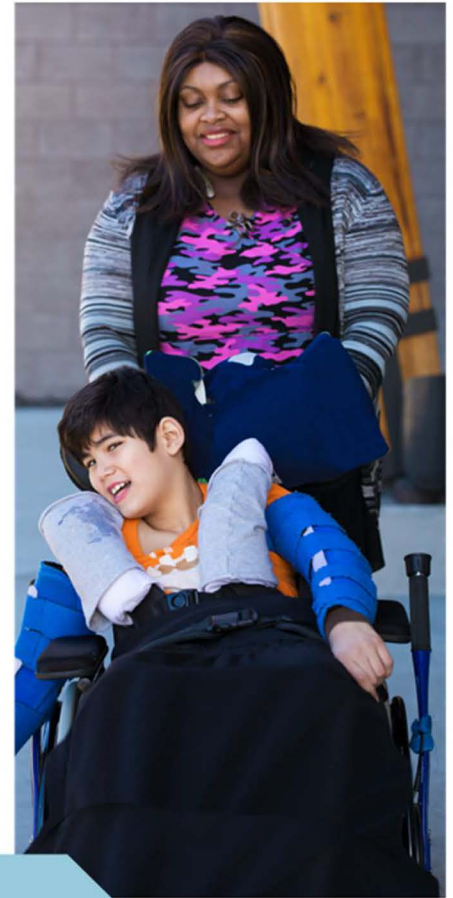


Nebraska Council on Developmental Disabilities

Needs Assessment Report | October 2020



Collaborate. Evaluate. Improve.

Interdisciplinary Center for Program Evaluation

Nebraska Council on Developmental Disabilities Needs Assessment Report

PURPOSE

The Nebraska Council on Developmental Disabilities 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 their mission, every five years the Council completes a needs assessment in order to identify ways to make a positive difference in the lives of individuals with developmental disabilities and their families. This report will provide the results of the 2020 Needs Assessment which will provide guidance for future activities of the Council.

METHODOLOGY

Process

Munroe-Meyer Institute (MMI), at the University of Nebraska Medical Center, was contracted to implement the needs assessment process 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. Data collection was conducted 7/1/2020 through 9/21/2020.

Needs Assessment Survey

The needs assessment survey was created based on guidance from the Developmental Disabilities Assistance and Bill of Rights Act. The areas of emphasis included: recreation, child care, housing, health/healthcare, quality assurance, education and early intervention, informal and formal supports, transportation, employment, criteria for eligibility of services, barriers of underserved/unserved, assistive technology, waiting lists, adequacy of healthcare facilities, emergency preparedness, and adequacy of waiver services. Family members, guardians, and community providers were asked to rate items on a 4-point scale (*very important* to *not important*). In addition to rating the questions, respondents were asked to select two top priorities from the areas of emphasis. Self-advocates were asked to answer a series of questions using a thumbs up (agree) or thumbs down (disagree). The Council reviewed the survey questions and provided feedback. The surveys were available in both English and Spanish and were offered in electronic and print formats. The survey was broadly distributed through targeted email lists and requests to agencies to assist in multi-modal dissemination, including text and social media posts. A concerted effort was made to reach minority populations. MMI staff partnered with key parent groups and a self-advocate group who helped to recruit participants to complete the survey or participate in focus groups.



Focus Groups and Interviews

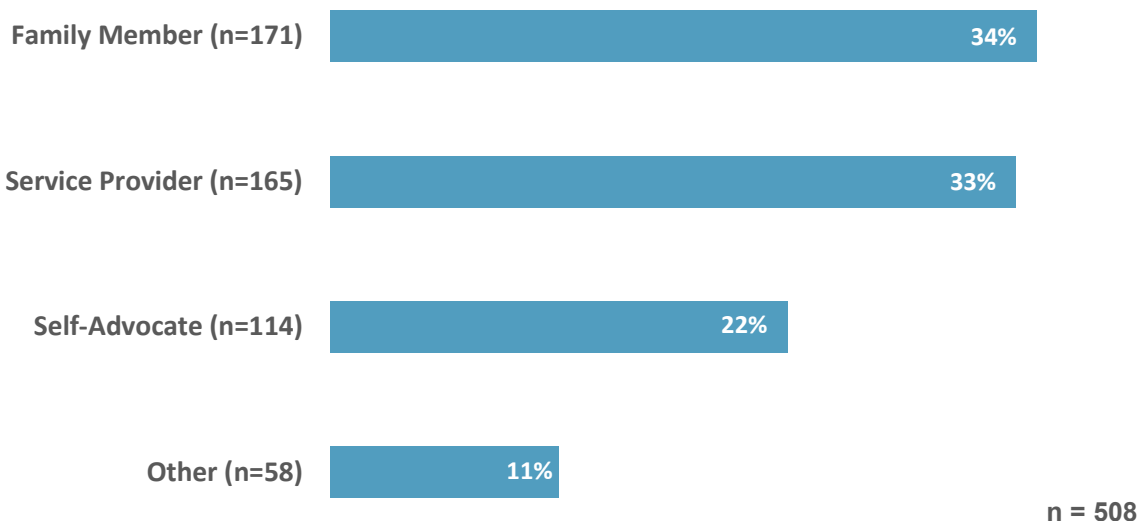
The second phase of the assessment process included the completion of interviews and focus groups. Participants either volunteered to be interviewed when they completed the survey or agreed to be participate in a focus group after being identified through a partnering group. The interviewees represented a cross section of family members and individuals with disabilities. Due to the low numbers of responses to the Spanish survey, a focus group with parents and guardians who speak Spanish was prioritized. A low survey response rate from minority groups was noted. An effort was made to identify a group or individual(s) from a minority population to participate in a focus group or interview; however, recruitment efforts were unsuccessful.

EVALUATION FINDINGS

Description of Survey, Focus Group Respondents

The goal of the survey distribution was to have a broad representation including geographic distribution and language and ethnic diversity. A total of 508 individuals completed one of the two versions of the Developmental Disabilities Needs Assessment survey. A small number of the respondents (4%) completed the Spanish language survey. Most respondents were family members or care providers. Of the 448 respondents who provided their race, the majority were Caucasian (83%) and some were African-American (3.6%) or 2 or more races (4.2%). Several respondents indicated their race as unknown/preferred not to answer (9.6%). Respondents lived in a mix of rural (43%) and urban (57%) settings. A small number of respondents (5%) were of Hispanic origin. Of the 360 respondents who responded to the sexual orientation demographic question, the majority (93%) self-identified as heterosexual.

The majority of respondents were family members and care providers.



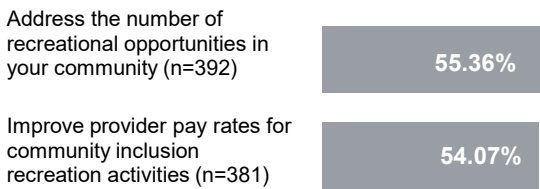
Three focus groups were held with a total of 20 participants. One group was comprised of self-advocates with nine participants, one of Spanish speaking parents/family members in a metropolitan area with 8 participants, and one included parents/family members in a rural setting with 4 participants. Eighteen interviews were conducted with a variety of participants including parents and self-advocates. The children of the participating parents ranged in age from 5-40 years of age and 39% reside in a rural area of the state.

Survey results are presented in the subsequent sections of this report. Family member and care provider responses are presented in blue if 60% or more of the respondents indicated the item was very important to address on the importance gradient. Self-advocates either agreed (thumbs up) or disagreed (thumbs down) with each survey item; therefore, if 30% or more of the respondents identified the item as an area of need, the item is highlighted blue.

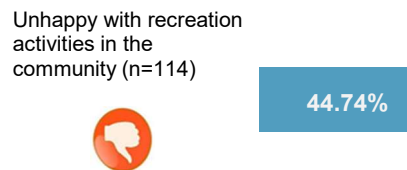
Recreation and Community Activities

Information was gathered on recreational, leisure, and social activities in communities that are available to individuals with developmental disabilities. Over half of the parents and providers indicated that it is very important to address the number of recreational opportunities available in their community (55.36%) and there is a need to improve the pay rates for providers for community inclusion recreation activities (54.07%). Similarly, many self-advocates (44.74%) expressed being unhappy with the number of recreation activities in their community.

Some family members and care providers feel it is very important to address recreation needs.



Many self-advocates are unhappy with the number of recreation activities in their community.



Families reported that there is a lack of opportunities for community inclusive recreation activities. These concerns were exacerbated in rural areas. In addition, where recreational activities exist, they are often difficult to get to or too expensive. “Families need to allocate their income towards living needs, and recreational needs fall low on the list...” This was substantiated by self-advocates who also identified lack of transportation and funds as key barriers to accessing recreational activities. Most public transportation such as “Ride” are only available during the day, with most self-advocates needing to rely on their families for transportation to recreational activities. Some self-advocates reported that they have informal gatherings at work, e.g., going out to lunch. Many enjoyed this type of activity, but some shared that they felt left out as they did not have money to participate. COVID-19 interrupted many activities that were previously available.

Several self-advocates reported that they have memberships to a fitness center, with some having that as part of their insurance package. Others would have liked to have this resource, but it was not



available to them. One downside is that many of the centers require that someone is with them, thus limiting their access to the facility.

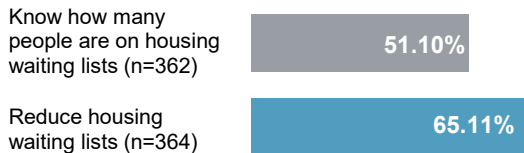
Especially lacking in all areas of the state are activities geared toward older teens and individuals with high needs due to severe intellectual disabilities, autism, or behavioral challenges. Community facilities were sometimes cited as not being very welcoming to older children with these disabilities. In addition, some venues for community activities are not accessible.

The need for greater community engagement and understanding was expressed, along with desires for relationships with members of the community. Many parents and providers voiced the need to address provider pay rates for recreational activities and improved provider training on how to provide inclusive community experiences.

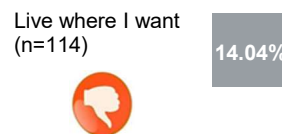
Housing

Information was gathered assessing the availability of affordable, accessible, integrated housing; housing supports and services, and services related to renting, owning, or modifying a residence. Many parents and caregivers expressed a need to know how many individuals are on the waiting list for housing (51.10%) and reducing housing waiting lists (65.11%). A small number (14.04%) of self-advocates indicated they do not currently live where they want to live.

Many parents and caregivers believe it is very important to address housing waiting lists.



A small number of self-advocates do not live where they want to live.



A primary theme emerged during interviews: the limited availability of safe, affordable, and accessible housing. There is concern about the amount of time individuals are on the waiting list to become eligible for housing. Several parents and providers indicated that there is limited public housing available in both rural and urban settings and the conditions of some options are unfavorable. These concerns are intensified as the parents grow older. For these families, it becomes critical to find alternative housing for their adult children. It was noted that there is a lack of residential programs in rural communities.

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There just is not a lot for my son to do in our rural setting unless I have my 16-year-old joining Kindergarteners at the splash pad.

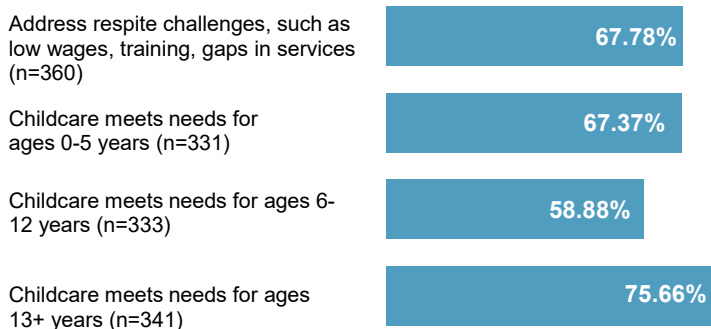
A parent reflects on recreational opportunities in her community

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Child Care and Respite Services

Information was gathered from survey, interview, and focus group participants to learn more about the before-school, after-school, early care services, and respite services in Nebraska communities. Parents and providers indicated that it is important to address child care and respite services in their communities. A large majority of respondents indicated it is very important to ensure child care meets the needs for individuals ages 13 and up (75.66%) and many indicated it is important to meet child care needs of children birth to five years (67.37%) and 6-12 years (58.88%). The need to address respite services was also rated as important. Over two-thirds (67.78%) believe it is very important to address challenges related to respite services, including low wages for providers, provider training, and gaps in respite services.

Parents and providers believe it is very important to address child care and respite services, particularly for children 13+ years



A predominant theme was the need for options for care for older children and teens. Many families also indicated that child care is unaffordable for those who are not eligible for subsidized child care funds. Families in rural areas indicated that child care and respite options in their area are very limited. Parents identified that care providers they used when their children were younger were unable to continue to provide that care after their children entered their teens due to some child care provider regulations (e.g. toileting needs). Some parents reported that the lack of child care led to loss of a job or inability to return to work. A similar theme emerged for respite services. As one parent said, “I think it (respite) is a great program if you can find the people. I don’t want to fill out a billion pieces of paper to be told I make too much money. It should be made available for anyone.” The lack of trained respite providers was noted across several interviews. Many suggested that the low wages paid to providers limited the number available. Additional barriers were encountered by Spanish speaking families who suggested that the application process for respite was difficult and time consuming for them and that it was difficult to find providers who were bilingual.

Health/Healthcare

Survey respondents, focus group participants, and interviewees provided information about available medical assistance, health and mental health services, and access to public and private insurance. Parents and providers indicated that it is very important (61.35%) to monitor Medicaid denials and support appeals. Similarly, nearly half (46.49%) of self-advocate survey respondents indicated that they need help or training to work with their insurance company or Medicaid.

Family members and care providers believe it is very important to monitor Medicaid denials and provide support during the appeals process.

Monitor planned changes to assessment of institutional level of care & implementation of changes (n=368)

59.51%

Monitor Medicaid denials & support appeals (n=370)

61.35%

Many self-advocates need help or training to work with their insurance company or Medicaid.

Know how to work with insurance or Medicaid (n=114)

46.49%



There were mixed responses related to access to Medicaid. Many self-advocates reported that they did not have problems with accessing



Medicaid, while others found the Medicaid process was difficult to maneuver. These individuals indicated that they needed help navigating the complex process to apply for Medicaid and wished for one place to go for help. The eligibility policy that is based on monthly income rather than

averaging the amount across multiple months or on an annual basis has created problems for some individuals with DD and limits their income.

Many barriers to access were noted by both family members and self-advocates. There are limited specialty healthcare providers (e.g., dentists, behavioral and mental health providers) who will accept Medicaid. It is often more difficult to find health providers who are trained appropriately or willing to serve individuals with significant disabilities or behavioral challenges. In addition, in rural areas, there is an overall lack of medical specialists, which results in extensive travel. This extensive travel poses a financial burden on the family.

Access to equipment and ongoing therapies was reported as an issue. Often equipment is denied, and individuals need to appeal. There is a concern that there is no one they can turn to for assistance with the appeal process. Even when equipment is approved, there are delays in getting it replaced if it does not work or is broken. Limitations on the amount of therapy services was noted to interrupt continuous access to services seen as necessary for sustainable progress.



Make the process easier and understandable for families, including having forms in different languages or offering services to help families fill out the application because it can be overwhelming and difficult.

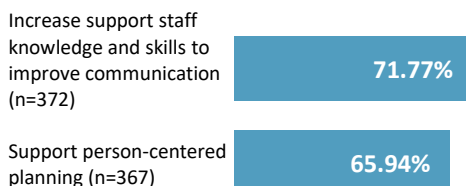
A parent reflects on the process of applying for Medicaid



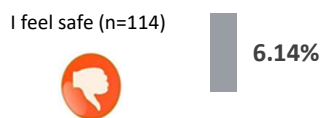
Quality Assurance

Information was gathered from survey, interview, and focus group participants to learn more about monitoring of services, supports, and assistance to prevent abuse and exploitation; interagency coordination and systems integration to improve and enhance services; access to person-centered planning; and training in leadership, self-advocacy, and training. Most parents and care providers (71.77%) who were surveyed indicated it is very important that support staff receive training to increase their knowledge and improve communication. Many of the respondents (65.94%) also rated the need to support person-centered planning as very important. While a small number of self-advocates (6.14%) reported feeling unsafe, many self-advocates (42.11%) reported that their staff needs more training to understand them and their needs.

Family members and care providers believe it is very important to improve communication with support staff and support access to person-centered planning.



A small number of self-advocates report they do not feel safe.



Many self-advocates believe their staff needs more training to understand them.



Information gathered from focus groups and interviews supported the survey data. Both family members and self-advocates reported that direct service providers need better training. One self-advocate reported that their gender identity was not respected and that direct service providers require additional training on how to respond to differences in gender identification and sexual orientation. Others indicated their direct service providers lack patience. There was concern that pay rates are low, which impacts attracting quality direct service providers and results in a high turnover rate for providers. It was expressed that programs need to support individuals across varying levels of need, and that assistance is needed to support decision making and accomplish person-centered planning.

Education and Early Intervention

Survey respondents, focus group participants, and interviewees provided information about general and special education services, early intervention services, early childhood services, education supports, and teacher training. Family members and care providers indicated that issues related to education and early intervention are important to address. Nearly three quarters (74.72%) indicated it is very important to improve the pre-service education preparation for secondary teachers to equip them with the skills necessary to support transitions. Approximately two-thirds of the respondents believe it is very important to increase recruitment and retention of special education workers (66.86%), support inclusion at all grade levels (65.13%), and provide training to prevent, reduce, and eliminate suspension and expulsion in early childhood programs (62.94%).

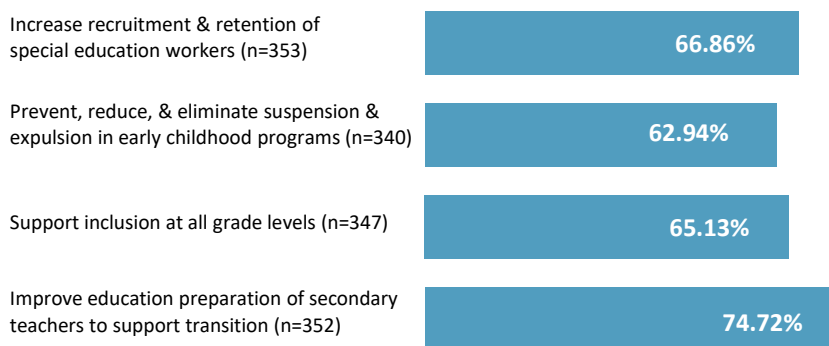
Families' experiences with the educational system varied greatly depending on the age of the child and the school district. It was suggested that efforts to increase consistency and quality between districts be considered. Most reported the best experiences in early intervention and in elementary classes, with a decrease in service satisfaction as their children

aged. A need for better training and pay (to increase retention) for school personnel, including paraprofessionals, was described by multiple parents. Others noted that there was a lack of professionals in certain specialties (e.g., deaf education), and more training on transition is needed at the pre-service level for secondary educators. Families noted being pleased with service coordination in early education programs and expressed a need for the same type of support in later years to improve communication and consistency.

Additional supports recommended include strategies that could connect parents with other parents who can provide guidance in engaging with their school. Some reported inclusion as critical, while others reported down sides to inclusion related to not receiving needed support in regular education classes. Transition services often were not started until the student was 16; many felt they did not have a good understanding of the process.

Many expressed concerns with the educational services they received once schools closed due to COVID-19. Many indicated that their students with disabilities did not get the same level of support as their peers without disabilities. For many families, online education did not work well for their children.

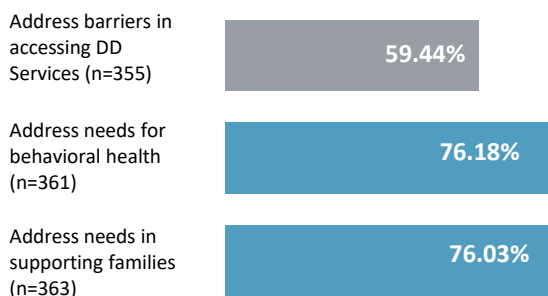
Family members and care providers believe it is very important to address multiple issues related to education and early intervention.



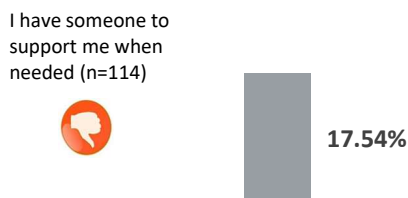
Informal and Formal Supports

Information was gathered from survey, interview, and focus group participants to learn more about social, child welfare, aging, independent living, and other services that are available to people with developmental disabilities and their families. Additionally, information was collected about family support efforts and policies, peer support initiatives, and home and community-based services. Most family members and care providers (76.03%) indicated that it is very important to address needs related to supporting families. They also expressed that there is a high level of importance (76.18%) to address behavioral health needs in the state. Nearly one-fifth (17.54%) of self-advocates reported not having someone to support them.

The majority of family members and care providers believe it is very important to address needs related to supporting families and behavioral needs.



Some self-advocates do not feel that they have someone to support them.



Themes from the focus groups and interviews supported the survey findings. Many reported confusion and frustration over their ability to find community resources and supports. The need for these supports was varied, whether that support was for applying for Medicaid, finding childcare, finding respite, housing, transition, seeking mental health or behavioral support. Several parents commented on the lack of resources for supporting aging caregivers. This was a recurrent theme in many areas with the issue being even more prevalent in rural communities. Two families who moved to Nebraska from other states commented on how difficult it can be to find information on the resources that are available. Respondents indicated a need for more training and resources available in Spanish and other languages.

Many families strongly recommended providing better supports to families by both providing a centralized on-line resource specifically for families of individuals with disabilities (DD) and providing a consistent contact that families could go to for support. It was recommended having one place or person to help with all the different services, rather than a contact for support for each type of service. Those families whose children received DD residential and/or day services and had a service coordinator reported a higher degree of satisfaction in this area,



It is difficult to get simple things for her that most people get naturally. I feel like sometimes I get nowhere.

A parent reflects on the process of getting resources in place for her daughter



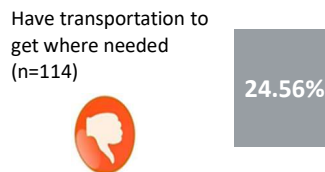
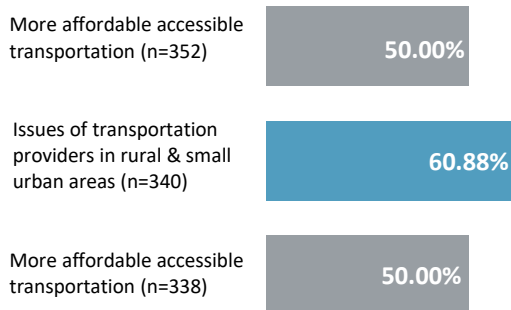
although there was some concern about turnover. Family members reported it is “confusing and frustrating” moving from the A & D waiver system to the developmental disabilities (DD) system. Families reported levels of frustration and stress in addressing financial, medical, or behavioral challenges. Families reported very little to very great financial impacts. Much of this depended on whether they had good insurance coverage - either through Medicaid, Medicare, private insurance, or a combination of those. Those who received DD residential and/or DD day program services reported less financial hardship.

Transportation

Survey respondents, focus group participants, and interviewees provided information on accessible public transportation services, paratransit services, and programs that promote community accessibility. Family and caregivers (60.88%) indicated that is very important to address transportation issues related to a lack of transportation providers in rural and small urban areas. Some self-advocates (24.56%) indicated that they do not have transportation to get where they need to go.

Family members and caregivers believe it is very important to address transportation issues in rural and small urban areas.

Some self-advocates do not have transportation to get where they need to go.



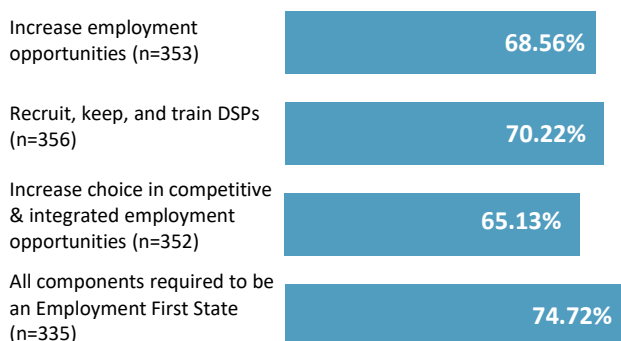
Self-advocates in the focus groups indicated that transportation was not an issue for most of them to get to their job or day program. Typically, either their parents drove them, they took public transportation, they could drive their own car, or the program provided transportation. One self-advocate indicated that transportation somewhat limited where she works as she needs to determine if she can get there herself instead of relying on other people. Family members reported a lack of affordable transportation as a barrier, especially in rural areas.



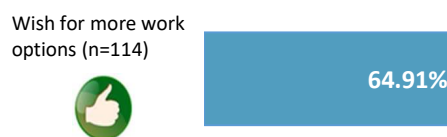
Employment

Information was gathered from survey, interview, and focus group participants to learn about issues related to employment such as job placement, vocational rehabilitation, integrated employment efforts, and employment policies. Family members and care providers identified employment as an area of importance across topics. Many of the respondents (74.72%) believe it is very important to address all required components for Nebraska to be an Employment First state. A high number of family members and care providers (70.22%) indicated that it is very important to recruit, train, and retain direct service providers. A common area of importance was identified across the respondents: many family members and care providers (68.56%) and self-advocates (64.91%) indicated that there is the need to increase employment opportunities, with many family members and care providers (65.13%) identifying that it is very important to increase choice in competitive and integrated employment opportunities.

Family members and care providers believe all employment issues are very important to address.



Many self-advocates wish for more employment options.



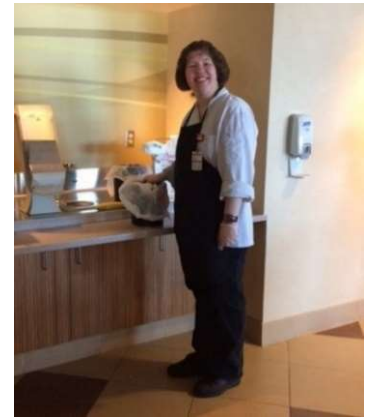
Many families were very positive about supporting individuals to work in the community, while other families criticized the Centers for Medicare and Medicaid Services (CMS) regulations and the state implementation of policies to eliminate the workshop model for day services. Those criticizing the move were typically happy with their previous day program experiences and did not see how individuals with high needs or behavioral challenges could be supported to work in the community. Multiple families referred to the practice of loading individuals on vans to meet community inclusion requirements for non-vocational day program services.

Other family members indicated there is a need to work with community employers to develop new job opportunities. Some mentioned a need to increase early employment planning in schools. For the individuals with complex or high support needs, a continuum of day service options needs to be expanded so that families can select the option that best fits the needs of the individual. It is important that there are options that are inclusive and include engaging activities within the community. Families need to have more support to find and work with employers or vocational and day programs.

Self-advocates reported that long waiting lists delayed them in seeking employment. They also indicated that limited transportation options impact employment possibilities. Others reported the Work Force Development is overwhelmed with requests for help. Several self-advocates reported that they have

been unemployed since COVID-19 started. Finding a job has been more difficult during this time. This has presented as a hardship for several. “We can’t get paid anymore.....it is harder to pay rent because we are not getting paid.”

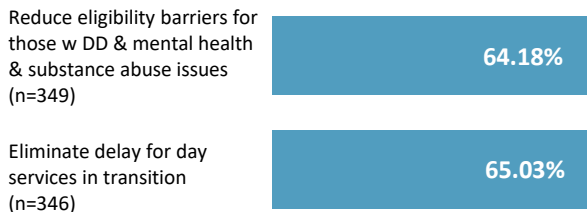
Families reported the need to expand the Vocational Rehabilitation system to provide on-site supports for individuals working in the community, and funding provided for DD services and vocational rehabilitation needs to be adequate to provide effective and consistent staffing. Some self-advocates reported that job coaches were not always viewed as helpful. “You have your own job coach who watches every move. It is really disturbing when someone is watching every move.” They reported that sometimes you get too much support, sometimes not enough.



Criteria for Eligibility of Services

Survey respondents, focus group participants, and interviewees provided information about eligibility criteria needed to access specialized services and supports. Family members and care providers identified that it is important to address barriers that delay and/or prevent access to services. Slightly less than two-thirds of respondents believe it is very important to reduce eligibility barriers for individuals with DD and co-occurring mental health and/or substance abuse issues (64.18%) and eliminate delays in receiving day services during transition (65.03%).

Family members and care providers believe it is very important to address eligibility barriers and eliminate the delay for day services in transition.



Information gathered through comments from family members and care providers on the survey further supported the need to address criteria for eligibility of services. Respondents commented that there are many barriers to work around just to receive basic service, and it is felt that denials and appeals are subjective and would benefit from monitoring so that individuals who are clearly eligible for services receive what they need. Some family members indicated that eligibility requirements result in many individuals needing services but being denied. It was suggested that the process of getting help for a child with disabilities should be clearly outlined in a form and on the website, and the information should be given to parents early. Multiple comments addressed the need to have substance abuse and mental health programs that are designed to serve individuals with DD, and it is believed that these programs should be covered by Medicaid.

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Support services seem out of reach and highly unlikely that our son will ever be considered in need enough, yet he is disabled in many cognitive areas that prevent him from getting and maintaining employment.

A parent reflects on the eligibility process

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Barriers of Underserved and Unserved Groups

Information was gathered from survey, interview, and focus group participants to learn about barriers that influence the ability of individuals with developmental disabilities from underserved and unserved groups to access and use services provided in their communities; participate in opportunities, activities, and events offered in their communities; and to contribute to community life. Survey results indicated that some family members and care providers believe it is very important to address the need for more cultural competency training and individualized services (44.94%) and that more intentional outreach to immigrant populations is needed (45.26%).

Some family members and care providers believe it is very important to address barriers for unserved and underserved groups.



Several themes related to underserved and unserved groups emerged from the focus groups, interviews, and survey comments. Multiple participants echoed the survey results in expressing the need to bolster directed outreach efforts to underserved populations, and the importance that we ensure all members of our communities are aware of service options. It was expressed that there is a lack of understanding of available services and that services are not equitable across groups. There is a need for translated materials, such as those needed to access services, and a need for bilingual providers (including providers who are fluent in sign language). Concern for the comfort level of immigrant populations in reaching out for services and supports due to immigration issues was expressed.



Assistive Technology

Survey respondents, focus group participants, and interviewees provided information on the availability of assistive technology, assistive technology services, and rehabilitation technology. Family members and care providers believe it is very important to increase awareness about assistive technology (50.28%) and professional development for changes in assistive technology delivery in schools (55.98%). Many self-advocates (42.98%) reported that they do not know how to obtain needed assistive technology equipment.

Family members and care providers believe it is very important to increase awareness about and professional development for changes in assistive technology delivery in schools.

Increase awareness about AT (n=356)

50.28%

Increase prof. dev. for staff in schools needed due to changes in AT service delivery (n=343)

55.98%

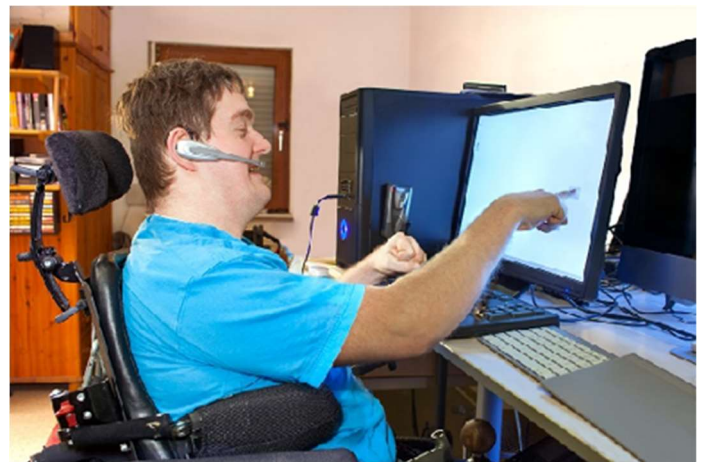
Many self-advocates do not know how to get assistive technology equipment that they need.

Know how to get needed equipment (n=114)



42.98%

Information gathered through comments from family members and care providers on the survey supported the need to explore assistive technology early and explore improvements that can foster independence. Respondents expressed a need to address the level of assistive technology training for service providers and ensure that thoughtful and flexible assessment of adaptive technology and thoughtful application of that technology is considered.



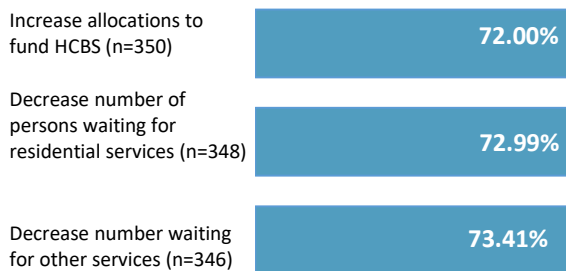
Waiting Lists



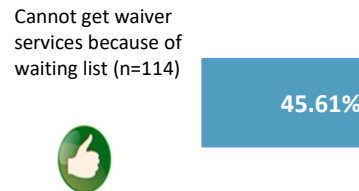
Information was gathered from survey, interview, and focus group participants to learn the experiences of individuals on residential and other services waiting lists, the eligibility and needs assessment process, and the issues and challenges of the state waiting lists. Most family members and care providers believe it is important to address issues related to waiting lists. Nearly three-fourths of respondents believe it is very important to increase allocations to fund Home and Community Based Services (HCBS) waivers

(72.0%), and decrease the number of persons waiting for residential services (72.99%) and on waiting lists for other services (73.41%). Nearly half (45.61%) of self-advocates reported that they are unable to get waiver services due to the waiting list.

The majority of family members and care providers believe it is very important to address allocations for home and community based services and decrease waiting lists.



Nearly half of the self-advocates reported they cannot get waiver services because of the waiting list.



Several themes related to the waiting lists for residential and other services emerged from the survey comment data. Family members and care providers shared that there is a need to assess how funding is administered and ensure that funding is maximized to its fullest potential impact with entities working together to eliminate unnecessary barriers. One caregiver shared that forcing individuals and families to wait 5 to 10 years for desperately needed services is a “stain on the soul of this state.” Others expressed that the length of the waiting list results in the loss of skills and poor outcomes for individuals who wait years for the services.

“
The people that have been waiting longer on the waiting list seem to lose more skills or seem to lose their way in life.

A family member reflects on the impact for individuals on the waiting list

”

Adequacy of Healthcare Facilities

Information was gathered from survey responses and comments to examine the adequacy of healthcare and other services, supports, and assistance that individuals with developmental disabilities who are in facilities receive. Some family members and care providers (41.38%) believe it is very important to address the adequacy of healthcare facilities, including staff training. Some indicated that there is a lack of regional services in their area to meet the needs of their family member. Views about having healthcare facilities as an option for individuals were mixed, with some expressing that the settings are “antiquated and should be closed” and others sharing that individuals in these settings deserve quality services, including staff that is trained adequately. Some family members expressed concern with the lack of access to their family member due to visitor restrictions during the COVID-19 pandemic.

Some family members and care providers believe it is very important to address the adequacy of healthcare facilities.

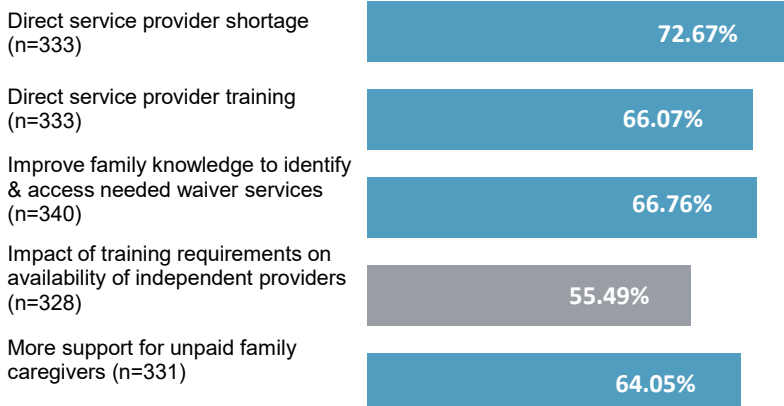
Adequacy of healthcare facilities, including staff training (n=319)

41.38%

Adequacy of Waiver Services

Survey respondents, focus group participants, and interviewees provided information about the adequacy of services provided through HCBS waivers for individuals with developmental disabilities. Many family members and care providers believe it is important to address the adequacy of waiver services. Family members and care providers identified issues related to direct service providers as very important, including the need to address service provider shortages (72.67%) and the need to provide adequate and appropriate training for service providers (66.07%). Additional areas rated as very important include the need to improve family knowledge to identify and access needed waiver services (66.76%) and provide more support for unpaid family caregivers (64.05%).

Many family members and care providers believe it is very important to address waiver issues.

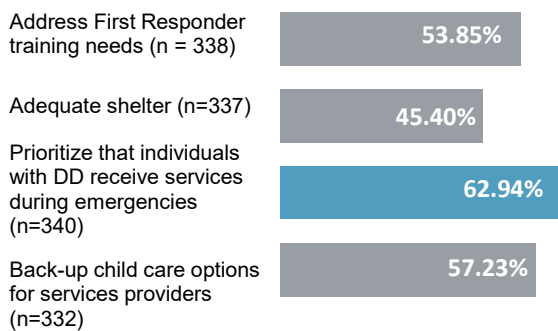


Family members and care providers provided additional information about the adequacy of waiver services in the comments section of the survey. It was expressed that there is a lack of services to meet the needs of individuals who need the services, and that once a child leaves the school system, it is “like falling off a cliff in regards to services.” One parent shared, that compared to other states they have lived in, it is much harder to access services in Nebraska than is necessary. Other parents shared it is very difficult to qualify for services if you are low income or child does not have high medical needs. Several family members shared that it is difficult for individual providers to meet requirements, leading to difficulty hiring and retaining providers. More family supports are needed to increase awareness of and access to services, and it was noted that it is important to address the lack of services needed or directed toward aging individuals.

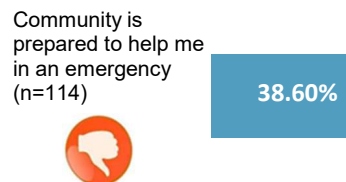
Emergency Preparedness

In response to recent natural disasters in Nebraska and issues related to emergency preparedness, information was gathered from family members, care providers, and self-advocates to assess the adequacy of addressing the needs of individuals with developmental disabilities during times of crisis. Results from both surveys supported the need to address preparation and planning for emergency situations. Many family members and care providers (62.94%) believe it is very important that services for individuals with developmental disabilities be prioritized during emergencies, and many self-advocates (38.60%) reported not feeling as though their community is prepared to help them if there is an emergency.

Family members and care providers believe it is very important to prioritize services for individuals with DD during emergencies.



Many self-advocates do not feel their community is prepared to help them in an emergency.

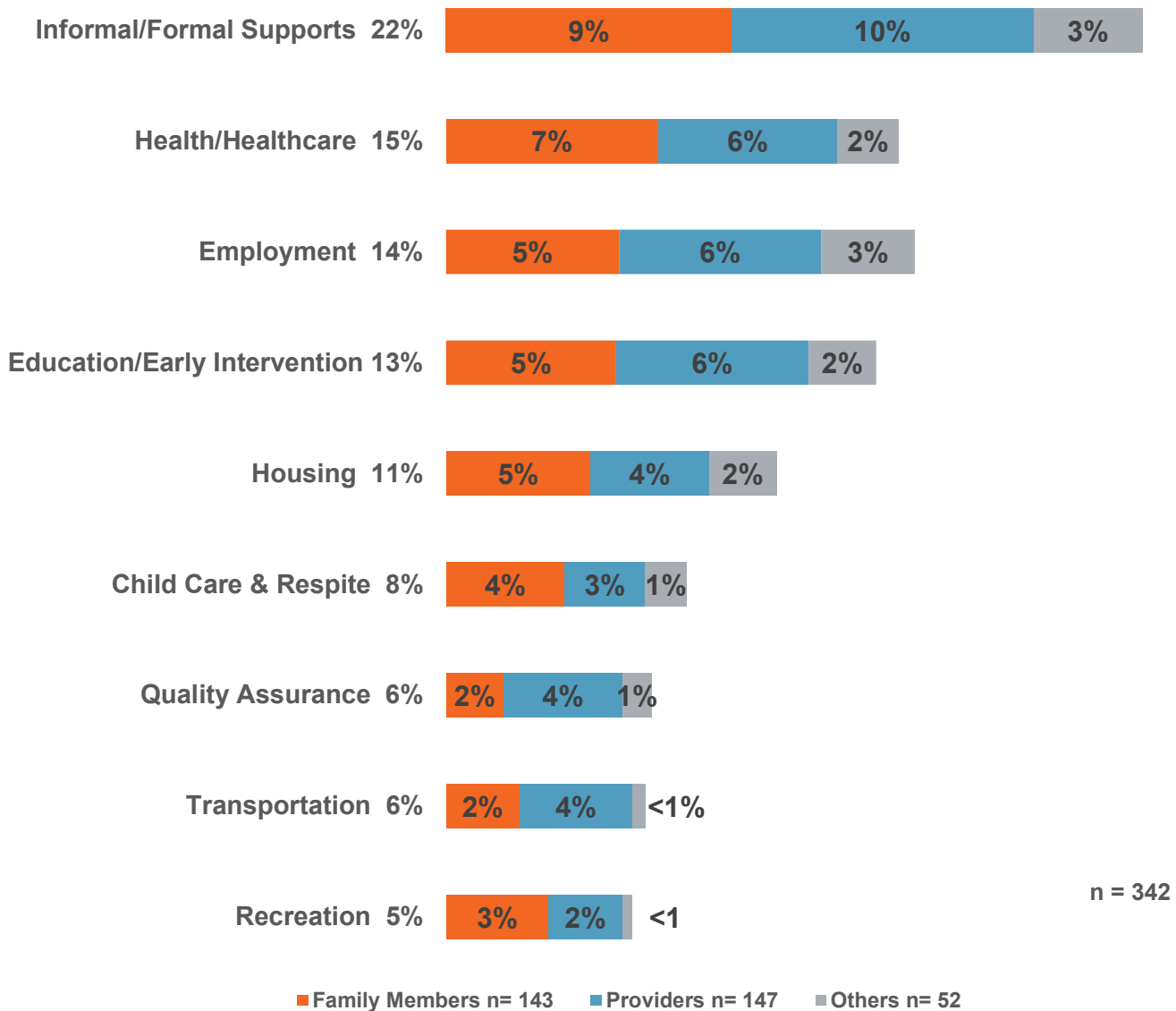


Information gathered during interviews, focus groups, and from survey comments provided more insight into the specific needs related to emergency preparedness. Many participants indicated that there is a need for first responder training and for community programs to understand how to interact with individuals with DD. The need for individual and community plans to be in place for emergencies and how to access services during an emergency (e.g., power supply, shelter) was a consistent theme. Some respondents indicated leadership and coordinated response is lacking during the current COVID-19 pandemic.

Priority Areas

Respondents who completed the survey were asked to prioritize the top two areas that they believe are important for the Nebraska Council on Developmental Disabilities to address. Of the 342 responses, informal and formal services and supports (22%) was the top priority followed by health/healthcare (15%), employment (14%), education and early intervention (13%), and housing (11%). Child care and respite, quality assurance, transportation, and recreation all had a priority ranking of less than 10% by participants who ranked those areas by importance. The overall responses for each area are displayed by respondent group (family member, care provider, and other) below.

Survey respondents rated informal and formal services and supports as their top priority area for the Council to address.



Populations Needing More Assistance

Survey respondents were asked to identify populations who they do not believe are getting their needs met and require more assistance. The need to assist individuals who do not have family members to advocate for them or assist them with supported decision making emerged as a primary theme. Multiple respondents expressed the need for paid advocates to assist those individuals who “cannot functionally represent themselves.” Additional populations identified as needing extra assistance include individuals with co-occurring DD and mental health needs, the aging DD population, children needing Applied Behavior Analysis services who do not qualify for Medicaid, and individuals whose needs are not profound enough to receive support services but need assistance to be successful in their job and community.

Summary

The needs assessment data collected for the Nebraska Council on Developmental Disabilities’ five-year needs assessment assists the Council in identifying ways to make a positive difference in the lives of individuals with developmental disabilities and their families. Data collected for this needs assessment identified both overall priority areas and specific needs identified by family members, care providers, and self-advocates as highly important for the Council to address. Specific needs identified as important include issues related to direct service providers, waiting lists and the availability of services, the need to bolster family supports, unmet behavioral health needs, and intentional outreach to support unserved and underserved populations, as well as individuals who do not have family support. It is recommended that the Council use the data holistically to guide their planning for future activities. While priority areas were ranked to provide a broad view, it is important to look at the importance-level ratings for specific needs within each area and to identify themes, such as the availability of and accessing services and a centralized resource access site, which are of high importance across areas, in order to identify specific goals and objectives.