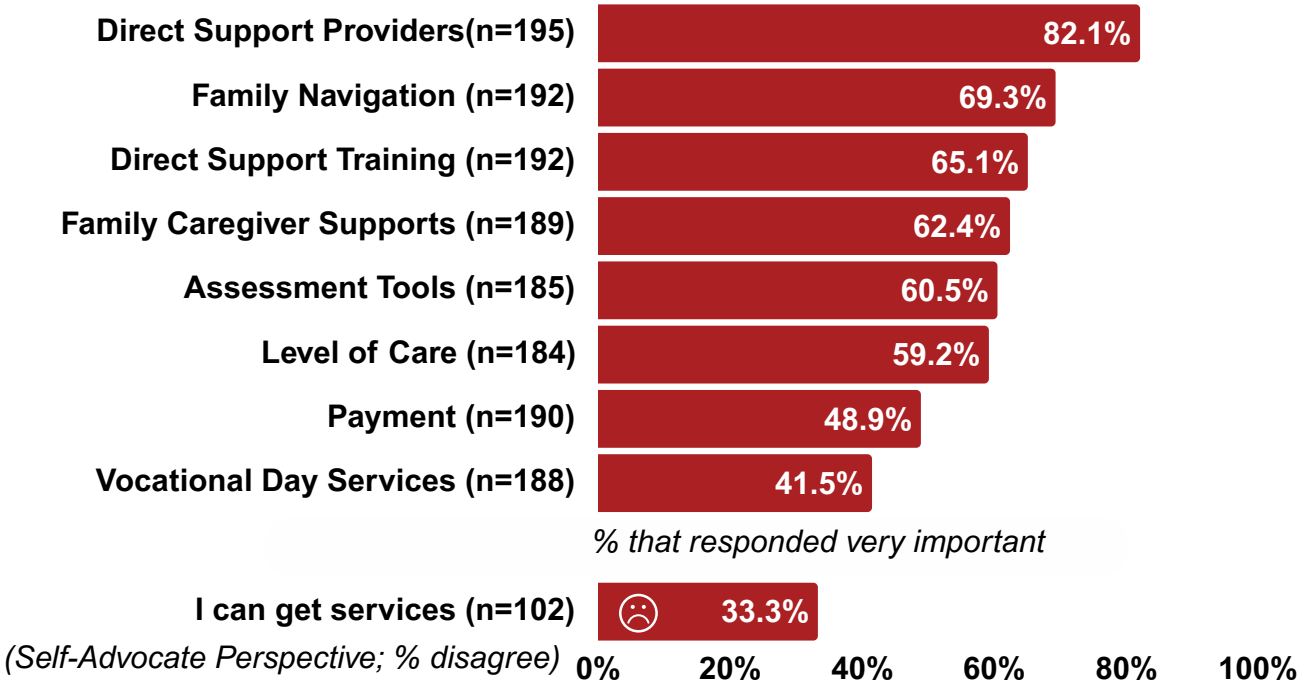
> ***We need access to numbers on the list to avoid despair.***
> - Parent, Survey Comment

Across all methods, waiting lists were identified as a critical barrier to accessing needed supports. Families and providers stressed the urgency of increased funding and transparency, while self-advocates described the impact of inadequate waivers on daily life. Together, these findings underscore the pressing need for system-level reforms to reduce delays and ensure resources match demand.

ADEQUACY OF WAIVER SERVICES
SURVEY RESULTS

As part of the survey, participants were provided with the following definition: A guardian has the legal right to make decisions on behalf of a person with a disability who is unable to make important decisions on their own. Information was gathered about waiver services, with findings highlighting workforce shortages, assessment challenges, and the need for greater flexibility and family support.

- **Direct Support Providers:** The large majority (82.1%) identified addressing the shortage of Direct Support Providers as very important.
- **Family Navigation:** Helping families understand and use available waiver services was emphasized by 69.3%.
- **Direct Support Training:** Providing more training for Direct Support Providers was prioritized by 65.1%.
- **Family Caregiver Supports:** Offering better support for unpaid family caregivers was highlighted by 62.4%.
- **Assessment Tools:** More than half (60.5%) raised concerns with the new interRAI assessment tool, noting its potential to impact access to services or reduce waiver budgets.
- **Level of Care Assessments:** More than half (59.2%) emphasized the importance of monitoring planned changes to institutional or nursing facility level of care assessments, which determine eligibility for DD and A&D waiver services. Families expressed concern that changes could limit access or reduce the level of support available to individuals who rely on these services.
- **Payment to Legally Responsible Individuals:** Allowing related individuals or guardians to be paid for providing services to their child or adult with disabilities was supported by 48.9%.
- **Vocational Day Services:** Removing the 35-hour cap on weekly vocational day services was called for by 41.5%.
- **Self-Advocate Perspectives:** One-third (33.3%) reported **they cannot get the services they need because their waiver does not provide enough money**, highlighting the direct impact of underfunded services on daily life.

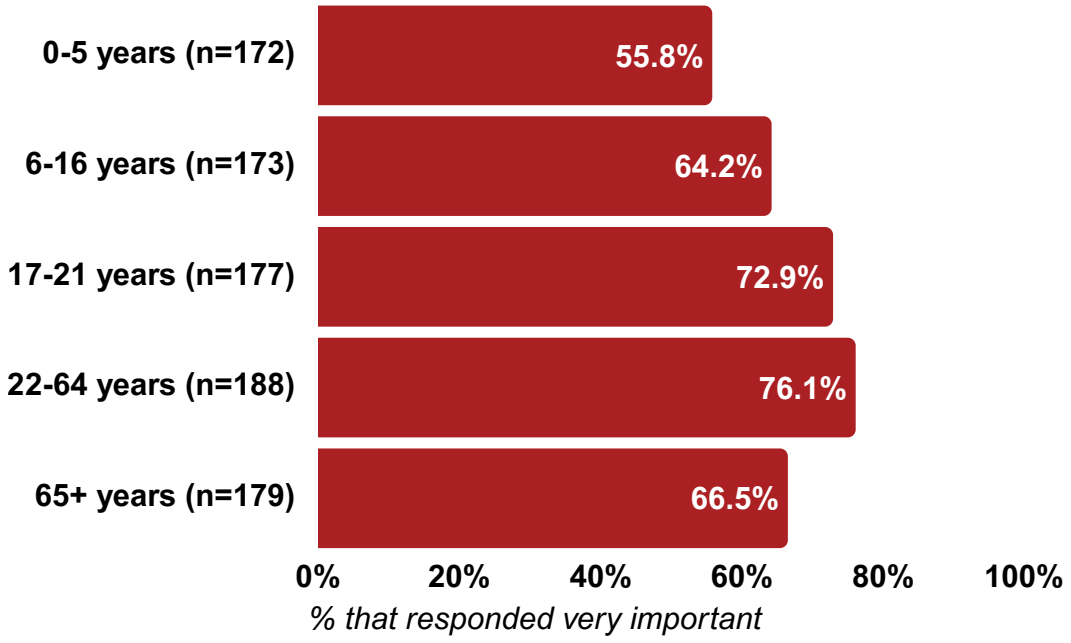


ADEQUACY OF WAIVER SERVICES BY AGE GROUP
SURVEY RESULTS

This section assessed the importance of current waiver programs that support families in Nebraska. Findings highlight the need for waiver services across the lifespan, from early childhood through older adulthood, with particularly strong support for services during the transition to adulthood and the working-age years.

- **Early Childhood (0–5 years):** Just over half (55.8%) emphasized the importance of providing waiver services for young children, recognizing the value of early intervention.
- **School-Age (6–16 years):** Nearly two-thirds (64.2%) said it is very important to ensure waiver supports for school-age children.
- **Transition to Adulthood (17–21 years):** Almost three-quarters (72.9%) reported that services for youth preparing to transition from school into adult life, employment, and independence are very important.
- **Adults (22–64 years):** More than three-quarters of respondents (76.1%), identified waiver services for this age group as very important, reflecting the need for ongoing support to sustain independence and community participation.

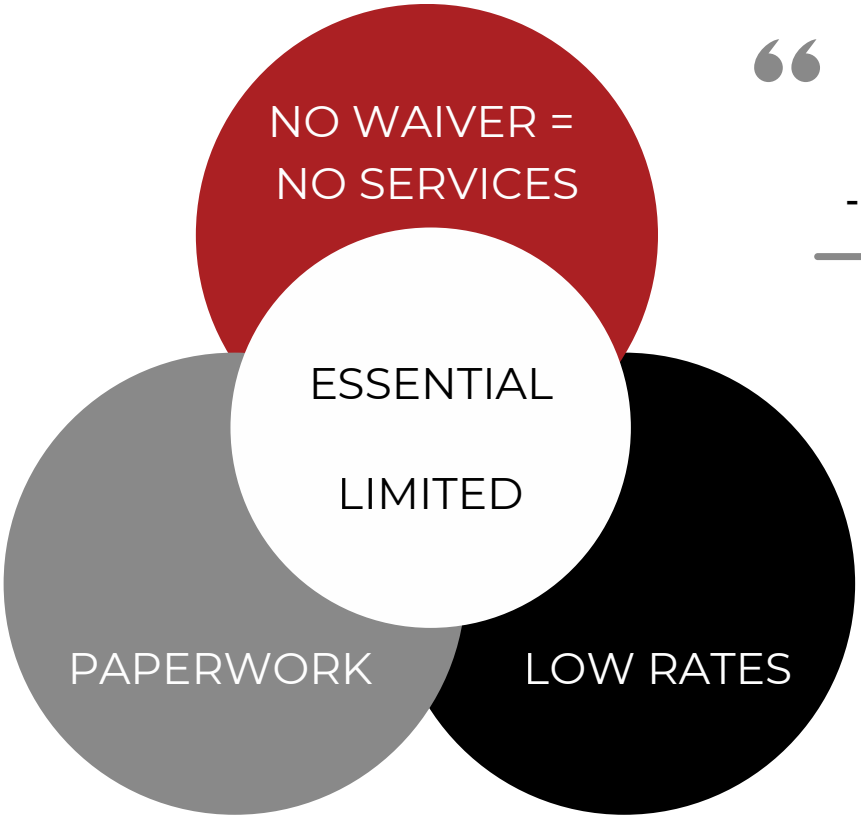
- **Older Adults (65+ years):** About two-thirds (66.5%) emphasized the importance of waiver services for older adults with developmental disabilities, ensuring stability and quality of life as they age.



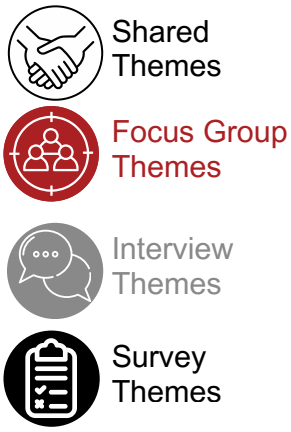
ADEQUACY OF WAIVER SERVICES
EXPERIENCES

The following section summarizes key findings gathered through focus groups, interviews, and survey comments related to waiver services. Participants emphasized the importance of these supports, while also noting changes in funding, as well as barriers to eligibility and availability. The figure presents themes for each group, as well as shared themes across groups.

Waiver programs were described as lifelines, but also as far too limited to meet needs. Self-advocates shared that those without waivers often have no meaningful supports. Parents described paperwork and renewal processes as overly burdensome. Families expressed concern that pay rates under the A&D waiver are extremely low and create unsafe conditions. Together, these findings underscore that while waivers are essential, they remain fragile and insufficient.



> ***If you're not on a waiver, there's nothing for you.***
> - Self Advocate, Focus Group



> ***The pay rate for my son on the AD waiver is pitiful and dangerous.***
> - Parent, Survey Comment

Survey and qualitative findings highlight workforce shortages, training needs, and family navigation challenges as major concerns. Families emphasized the need for flexibility across the lifespan, including early intervention, transition to adulthood, and aging services. Self-advocates echoed that delays and limits in waiver services restrict independence. These findings point to the importance of a comprehensive, well-supported waiver system that adapts to individual and family needs.

PRIORITY AREAS

Respondents were asked to identify their top two priority areas. A total of 184 people provided a first priority, and 179 people ranked a second priority.

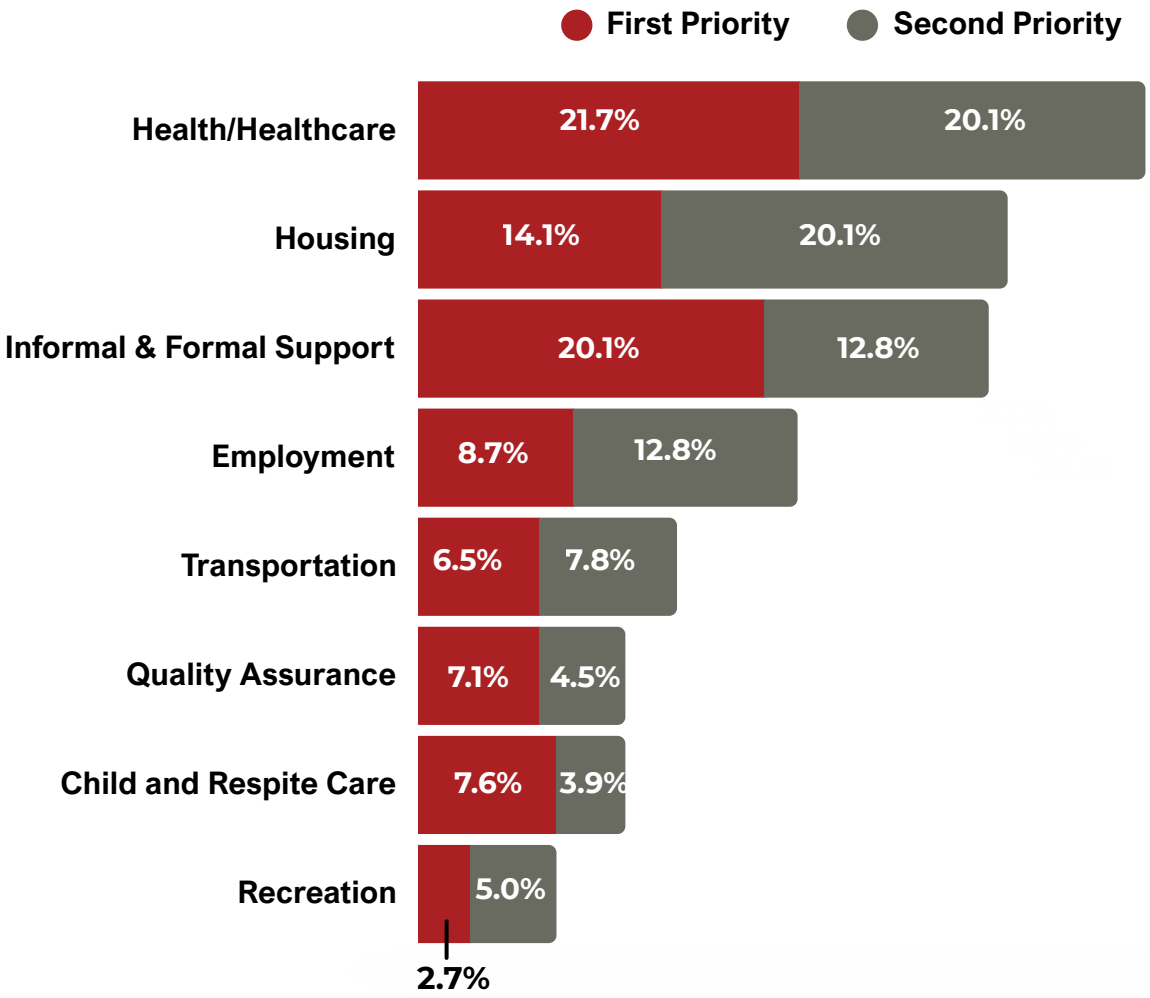
Health and healthcare was the leading concern, with 21.7% selecting it as their first priority and 20.1% naming it as their second. Housing was also highly ranked, with 14.1% identifying it as their first priority and 20.1% as their second. Formal and informal supports were another major focus, receiving 20.1% of first-priority responses and 12.8% of second-priority responses.

Other areas identified as important area of focus included employment (8.7% first, 12.8% second), transportation (6.5% first, 7.8% second), and quality assurance/self-determination (7.1% first, 4.5% second). Childcare and respite care (7.6% first, 3.9% second) and recreation (2.7% first, 5.0% second) were also noted, though to a lesser extent.

These results highlight healthcare, housing, and support services as the highest priority areas for respondents.

Health and healthcare was the top priority

Housing was the second highest priority



AUDIO NARRATION USE AND SATISFACTION

Audio narration was available for all questions on both the English and Spanish Needs Assessment and the Self-Advocate surveys.

Needs Assessment Survey

236 individuals completed the survey

8 (4.3%) of participants **used the narration option. 75%** of those participants used it **often,** and the other **25% sometimes used it.**

100% 100% of respondents reported being happy with the narration.

Self-Advocate Survey

102 self-advocates completed the survey

13 (12.7%) of the 102 self-advocates **used the audio narration feature.**

100% 100% of respondents reported that the voice narration was helpful.

Overall, these findings show that while use of the narration option was relatively limited, those who relied on it found it helpful and expressed high levels of satisfaction.

KEY FINDINGS AND PRIORITIES

The 2025 NCDD Five-Year Needs Assessment gathered input from families, self-advocates, professionals, and community members across Nebraska to identify the most critical needs and priorities for individuals with developmental disabilities. Guided by the federally defined areas of emphasis in the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), and expanded with Nebraska-specific priorities identified by the NCDD planning committee. The assessment was conducted to guide the NCDD's planning process and ensure that future resources, policies, and advocacy efforts are responsive to the most pressing needs of individuals with developmental disabilities and their families. This assessment provides a comprehensive picture of current challenges and opportunities.

> ***People with disabilities want the same things as anyone else—to live, work, and be part of their communities.***
> -Self-advocate, focus group

Findings highlight strong needs across multiple areas. Health and healthcare access emerged as the highest priority area, particularly improving Medicaid navigation, access to providers, behavioral health services, and coverage for specialists. Housing was the next most pressing concern, with families and individuals stressing the need for affordable, accessible options and flexible supports such as intermittent waiver services. Informal and formal supports, including respite, waiver navigation, and peer support, were also noted as essential for sustaining caregiving and promoting independence.

Other areas of importance included increasing employment opportunities and strengthening early transition planning, addressing persistent gaps in transportation access and reliability, and supporting inclusive education at all levels. Quality assurance and self-determination were also prioritized, with emphasis on improving staff training, providing education to family members and guardians, and promoting Supported Decision-Making. Additional concerns were raised around reaching underserved communities, expanding access to assistive technology, reducing waiting lists, and ensuring waiver services are adequately funded and flexible enough to meet the diverse needs of families across the state.

These findings provide a roadmap for addressing systemic barriers and expanding opportunities for individuals with developmental disabilities to live full, inclusive lives in their communities. This needs assessment will directly inform the NCDD: Nebraska Council on Developmental Disabilities next five-year plan, ensuring resources and advocacy efforts focus on the most urgent priorities identified by families, self-advocates, professionals, and community members. By centering these priorities, the Council can advance equity, inclusion, and meaningful opportunities for individuals with developmental disabilities and their families across Nebraska.