



# Nebraska Planning Council on Developmental Disabilities Needs Assessment

December 2015

Interdisciplinary Center For Program Evaluation

Collaborate

Evaluate

Improve



# Nebraska Planning Council on Developmental Disabilities Needs Assessment Report

## Purpose

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The Nebraska Planning Council on Developmental Disabilities (the Council) believes that all people with disabilities should be supported to live as they choose, with least restrictions in their communities. 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 those with developmental disabilities and their families. This report will provide the results of the 2015 Needs Assessment which will provide guidance for future activities of the Council.

## Methodology

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**Process.** Munroe-Meyer Institute (MMI) was contracted to implement the needs assessment process in partnership with the Council. Three key informant groups were identified: individuals with developmental disabilities, their family members or guardians, and community providers. Data were collected through surveys, interviews, and focus groups. Data collection was conducted from June through November 2015.

**Needs Assessment Survey.** The Needs Assessment Survey was created based on the guidance from the Developmental Disabilities Assistance and Bill of Rights Act. The eight areas of emphasis included: child care, community services and support (including recreation), special education (birth through age 21), employment, health, housing, quality assurance, and transportation. Items were rated on a five point scale (very inadequate to very adequate). In addition, individuals were asked to select two service areas they felt Nebraska should prioritize. The Council reviewed the survey questions and provided feedback. The surveys were available in both English and Spanish and were available in web and print formats. The survey was broadly distributed through targeted email lists and requests to agencies to disseminate. A special effort was made to reach out to minority populations. In the Omaha area, MMI staff partnered with two key Omaha parent leaders who helped to recruit participants to complete the survey or participate in interviews.

**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 were identified by the Council Executive Director and agreed to participate. The interviewees represented a cross section of providers, family members, and individuals with disabilities. Due to the lower number of self-advocates who completed the survey, they were prioritized as focus group participants.

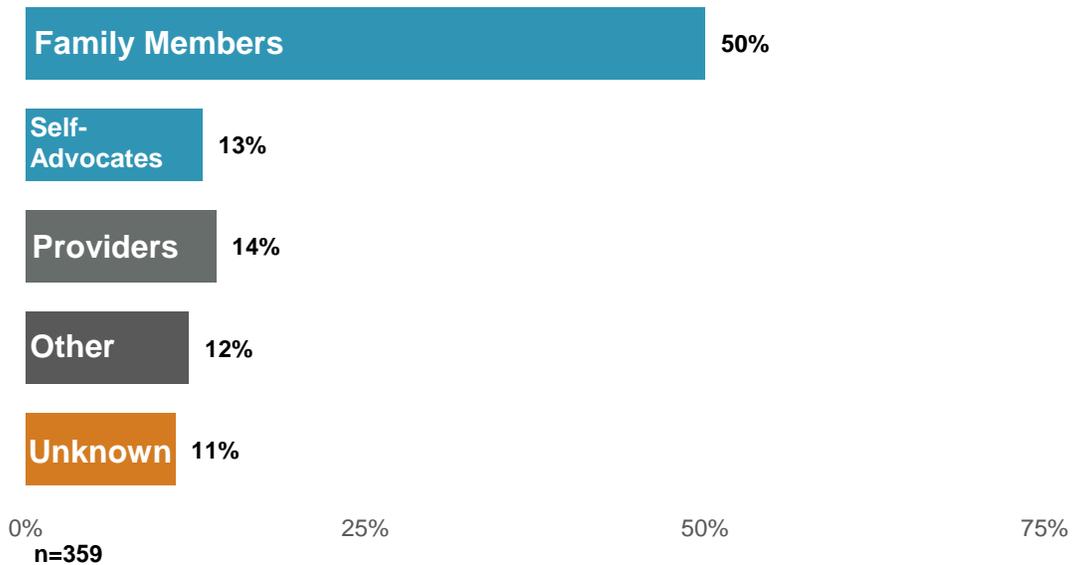
# Evaluation Findings

## Description of Survey and Focus Group Respondents

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The goal of the survey distribution was to have a broad representation including geographic distribution, language and ethnic diversity, and multiple developmental disabilities. A total of 359 individuals completed the Developmental Disability Needs Assessment questionnaire. The majority of the respondents were individuals with developmental disabilities or their family members. A small percentage (4%) of the respondents completed the Spanish survey. Four focus groups were held, with a total of 51 participants (49% were self-advocates, 14% family members, and 47% providers). Eight interviews were completed (37.5% were self-advocates, 25% family members, and 37.5% providers).

Family members and self-advocates made up the majority of the survey respondents.

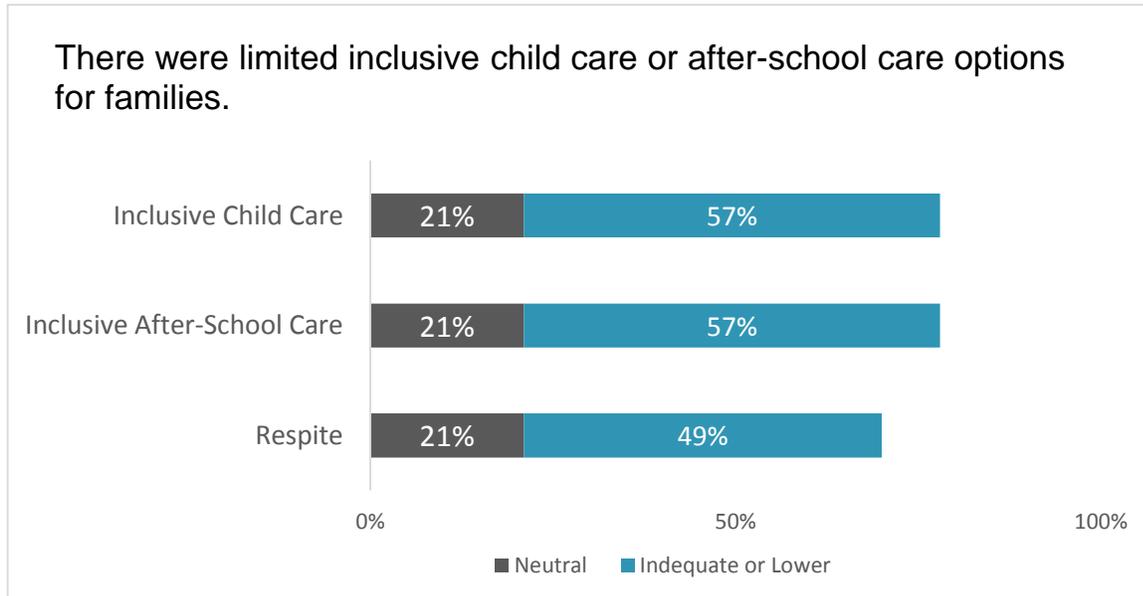


**Self-advocates.** Specific information was collected on the 45 self-advocates who completed the survey. A total of 89% of the self-advocates who completed the survey were over age 21. There were equal percentages of young adults (44%) who were between age 22 and 40 and those who were over age 41 (45%). A total of 71% were receiving Medicaid and 23% reported being on the waiting list for services.

The majority of **self-advocates live** either at **home** (41%) or with **family members** (41%).

## Child and Youth Needs (Birth to 21)

### Child Care/ Respite Services



Three primary avenues emerged as child-care options for families including: community child care, after-school programs, and respite care. The need for increased opportunities and awareness of existing services were noted across these three options. Child care was most difficult to find for several populations including those children with diagnoses of special health care needs, behavior problems, and autism or for those youth ages 12 to 21. One participant reported, “Inclusion still has a long way to go with all services provided. There are pockets of good things happening, but it is not consistent. This needs to be driven by policy to be effective.”

**After-school.** Families’ experiences varied regarding their child’s access to after-school programs. Several families indicated they did not know of any after-school programs that accepted students with disabilities. Other families reported schools were doing a better job of including students with disabilities in their after-school programs. One parent felt that the schools needed to be more inviting of those with disabilities into their after-school activities, e.g., clubs, sports, etc., and that few families knew that they had a right to have their children participate in these extra-curricular activities. Parents who knew their rights often were successful in advocating that their children participate in a number of school activities.

**Child care.** Families reported that many child care providers would not accept children with disabilities, limiting their options for a much needed service. This lack of openness to accept children with disabilities in child care may be attributed to lack of directors’ and teachers’ experience with children with disabilities and/or a lack of training needed to build the

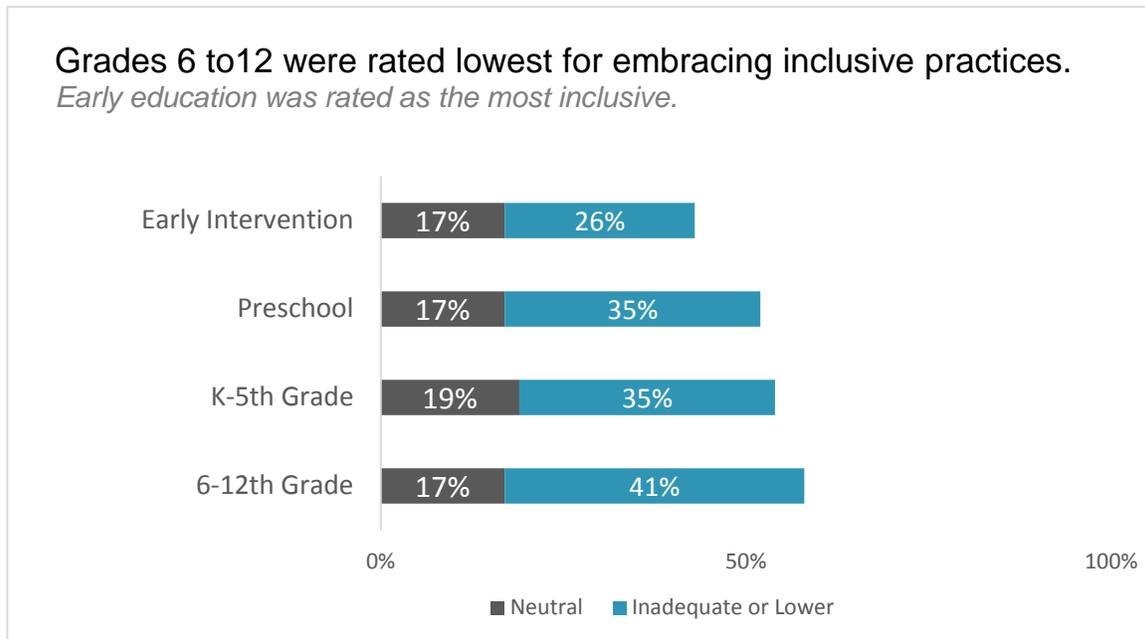
confidence of these providers to serve this population of children. Often parents have to find less than optimal alternatives, e.g., to hire people who do not have child care experience. Although there were some options for inclusive child care, these options were limited for children with behavioral problems or medical concerns. As one parent voiced, “Given the law, it’s surprising that there are not more options. Families as a whole are so busy trying to take care of day-to-day business that they don’t have time to push the legal aspect of it.”

**Respite services.** Respite services were not meeting the needs of many families. Primary issues were the lack of well-trained providers, limited available funds, and lack of awareness of the service itself. The problem was compounded if the child had a medical or behavior problem. As one provider noted, “We need to build a base of respite providers and pay providers to adequately be able to care for individuals who have high behavioral health needs and high medical needs. Those are the two areas that I think we really fall short. And those are, in my opinion, the individuals and the families who need the most support and there’s nowhere for them to go.” The pool of providers narrows even more for families whose primary language was not English.



Caregivers need to be provided with sufficient compensation in a timely manner for their services. Providers indicated that the subsidy needed to be increased from \$125 per month, a rate that was established several years ago and is no longer adequate. Others commented that the type of provider covered needed to be expanded to include camps. As one parent noted, “Many (families) can’t afford camps, so they stop bringing their children.” Using respite dollars would be one way to help support this service that families overwhelmingly found helpful.

## Education



**Student benefits.** Overall, early intervention and preschool services were viewed positively. Parents reported that their children benefited from the services. Many parents commented that their children were benefiting from their school experiences and they were getting the needed therapies.

**Improve inclusive practices.** Interview respondents confirmed the survey results: as students became older, there were fewer inclusive options. Several suggestions were offered to promote inclusive practices. One suggestion was to establish an award, similar to the Buffett Award, which would honor teachers who exemplify high quality teaching using inclusive practices. A second suggestion was an awareness campaign targeting families and advocates that would highlight the benefits and promote strategies to increase inclusive opportunities in the educational setting. It was recommended that Nebraska Department of Education increase school district accountability for implementing inclusive practices.

**Curriculum.** Several families commented on their child’s educational curriculum. As one stated, “I find the communication and adaptation of curriculum in inclusive classrooms to be very lacking. I consider the resource teacher a great help, but I do find that sometimes, life skills are taught more often than academics and frankly, I teach life skills at home.” Some reported that the resource teachers were of high quality, but when they were not available in the classroom, their child’s learning experience was diminished. Many parents indicated that they had to be strong advocates in order for their child to receive the curriculum and services needed.

**Provide additional training and supports to teachers.** Respondents recommended that teachers continue to participate in training to enhance their services to students. Specifically, additional training to regular education teachers on inclusion was expected to help students' experiences. Skills to address behavioral problems was another area suggested for teacher training. As one mother commented, "When the staff don't know how to support my child, they call and I have to pick her up from school," which limited her child's opportunities to learn. Other topic areas included how educators can help parents understand their rights and additional training and information on specific disabilities and/or medical conditions. Some parents reported that teachers were dedicated and trained, but were limited due to administrative guidelines and attempts to cut costs.

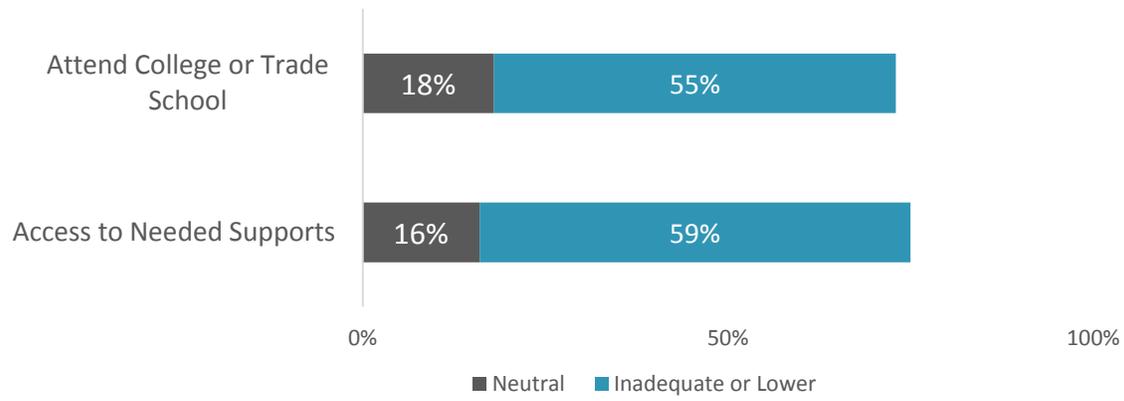
Less than half (43%) rated the **teachers or therapists as adequate**, with 20% neutral on the subject.

**Transition services.** Respondents reported more planning needs to happen in the school to assist students making the transition into adulthood. This should include career preparation and life skills training. In some school districts there was reportedly no designated transition program, and as a result, teachers had to address multiple student needs, limiting the transition experience for students. Opportunities for work training were often reported as restricted, with parents indicating the training settings needed to be expanded. In situations where students were provided multiple training site opportunities in real businesses, it was more likely to lead to successful employment in those settings. In other situations, parents reported positively about the skills learned and the experiences that were available through their school programs. However, there was concern that after the students graduated, there were long waiting lists to get the employment supports they needed, which resulted in loss of skills learned in the school setting.

Only **34%** rated that there was adequate **transition planning** in the schools.

Continuity in transition planning was viewed as important. It was recommended that community involvement start earlier with a Service Coordinator joining the transition planning in the school and being available for continued support as the student transitioned into adult services. One parent explained that she was told that her youth's Service Coordinator could not join the IEP meeting as it would be "Medicaid fraud." The Developmental Disabilities Division needs to clarify the role of Service Coordinators in supporting students prior to age 21 and disseminate a consistent message across the state.

Few individuals had the opportunity to attend college or trade schools or had access to needed supports.



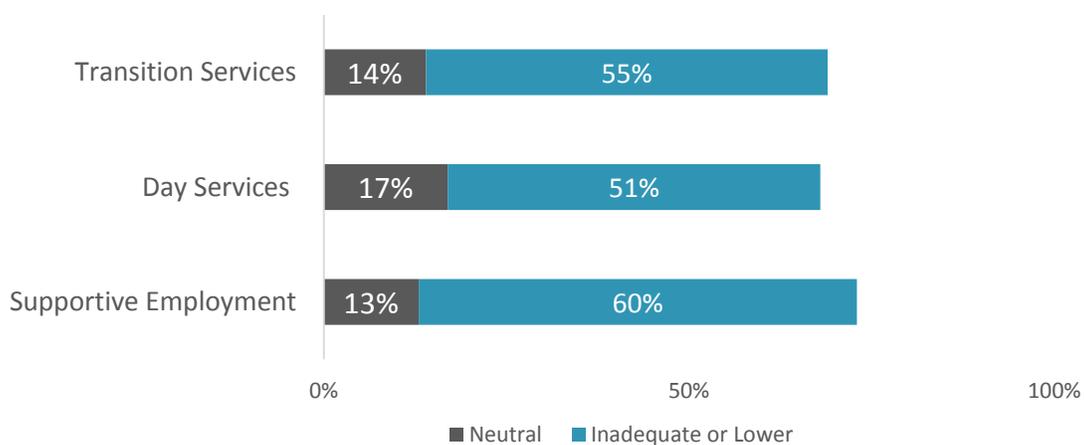
Respondents also indicated a need for better understanding of the post-secondary opportunities that exist for individuals with disabilities and felt more opportunities should be available in these areas. Few success stories were identified in this area. Multiple barriers were identified, including: lack of funding, limited support services, transportation, and limited colleges and/or trade schools or higher education options.

## Adult Needs

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### Employment

Few participants rated Supportive Employment opportunities as adequate.



Self-advocates who were interviewed in focus groups were generally pleased with their employment options. Over half worked for a competitive wage (minimum wage) in a variety of settings, e.g., restaurants, retail stores, grocery stores, hair salons, student centers, and theaters. Some had employment coaches who helped them, e.g., provided cards with what needed to be done. Many expressed that it was helpful for the employer to understand their disability and in most cases the employers were very understanding. Simplifying the hiring process (e.g., an interview vs. an application) was viewed positively by self-advocates. Coaches were also reportedly a good resource during the interview process. Those who did not currently work indicated that they would like to have a job.

It was recommended that employment services be customized where the money would follow the individual. Currently it is difficult to serve individuals in multiple ways using different providers or across different services.

Continued work with businesses was reported as important so that they can see the benefits of hiring individuals with disabilities. Respondents also noted a need for increased meaningful employment options: “All too often these services are glorified babysitting areas and in community employment, the jobs are menial and not as challenging to some individuals as they could be. Offer choices! Gain input! Help these individuals have a voice in their world.” There was some frustration with current resources, e. g., an inability to find meaningful employment and lack of job coaches. Several parents indicated that they then have been the ones to help their adult child access employment.

In rural areas, both transportation and lack of employment opportunities were cited as key barriers. For example, for individuals who lived in small communities, jobs were only available in larger communities and transportation was very difficult. As one self-advocate explained, “When I had to take the bus or taxi to a job, it was really hard. Now I am really lucky that I got a job close to my apartment, because I can just walk. And I am saving about \$60 to \$70 per month because I don’t have to take a taxi or bus.”

**Fear of losing benefits.** Many families fear that their adult child will lose their Social Security benefits if they earn too much. Both self-advocates and parents need to understand the laws to aid the balancing act of earning money and losing benefits. Not only was it difficult for many parents and self-advocates, it was reported that some Service Coordinators did not have a good understanding of the benefit analysis process. Discussions illuminated a clear need for benefit planning, which may include additional training and supports for family members, self-advocates and Service Coordinators.

It was recommended that Nebraska Vocational Rehabilitation Services could be a good resource. Respondents indicated that anyone with a disability could apply for vocational rehabilitation for employment services. One of their supports is benefits analysis which provides information in order to make the most appropriate decision for the individual. Goodwill and Easter Seals are additional resources in this area.

“Managers do not realize the potential that people with disabilities have. They have no idea...I had three people who worked on my line who had developmental disabilities and they were some of the best employees I had. I had to fight with my boss left and right to hire them. Because they (bosses) don’t understand.”

**CMS new regulations.** Most self-advocates interviewed were not aware of the new Centers for Medicare and Medicaid Services (CMS) ruling about workshops. Many parents expressed concern over not having workshops available for their adult children. For many individuals, workshops not only provided an opportunity for learning work skills, but also a setting where social networking occurred. Other concerns included a fear that the current infrastructure for employment outside of workshops was inadequate, making these respondents apprehensive of the transition away from the workshops. More education for family members and self-advocates is needed to provide guidance on this regulation change.

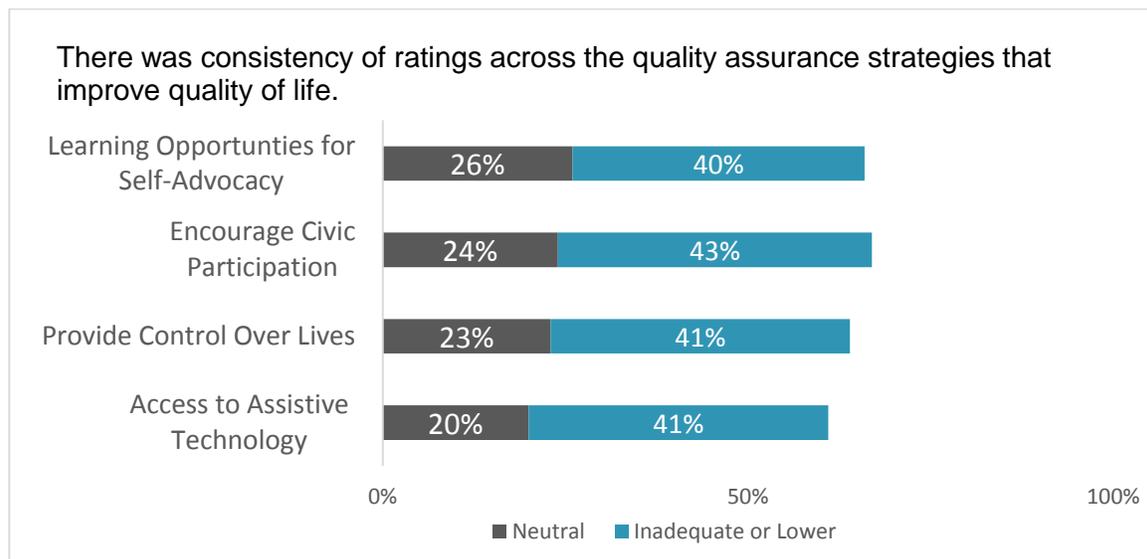
## Housing

Two primary themes emerged in this area, lack of awareness of potential resources and a need for supports for budgeting. Participants reported that there were a number of resources that were under used due to a lack of awareness of the available resources. Families and self-advocates need to know all of their options for housing. Rentwise and housing.gov or AT4All programs were recommended resources. The Extended Family Home setting provided an alternative for one family’s adult son, which resulted in a very positive outcome for him. They had not been aware of this option and only found out when the group home experience was not working out well for their son. Having interpreters or staff trained in another language (e.g., American Sign Language or Spanish) is essential for positive outcomes for the individual to maximize their residential experience.

One self-advocate indicated budgeting help was what she needed to help her live independently. Easter Seals was able to support her. The majority of the young adults interviewed were still living at home or with a relative.

Over **55%** of participants believe access to **safe** and **affordable housing** is **inadequate** or **very inadequate**.

## Quality Assurance

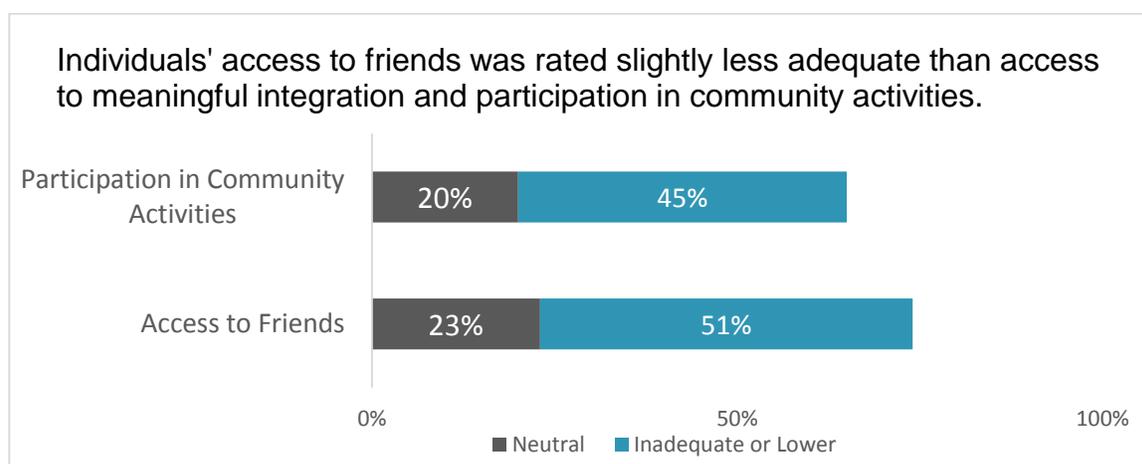


Many noted the need to support individuals in making decisions and controlling their lives. Many families have a voice, but continued training and support in advocacy was recommended. Assistive technology is available, but the equipment is expensive with little support to help fund it. Insurance companies are frequently denying claims for those products. Financial support for assistive technology products is very limited.

## Cross-Population Needs

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### Community Services and Support



**Friendships.** Generally, there was a reported need to identify strategies for individuals with disabilities to have opportunities to develop friendships that were not paid support. Funding and opportunities needed to be increased so that providers and families could support individuals to meet new people and to participate in the activities offered. Development of friendships as reported by one family member is “largely tied into the school system and so is also negatively affected by the inconsistent implementation -or existence- of inclusive classrooms.” School experiences were seen as a building block for later friendships. Lack of transportation also negatively impacted individuals’ ability to meet with friends. Without the aid of parents or providers offering transportation, there are few opportunities for children, youth, and adults to participate in activities with their friends.

**Recreation/community activities.** For children, there were more options reported in urban than in rural areas. These included sporting activities (e.g., baseball programs, Special Olympics, and YMCA programs) and a variety of camps. There were a number of recreational programs and peer mentoring programs run by advocacy groups. Participants noted Rose Theater in Omaha did a number of adaptive programs and some theaters have sensory showings. The issue, respondents believe, is expanding family awareness of these options.

**43%** reported that **inclusive and accessible recreational activities** were **inadequate**.

Many of the self-advocates interviewed participated in community activities that were primarily organized for individuals with disabilities. These social events included book clubs, theatre productions, Special Olympics, dances, etc., and were sponsored by community advocacy groups (e.g., local Arc chapters) or agencies, (e.g., Munroe-Meyer, Easter Seals). Many enjoyed attending community/school sporting events. There were still some venues that were not accessible.

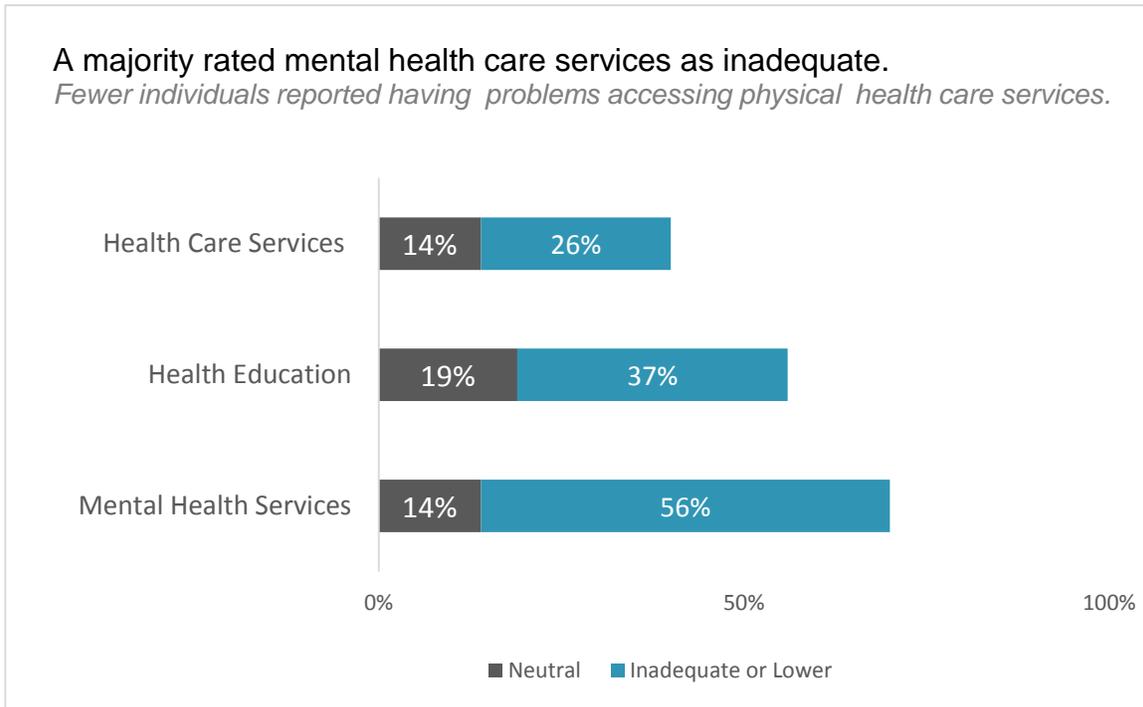
Continued work needs to be done to determine the interests of these individuals and help them to find community experiences that match those interests. This will require building community awareness of those with disabilities and partnering with community agencies to build these opportunities, (e.g., YMCA, senior centers). One respondent stated that “I love some of our programs here at MMI where they do social outings for adults that have disabilities and really give them inclusive opportunities. That would be awesome to see scaled up.” This illustrated the importance of increasing opportunities for individuals,

whether it be to go to the theater or baseball game, in order to be with community peers.



For adults, having adequate funds left to pay for recreational activities was noted as a barrier. This may also be related to low wages or lack of employment. Others found the lack of information about available options was a barrier. Strategies to disseminate the information using social media was recommended.

## Health Care



**Access Nebraska.** There was variability in responses related to the ease of enrolling in Access Nebraska. A few indicated no difficulty navigating the system and getting signed up each year. However, the majority of the respondents resoundingly indicated that navigating the Access Nebraska system was very difficult. One parent reported, “I know many people would have a hard time navigating the system or getting assistance to navigate it. People probably need to be connected to a person who can actually help them walk through that process or if they have questions.” In addition, it was reported that individuals were dropped from Medicaid without proper notice.

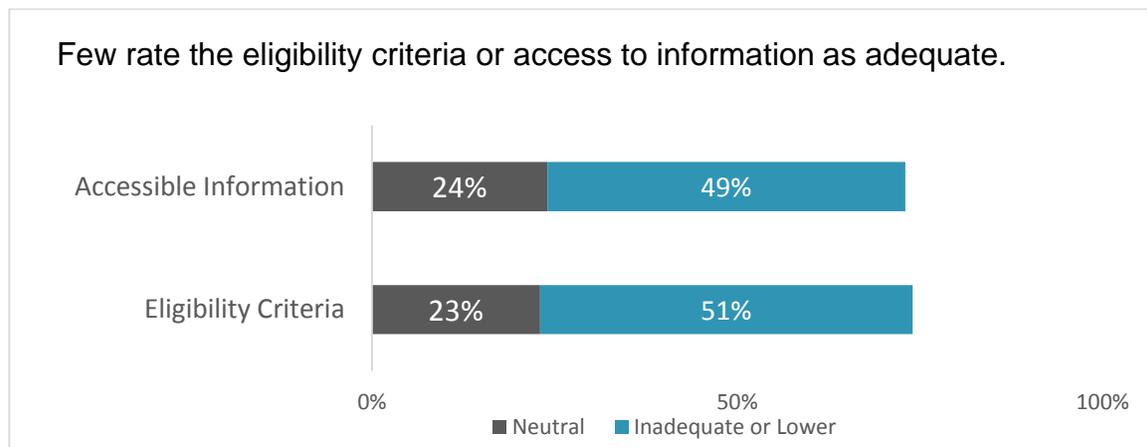
**Health care.** Families who lived near urban communities and had private pay insurance reported the best access to services. For those in rural areas, families reported driving long distances to get adequate care. As one parent noted, “Most of the time local doctors have no knowledge how to respond to my child’s diagnosis.” Others encountered denial of care or delays in care as families awaited approval for procedures or medications. Access to dentists who accept Medicaid continued to be a major problem.

**Mental health.** One of the primary health care gaps was mental health services. Across the state there was a reported lack of providers who either had the expertise to work with individuals with disabilities and/or accepted Medicaid payment. Additionally, there were barriers related to medication payments, e.g., an individual who doesn’t have Medicaid needs to pay the first \$1,800 before Medicare will pay. Access to services is even more difficult for those with extreme behavioral or mental health problems.

Blending the appropriate services for individuals with dual diagnoses is made more difficult by funding issues because Medicaid typically only provided funding for one service. A provider reported, “As we march down the path of managed care we will have to be cognizant of this issue for people with developmental disabilities and mental health issues – because with that co-occurring occurrence, it is always about the money. Who’s going to pay for what?” It was reported that there was little coordination between developmental disabilities and mental health providers. It was recommended that cross-training occur to widen providers’ awareness of each other’s expertise. Participants also noted that it was difficult to find services for elderly individuals who lived in nursing homes where there was a decline in the individuals’ functioning at the same time there was an increase in behavior issues. Also of concern were those students with behavior issues that were not addressed adequately; some of these students ended up arrested and enter the juvenile justice system instead of getting the care they needed.

**Transition.** There continued to be an issue of finding adult health care providers to care for individuals with disabilities, especially if they had special health conditions. As a result, young adults tended to extend their care with their pediatric-trained specialists. It was recommended that tools be created to help family members and their young adult children support their transition to adult health providers.

### Eligibility Process

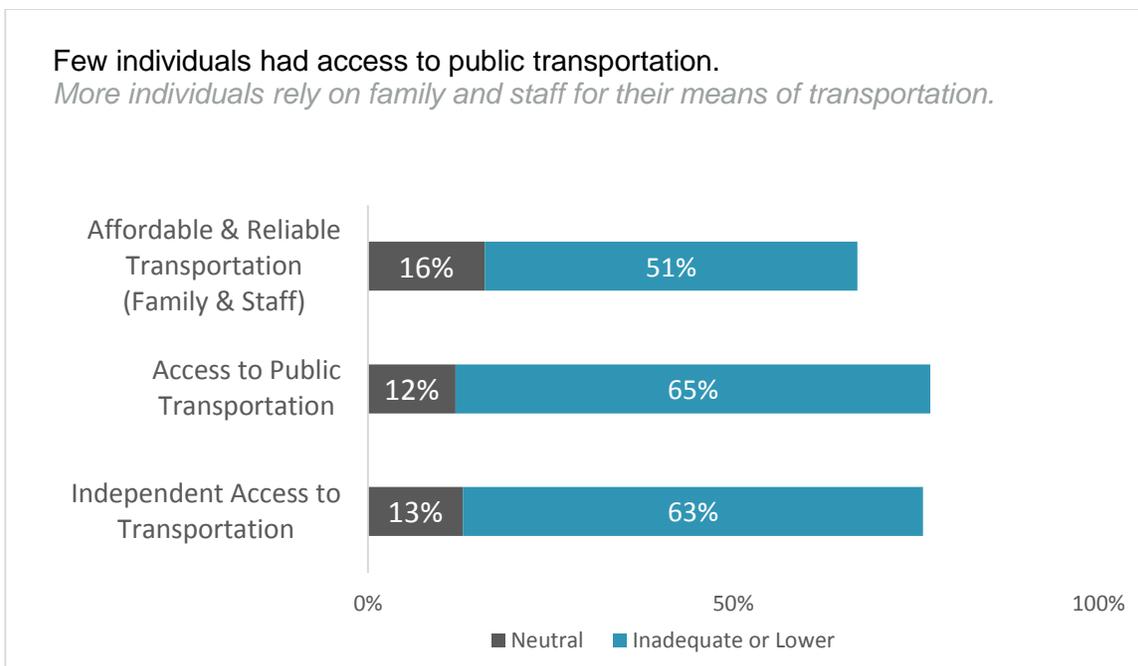


**Increase access to information.** Most expressed that there was no easy way to seek out needed information. A one-stop shopping approach was recommended, as well as, better use of social media. Many requested having a person to talk to who could help them understand the systems, as the online resources were often very difficult to navigate and/or too time consuming to research given the other demands on families’ and providers’ time. It was recognized that frequently word of mouth may be one of the best tools to share information.

The lack of bilingual staff was a common theme of those interviewed whose native language was not English. As one parent indicated, to call an agency that they do not know “was out of my safety zone.” And if the agency also did not have someone who spoke her language,

that made it even more difficult. She indicated that families she knows will quickly give up if faced with these types of barriers and will not pursue the services their family might need.

## Transportation

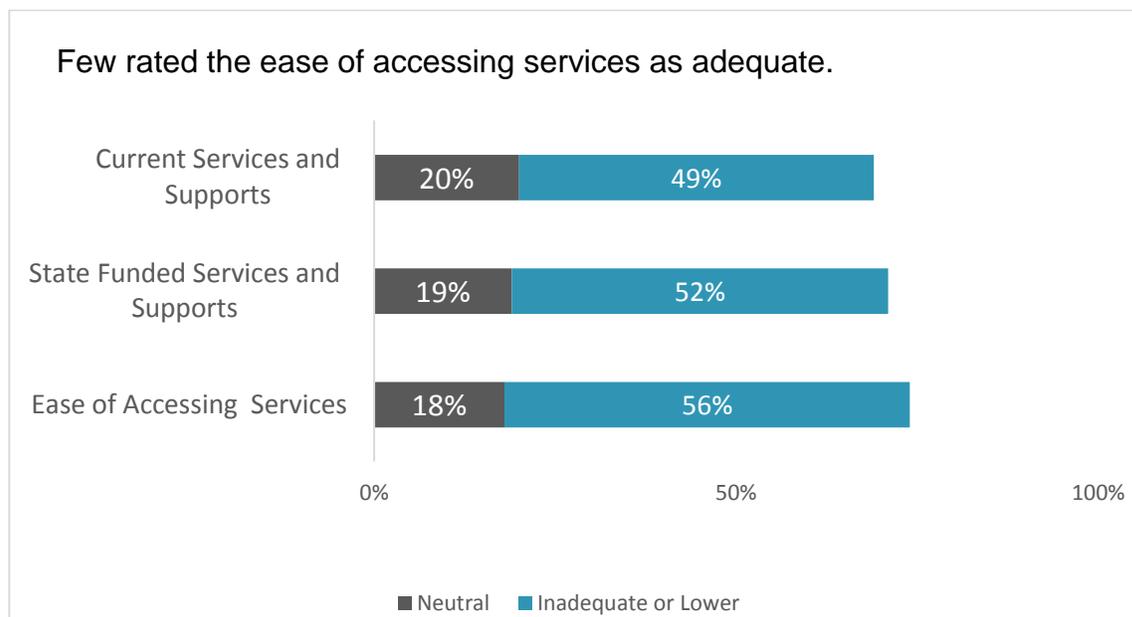


Families were reported to be the primary source for transportation for children, youth, and young adults. For those who did not have family members as a resource, transportation was limited. A primary issue was a lack of public transportation options. Many limits of the existing public transportation system were described across participants. Overall, public transportation hours were not long enough, frequently late, and were only available in certain portions of the community. In larger urban areas, bus routes were limited and taxis were not affordable. One respondent noted, “Even as individuals get older and want to be more autonomous, our bus system... is really not set up to help individuals be able to navigate... It doesn’t cover the whole community. There are very specific barriers. Individuals who ride it have complaints with the friendliness of the staff, the reliability, meaning you better leave them a window of a couple hours or more for pickup.” An employee of MOBY, a transportation service for individuals with disabilities, suggested to one young adult that she change jobs as they would not accommodate her schedule. Fortunately for her, she had family support so she did not have to change jobs. Transportation for individuals in wheelchairs posed additional barriers. Access to personal wheelchair-accessible vehicles is very cost-prohibitive. Respondents noted a need to provide information to families or individuals for simpler and less costly options for modifications of family vehicles.

It was recommended that communities be studied where there had been success in improving transportation needs for individuals. In Kearney, they have established the Ryde Transit program as a result of advocacy efforts with the University of Nebraska at Kearney

and aging organizations. In communities that are doing transportation planning, it was recommended that individuals with disabilities or other advocates be part of the transportation planning efforts. With the onset of Uber, an alternative to taxis, there may be additional options.

### Overall Rating

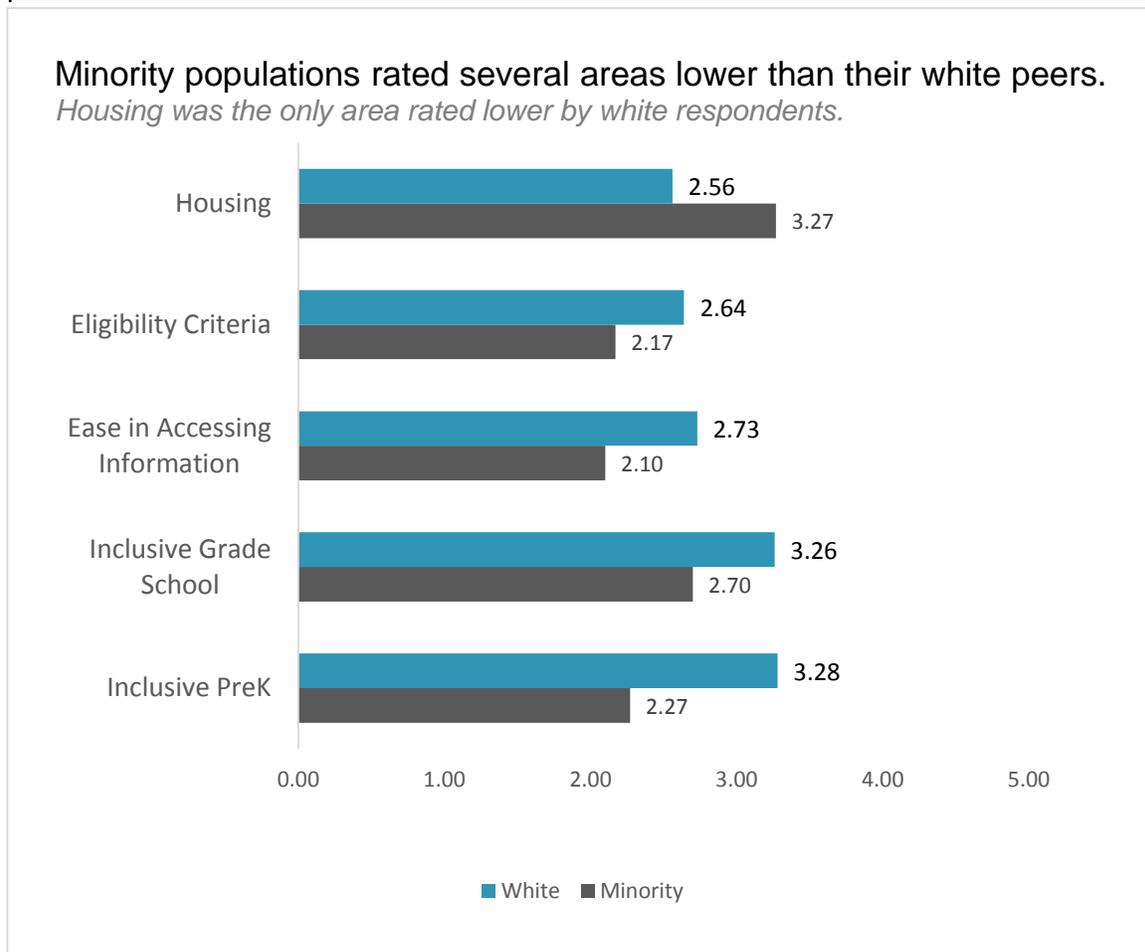


**Community services.** Access to quality caregivers was an issue for many individuals. As indicated by one provider, “A lot of it just goes back to caregiving. I hear of so many people looking for people to help. I think a lot of people are not getting adequate care because of it and it was suggested if there were more peer mentors, it would increase individuals’ integration into the community.” Pay for people who work with individuals with disabilities is low, and often times there is high turnover, similar to the childcare system. When you have lower wages for those working in this field, the quality of care and level of education tends to be lower, even though staff intentions are good and they are caring individuals. Some indicated the need for “better trained providers and Service Coordinators so they can be a better resource for families on waivers and how to access services they need.”

**Access.** Lack of access to and awareness of services emerged as a general theme among respondents. One participant, who identified as Hispanic, felt that there were no community supports in her immediate community of South Omaha. Many barriers were cited, including lack of knowledge on where to access different community supports or of the 211 line, the community resources hotline that is available to the public 24 hours a day, 7 days a week. Parents indicated that for many, the school did or could serve as a resource hub where parents could come for community resource information as families have often already developed a trusting relationship with the school.

## Voice of the Minority Population

A number of strategies were adopted to obtain the views of parents and self-advocates from minority populations. Of interest was whether their experiences with services and supports were similar to the majority population. An independent t-test statistical analysis was completed across each of the items rated in this report to compare the responses from those who represent minorities and those who were white. There were no significant differences between the responses of these two groups on the majority of the items. There was only a small subset of items where significant differences emerged. These differences were found in the areas of inclusive education, ease in accessing information, eligibility criteria, and housing, where minority populations often rated areas lower than their white peers.



## Recommended Priorities for Nebraska Planning Council on Developmental Disabilities

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Survey respondents were asked to prioritize the top areas where Nebraska should focus future efforts. Employment (22%) was the top priority, closely followed by community services and support (20%). Housing (13%), Special Education (12.8%) and Health (10%) also had very similar ranking percentages.



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The University of Nebraska Medical Center's

Munroe-Meyer Institute: A University Center of Excellence for Developmental Disabilities

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