



Report on the Nebraska 2013 Family Support Survey

Prepared by

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The Family Supports Project

Introduction

Raising a child with special needs is incredibly difficult, stressful and challenging yet rewarding. We put an incredible amount of effort into making them be the best they can (just like all our children), so eventually they can contribute to our society as well. Help us do that.

Driving along Interstate 80, a motorist entering Nebraska is greeted by a large sign touting the tagline: Nebraska The Good Life. Unfortunately, for many families who have a child with a disability, this may not be the case. The 2011 State of the States in Developmental Disabilities, a biannual report issued by the Coleman Institute for Cognitive Disabilities at the University of Colorado, estimated that of the 16,554 caregiving families, 712 were receiving supports. With only 4% of caregiving families receiving supports, Nebraska was ranked 49th in state rankings of expenditures for families with a child with an intellectual and developmental disability (I/DD).¹

On its face, the statistic may or may not represent unmet needs in the state. A report was requested by the Health and Human Services Committee of the Nebraska Legislature to determine what services are available to children with

¹ Braddock, D., Hemp, R., Rizzolo, M. C., Haffer, L., Tanis, M. S., & Wu, J. (2011). The State of the States in Developmental Disabilities 2011. Department of Psychiatry and Coleman Institute for Cognitive Disabilities. University of Colorado.

developmental disabilities in Nebraska. Four programs were identified: The Children's Waiver, a 1915(c) Home and Community Based Service;² the Disabled Persons and Family Supports Program;³ The Aged and Disabled (A & D) Waiver;⁴ and Special Education. The report provided a description of supports available through the programs, eligibility requirement and utilization, and state and federal legal authority.⁵ Seven additional programs available to families in Nebraska were identified through the research for that report. However, these programs were not analyzed for eligibility or utilization.

The Braddock Report⁶ references only programs administered by the Nebraska Division of Developmental Disabilities contrasted with the latter report⁷ which reviewed programs administered by the divisions of Medicaid and Long Term Care and Children and Family Services in the Nebraska Department of Health and Human Services. Additional research was recommended to determine how families experience supports in Nebraska and how implementation of available programs meets their needs.

² 42 CFR 440.180 and part 441 Sub part G; 404 Neb. Admin Code 10 (2011).

³ Neb. Rev. Stat § 68-1504; 472 Neb. Admin. Code (1988)

⁴ 42 CFR 440.300; Neb Rev. Stat. §68-901 to 68-974; Neb Rev. Stat. § 81-2229; Neb Rev Stat. § 81-2268; 480 Neb. Admin. Code (1998).

⁵ Fischer-Lempke, M. (2012) Research Report: Programs Serving and Supporting Children with Developmental Disabilities and Their Families. The Arc of Nebraska

http://dhhs.ne.gov/developmental_disabilities/Documents/The%20Arc%20of%20Nebraska%20Family%20Support%20Report.pdf

⁶ Braddock, *op cit.*

⁷ Fischer-Lempke, *op cit.*

Methodology

The intent of the Family Support Project was to determine what systems and programs are accessed to support Nebraska's families. Information was obtained directly from stakeholders to develop a better understanding of what is currently in place, how the availability of those systems and programs are presented to families and what changes may be necessary in order to significantly improve the State's responsiveness to caregiving families. It was identified that a clear statewide vision is needed and communicated directly to legislators and policy makers so that effective and efficient change will be possible. The Family Supports Project is designed to begin the conversation.

For successful systems change to occur, policy makers must have a clear understanding of the current situation. Project staff from The Arc of Nebraska and the Munroe-Meyer Institute at the University of Nebraska Medical Center assembled an Advisory Group to help guide the work of the project. Advisory Group members included legislative aides, representatives from the State Ombudsman's Office, family members, and advocacy organizations, the Munroe-Meyer Institute, and service providers. Because the Family Supports project focused on the needs of families, at least two-thirds of the composition of the Advisory Group included people with disabilities and/or family members.

The group identified key professionals in each of the six state Developmental Disabilities Planning Council regions⁸ to

⁸ Nebraska Planning Council on Developmental Disabilities. What is a regional council?

facilitate work groups that would assist in the development and dissemination of a statewide survey as well as participate in developing recommendations for moving forward. Facilitators drew from local Arc chapters and other strong organizations within the regional areas. Project staff and facilitators then identified five to seven members representing the diversity of families in Nebraska to comprise each workgroup.

Using a focus group format, the first workgroup meeting included an overview of the initial study. This was followed by a discussion of the structure of the Family Supports Project and their role in the process. Each meeting was scheduled to last for approximately 2 hours. Five questions were presented and responses were recorded and reviewed to ensure accuracy. The following questions guided the discussion:

- What family and child support services are you aware of?
- What services are you using or have used in the past?
- What is good about the family and child support system in Nebraska?
- What would you like to see in the family and child support system in Nebraska?

Group meetings were conducted in Region II in Ogallala, Region III in Kearney, Region V in Lincoln, and Region VI in Omaha. Due to time constraints and scheduling conflicts, workgroup members in Region I, Scottsbluff and Region IV, Columbus

http://dhhs.ne.gov/developmental_disabilities/Pages/ddplanning_regcouncils.aspx. See Appendix A for a map of the Regions in Nebraska

and Norfolk submitted written answers to the questions.

Seven themes emerged from the discussions:

- *Inadequate training.*
 - Group members expressed concern that provider staff were inadequately trained to work effectively with the individual children and families in their charge. Families reported that providers did not seem to have adequate information about the needs of the child and family members had to be available to train staff. This created difficulties as staff changed frequently.
 - They reported that state service coordinators seemed to be unaware of programs that may be useful to families. They often failed to steer them to programs that would be beneficial. Families reported that this left them struggling to find supports that might help them.
 - They stated that families received little training from medical professionals or providers on the programs and therapies put in place to support their children. This failure made it difficult for them to provide consistency and ongoing support for their children.
- *Difficulty in the referral process.*
 - Participants reported that medical professionals who were responsible for referring infants at risk of having a developmental disability often failed to do so.
 - The verification process for early childhood services was reported to be inconsistent across school districts and schools. Verification is a process through which a Multidisciplinary Team (MDT) gathers information from a number of sources to determine if a child meets the criteria to receive special education. The State offers guidelines for the MDT in making a determination, however there is no standardized instrument in use. Each school district determines the members of the MDT. Group participants reported that children who failed to be verified in one district could move to the neighboring district and be verified.
 - Participants reported that most information about available programs came from other families or friends rather than the professionals they contacted.
- *Respite*
 - Difficulty accessing respite for caregiving families was identified throughout each

group meeting and in the written responses. Participants reported that families who failed to use the allotted number of hours within specific time periods would be deemed ineligible for the service.

- Low reimbursement rates made it difficult to find dependable and qualified people to provide the respite services. This was particularly true for children who had challenging behaviors or high medical needs.
- Respite providers are reimbursed only for time caring for the child. They do not receive payment for time in training, travel time or mileage. In the rural areas of the state, families had difficulty finding respite providers who were willing to drive long distances to provide care.

- *Transportation*

- Participants reported confusion regarding eligibility for transportation services. A recent move toward privatization of the scheduling and payment services made access difficult. Scheduling required a seven day lead to provide services. This made arranging transportation very difficult particularly in communities

that had limited or no public transportation services.

- Therapies and other services often required long distance travel which was costly to families requiring caregivers to take time off work. Families also reported difficulties with unreliable vehicles for long distances.

- *Medical Capacity*

- Participants reported difficulty finding specialized medical services in their communities. The University of Nebraska Medical Center offers a number of programs to have specialty doctors in rural clinics, which participants identified as very helpful. However, shortages resulted in specialists being available on limited number of days in a month families had to wait for several months to be seen. Waiting for specialized medical care was stressful to families and delayed needed diagnoses and treatment for their children.

- *Special Education*

- Some participants reported that children in special education programs continue to be segregated and isolated. The Individuals with Disabilities Education Act (IDEA) mandates that students be educated in their classrooms with appropriate

supports and services. Some families reported that schools struggled to find the necessary support to keep students in the classrooms and resorted to congregate settings for many students and isolation for those with challenging behaviors.

- Families perceived that the IEPs that were developed for their children were not being implemented as written.
- Group members reported that schools often used 504 plans rather than developing an IEP for students with special needs. A 504 plan is written to describe supports that a child needs to experience academic success and to have access to the learning environment. These plans do not have instructional goals. Families reported that in these instances their children did not receive the instructional support they needed. One example given involved a child who missed class time due to seizures. Accommodations were in place to keep the child safe and ensure that he could return to class, however additional instructional supports were not identified to accommodate for lost instructional time.

- *System Responsiveness*

- All group participants reported difficulties using the ACCESSNebraska system. ACCESSNebraska is an online or call center system to apply for Nebraska public assistance benefit programs. They reported long wait times and interviewers who were not knowledgeable.
- The gap in access to a service coordinator between the ages of 3 and adulthood was also identified as problematic for families. Prior to the age of three, children identified as having a disability receive service coordination from the Early Childhood Network. After the age of three this person is no longer available to them. Families reported that prior to the implementation of ACCESSNebraska case managers were appointed to help families apply for and renew public assistance programs. These caseworkers knew the needs of the family and provided families access to information about programs that could benefit them. Participants reported that ACCESSNebraska workers had no knowledge of their individual situations and were unable to provide the same quality of information.

The Survey

The survey developed by project staff in conjunction with the advisory committee was very comprehensive (Appendix B). In addition to the 11 programs identified in the initial report⁹, five more programs offered by the Nebraska Department of Health and Human Services were chosen to be included in the survey. A total of 16 programs were included in the final survey. In some of the items, respondents were asked a question and offered a list of responses to choose from. Respondents could choose more than one response to describe their situation. Respondents were also offered the option of open-ended questions to describe their experiences. Three items asked respondents to enter their responses in a narrative format.

Those participating were assured that all responses would remain anonymous. Respondents indicated consent by beginning the survey. There was no requirement to complete the entire survey and respondents could exit at any time.

The survey was available for approximately 90 days. Respondents could access it online or through a paper and pencil format. PTI-Nebraska provided Spanish language interpreters to ensure representation from Spanish-speaking families. A link to the survey was posted for both English and Spanish version on The Arc of Nebraska website. Copies of the survey were available at several conferences throughout the late spring and early summer of 2013. It was also disseminated by workgroup members through newsletters, websites,

direct mailings, phone calls, and list serves.

Four hundred seventy survey responses were recorded. However, the survey could be accessed, discontinued and restarted at a later date resulting in duplicate respondents. In addition, respondents could exit and not complete the survey. Three hundred forty-six family surveys were analyzed and 105 professional only surveys were included. For items that allowed respondents to choose more than one option the responses are represented as a percent of the total number of respondents answering the question. This resulting in percentages in many cases total more than 100%.

The survey responses were representative of the geographic and ethnic diversity in Nebraska. Both professionals and families responded to the surveys. The survey resulted in both quantitative and qualitative data. A grounded theory approach was used in analyzing the data¹⁰. Simple descriptive statistics were used to analyze quantitative information. Narrative responses were evaluated using a constant comparison method¹¹.

The Sample

The 2010 census¹² reports that the population of Nebraska is 89.9% white,

¹⁰ Glasser, B. G. & Strauss, A. L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New York: Aldine de Gruyter.

¹¹ *Ibid.*

¹² US Census Bureau, "State and County Quick Facts". Generated by Pat Cottingham <http://quickfacts.census.gov/qfd/states/31000.html> (28 September 2013).

⁹ Fischer-Lempke, *op cit.*

9.7 % Hispanic or Latino, 4.8% Black, 2% Asian, 1.3% Native American, and .1% Hawaiian or other Pacific Islander. These same categories were included in the survey. Respondents were directed to describe the race or ethnic makeup of the family and could select as many as applied. Many families selected more than one description.

Eighty two percent of the respondents identified their family ethnicity as white only, 4% identified as Hispanic or Latino only and 2% identified as Black/African American only. Twelve percent of the respondents reported mixed ethnicity in their households. Figure 1 provides an overall picture of the respondents.

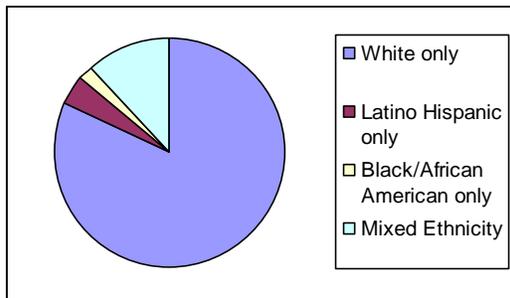


Figure 1: Ethnic make up of Respondent Families

Surveys were distributed throughout the state by the workgroups whose members were geographically located in each of the six Nebraska Developmental Disabilities Council regions (see Appendix A). Four percent of respondents were in Region I, 16% were from Region II and III respectively, 8% were from Region IV, 25% from Region V and 30% from Region VI (Figure 2).

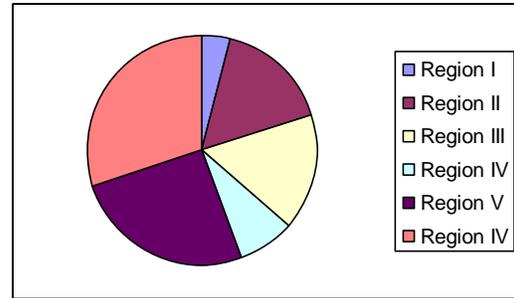


Figure 2: Percent Respondents in DD Council Regions.

Respondents were asked to identify the child's disability. A constant comparison method was used to categorize the disabilities into 11 types. Figure 3 shows the percent of disabilities reported by the respondents. Because some respondents were caring for multiple children with different categories of disability or because respondents were reporting on a single child with multiple disabilities, the percentages total to more than 100%.

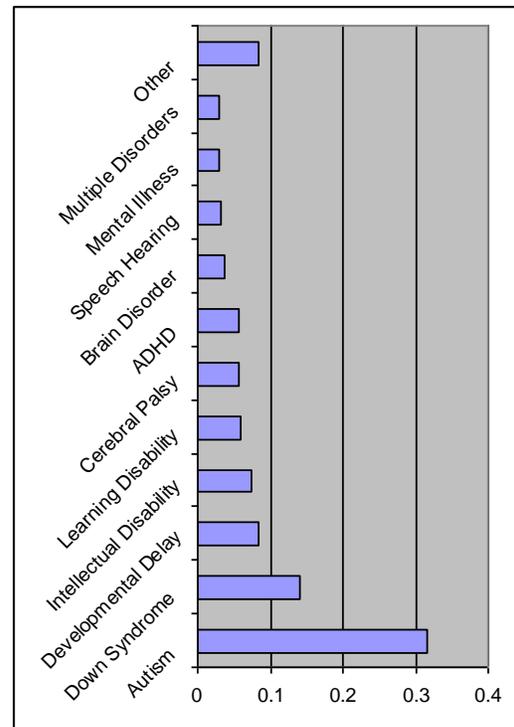


Figure 3: Percent reported disabilities

Roughly, one third of the respondents reported caring for children with Autism Spectrum Disorder. This may be the result of a higher incidence of diagnosis in recent years or a sampling bias. However responses to survey questions tend toward challenges related to having a family member with autism.

Over all, the sample obtained from this survey presents a fair representation of the diversity in the care giving families of Nebraska.

Programs of Support

Families were asked how they felt about the availability of supports for their children and their families in Nebraska. Many respondents (59%) reported that services existed but there were barriers to accessing them. Twenty-eight percent of families felt that they were enough services to meet their needs, while 12% were unaware of any services that would meet their needs.

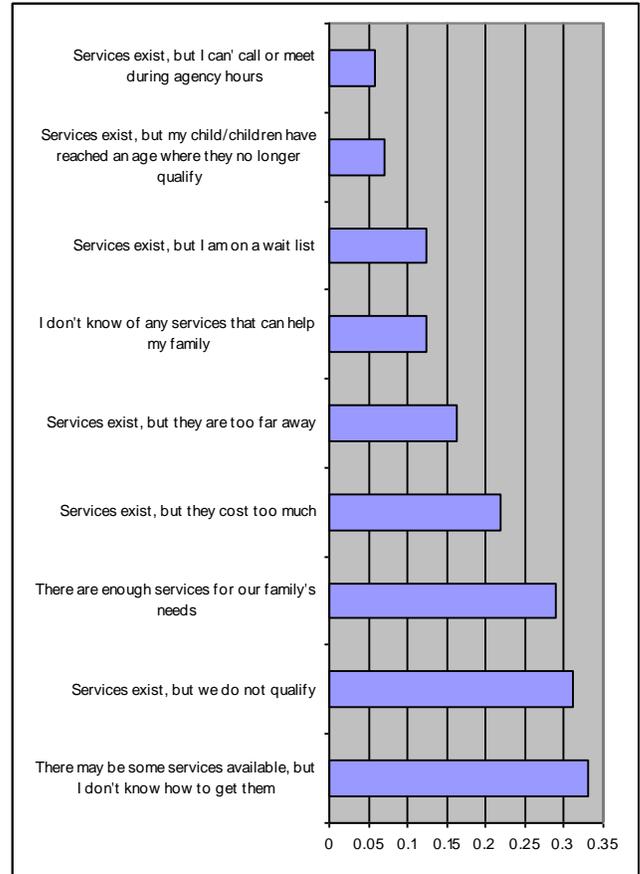


Figure 4: Percent reported availability of services.

Sixteen programs were identified that caregiving families in Nebraska could access¹³. A link was included for surveys taken on-line that would take responders to a Nebraska.gov page describing the program. Respondents were directed to choose from seven possible responses using the following options:

- Unaware of this program before today
- Applied for this program on my own
- Applied for this program with the assistance of a service coordinator

¹³ State and Federal statutory and regulatory authority for these programs can be found in Appendix B.

- Denied eligibility for this program
- Receiving program and satisfied
- Receiving program and dissatisfied
- N/A

One response for each program was required for participants to continue with the survey, but respondents could choose as many options as applied to their situation. Forty-eight respondents dropped out of the survey prior to completing this section and 46 respondents selected only N/A for all items¹⁴.

Project staff have little confidence that this section of the survey yields precise information. Many of the programs offered by the State of Nebraska are targeted to children with high medical needs and may not be known to families with children who have cognitive or sensory disabilities. For example, The Katie Beckett¹⁵ program and the Disabled Persons and Family Supports Program¹⁶ are targeted to individuals with complex medical needs that would require hospitalization or a skilled nursing facility. Fifty-eight percent of the respondents reported that they were unaware of these programs. However, this program is very specific to children who use a ventilator, have a tracheotomy, or require complex nursing care and medical equipment; lack of awareness is not significant.

In addition, many families access programs but may not necessarily know the official title of the program they are

¹⁴ Respondents experience with the programs can be found in Appendix C.

¹⁵ 471 Neb. Admin. Code 12-014.07

¹⁶ 472 Neb. Admin. Code 2-001.02 (1988)

using. For example, respondents were asked about the Autism Waiver, a program that has statutory and regulatory authorization but has not been funded and is therefore not available. Four respondents selected receiving program services and satisfied while three respondents selected receiving program services and dissatisfied.

Respondents also did not always select all options that may have applied to their situations, for example when responding to Medicaid, only 60 respondents indicated that they had applied for this service either on their own or with a service coordinator while 71 reported that they were denied eligibility for the program and 113 indicated that they were using the program. (Data Tables can be found in Appendix B)

A significant finding from this part of the survey comes from the reported awareness of large programs that are less disability specific and have greater outreach. Of those programs WIC, Medicaid, Early Development Network and Special Education were well known by the respondents to the survey.

Professionals who responded had a higher level of awareness of the programs offered in Nebraska. Of 105 respondents who identified themselves as professionals who did not also have a family member with a disability, one fifth were unaware of many of the programs.

Ninety-six families reported having to apply more than once for a program. Fifty-seven reported that they had appealed after being denied eligibility and 46 reported that they were on a waiting list for the program they needed.

Two primary points of access and information to supports are Service Coordination and ACCESSNebraska. Respondents were asked about their experiences with each of these programs.

Services Coordination

Service coordinators is defined as: An individualized, goal-oriented process, based on client choices, that makes the best use of resources to maximize independence and attain the level of care that is consistent with the client's level of need. Services coordination is referred to as case management.¹⁷ Title 404 Community Based Services for Individuals with Developmental Disabilities defines service coordination as an activity that is responsive to the needs and desires of the individual and promotes independence, interdependence, productivity, and inclusion¹⁸. Service Coordination is available to individuals who access DD Waiver programs and to Families with children 3 and younger through the Early Development Network.

One hundred fifty-two families reported having used a services coordinator. Respondents reported a high level of satisfaction with this service (Figure 6). They felt that Service Coordinators were knowledgeable and respectful of their families. However, 50 or one third of those families reported that they had multiple Service Coordinators and expressed frustration with these frequent staff changes.



I am on coordinator number 6. I had one coordinator work with us, get taken away, then sent back after a few years only to be taken again. I don't like this

¹⁷ 480 Neb. Admin. Code 5-001.E (1998).

¹⁸ 404 Neb. Admin. Code Chapter 2 (2011)

as I just get one to know my family and then they are taken and I have to start all over again, Also, I have not felt that 2 of the SC were really there for my family.

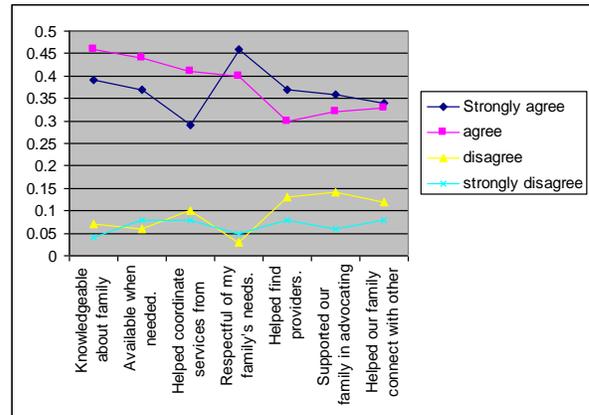


Figure 5: Experience with Services Coordination

ACCESSNebraska

Prior to ACCESSNebraska Medicaid workers fill the role of service coordination for families who needed a guide or had no one to call. ACCESSNebraska is the electronic process for making application for many of the programs offered by the Nebraska Department of Health and Human Services. Applicants may complete their application on line. They may also submit paperwork either electronically or through the mail. Depending on what they are applying for, they may participate in a telephone interview with an intake counselor. In-person assistance may be available for those who need it.

Not all programs offered by DHHS require applicants to use the ACCESSNebraska system. For example, the developmental disabilities waiver programs use a different application

process. However, applications for Medicaid must go through the ACCESSNebraska system, and many programs require that participants qualify for the Medicaid program.

Since its inception, ACCESSNebraska has been criticized for long wait times, lost paperwork, and dropped cases¹⁹. One hundred ten participants reported having used ACCESSNebraska. Respondents were evenly divided in their assessment of ACCESSNebraska being easy to use; however, they reported that there was difficulty in being put in touch with someone who could answer their questions. (Figure 6).

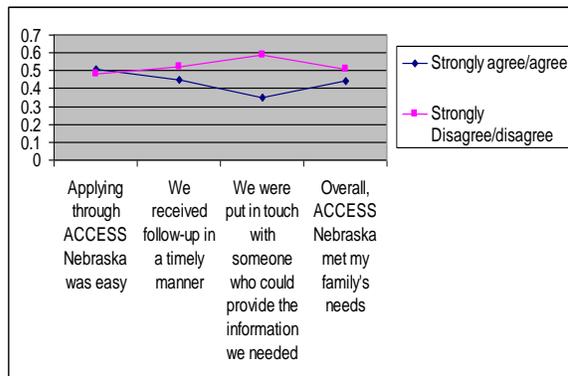


Figure 6: Experience with ACCESSNebraska

Thirty-eight respondents offered comments on their experiences and reported frustration with wait times and inability to get the information they needed.

I have utilized this program personally and with students in my work as a high school counselor. The automated service takes forever- I have been on hold for

¹⁹ Nebraska Appleseed, ACCESSNebraska Working Group Issues Statement of Principles to Guide Reform of Troubled System. Retrieved 12/22/2013 from <http://neappleseed.org/blog/tag/access-nebraska>

more than 2 hours, sent my students back to class while waiting for someone to answer, only to be put back on hold while they find the answer or correct person to help me. Personally, I will email and ask for people until I get to a living person on the phone to answer my questions- I am appalled that this is the best we can offer to persons that need support.

Themes of Narrative Responses

Respondents were given the opportunity to describe their experiences with services in Nebraska by responding to several open-ended questions (See Appendix D). Narrative data was analyzed using the constant comparison method²⁰. Four themes emerged from the analysis:

- Challenges for Families
- Service Responsiveness
- System Barriers
- Unmet Family Needs

Challenges for Families

My daughter was unable to attend a regular day care when she was younger because all of the noise and activity were too overwhelming. I was forced to quit working and stay home with her. Between the lost wages, the high deductible and out of pocket costs associated with autism counseling, treatments, medications, programs, etc., my family has accrued a large amount of debt. We are not alone. Many of the parents we talk to (with children with

²⁰ Glasser, *op. cit.*

disabilities) are in the same boat. We make too much a year to qualify for most services and live paycheck to paycheck due to our debt. We should not be facing the possibility of losing our house or filing bankruptcy because we are trying to give our daughter the treatments and support she needs to become an independent and productive member of society. We have given serious consideration to divorce and/or moving out of the state we love because of these issues.

The increased need for medical and social supports and environmental modifications presented families with financial challenges. Many insurance companies restrict the options available to plan participants by limiting the number of sessions for specific therapies or requiring higher out of pocket payments for out of network providers and specialized supports. Recent changes in the requirements for insurance plans may alleviate some of these challenges.

Insurance will not cover services for my child as she has a chronic/long term condition. They will cover counseling, but not OT/PT etc because it would be more than 10 sessions. I pay \$152 a week for my company's family plan for insurance and they won't cover it, not sure what I am paying for, as they won't cover the therapies my child so desperately needs. With a cost of \$210 a week out of pocket I cannot afford to send her to OT. The schools won't provide it as she has a medical diagnosis, not a learning disability. So we just do the best we can on our own

Families identified challenges when accessing healthcare for their children. Respondents cited the cost of therapies for their children that were not covered by health insurance policies, high out-of-pocket expenses and the income limitations required for access to Medicaid.

Respondents also reported that they were unaware of what services were available to them or that there were too many points of contact in trying to locate the services they needed.

I keep getting the run around: call here do this, do that. I do it. Then: "Oh, you don't qualify, you make too much money" or after I had done all that "you don't qualify" or it has taken so long for them to get back to me I need to re-apply

Once families have been determined eligible for supports many expressed frustration that they were subsequently disqualified due to improved health of their children. Waiver services require that the individual receiving supports qualifies for nursing home level of care. Improvement in one area that would put the child over the threshold criteria for nursing level of care can remove all the supports the family has been using.

My daughter takes multiple seizure medications. She had been on the AD waiver program due to her severe seizures (some lasting an hour or more). We finally found a doctor that helped us achieve a degree of seizure control, which then removed my daughter from the waiver program because she "wasn't

medically fragile enough". The fact that she takes more than 2 medications daily, has a history of prolonged seizures along with hydrocephalus and CP, and could easily begin having prolonged seizures again should qualify her. Seizure control is hard to get, so now that we have to pay out of pocket for all of her daily medications as well as her emergency medication puts us in a very difficult position. While I love that she is having fewer and shorter seizures, I am angry that the "system" doesn't support that. Also, because we live in a more rural area, any services are an hour or more away.

Service Responsiveness

Services exist, but they are very, very poor. Child development & speech professionals that we have been forced to work with do not communicate with the parents & when they do it is not in a professional manner. Questions are rudely ignored & certain service providers would rather create drama than help. Many attempts by us or other teachers to reports such instances have fallen on deaf ears...who if anyone is really following up on our complaints? We feel extremely helpless, disappointed & angry. So I don't know of any services provided to us that can help. If we could get people to work & communicate in a professional manner with us the parents and our child I would gladly use them.

Respondents reported several difficulties they faced with the responsiveness of services that were available to meet their specific needs. Many respondents

reported that available services often were not designed to meet the individual needs of the family.

Overall the lack of consistency of the supports they needed statewide was an issue. Many respondents reported that moving from one area of the state to another affected the availability and quality of supports they received.

Families cited problems with the verification process in individual school districts. A child must be determined by the multidisciplinary team as meeting the verification criteria and is in need of special educational services to achieve his or her educational goals. Because there is no standardized verification instrument in use by the State, some respondents commented that a child could fail to be verified in one school district but be verified in a neighboring district.

Families felt that much of the inconsistency was the result of lack of accountability. Many respondents perceived that providers had little oversight and that their concerns were not addressed.

Despite the numbers of services that Nebraska has to offer a number of respondents reported that there was very little outreach to families so they could understand and benefit from them. Many respondents reported that much of the information they had about services came from other families. Respondents remarked that ACCESSNebraska workers were often unaware of programs that callers could apply for.

Many of the sources of information in Nebraska have moved to an on-line

format. ACCESSNebraska is a case in point. Applications are taken on-line, by phone or in special circumstances in a face-to-face interview. The Aged and Disabled Resource Centers have focused on web-sites like Answers4Families. Families expressed frustration at the lack of access to other people who listen to their concerns and have the knowledge and skills to guide them through the system.

We need more services out here in Western Nebraska. There are people in need all through the state, not just Lincoln and Omaha! We have next to nothing out here. Why don't I know about these services? My son is currently a ward of the state and has case workers, but I have not heard of the things you listed. My daughter goes to a private special needs school, so I am completely connected with the special needs community and don't know these things. I am the PTA president of my child's school and don't know these things - you must do a better job of making it easier for folks.

Families reported receiving little support for transitioning from early intervention services to school and from school to adulthood. When children turned three and moved from the early intervention programs to preschool programs, families lost access to service coordinators. They perceived that there was little in place to help them adjust to new programs and services that were available. By the same token, families felt that there was little information made available to them during the transition from education supports to

adult services. Families reported feeling left out of the planning process.

I wish it was not so hard to find vocational services, independent living services, and support through college. My son is 18 and I have had to navigate this myself. Working with his school district has been very stressful at times. They have finally promised that they will not put him in seclusion for day(s) at a time anymore.

System Barriers

While supports for families exist in Nebraska, Families identified a number of difficulties that derived from the application process. The current reliance on ACCESSNebraska for the application process and the problems that have been identified with the system resulted in families perceiving a lack of knowledge among workers. Already burdensome eligibility requirements were compounded by lost paperwork and contact with people who could not answer the questions families had.

Bring the caseworkers back. I've always wondered why when a child is given a diagnosis of a disability there is not information in one pamphlet that tells you what services are available to help your child and how the system works. The only way I found out about a lot of things was talking to other parents and making tons of phone calls. If you don't know something exists, you don't know to ask or search for it.

Respondents also cited the waiting list as a barrier to getting the supports that they needed. Nebraska currently maintains a registry of need that arranges people who have been found eligible for DD waiver services according to their date of need. In 2013, The Nebraska Division of Developmental Disabilities reported that there were 1,775 individuals who were past their date of need and therefore “waiting” for services²¹. This list does not differentiate between children and adults and therefore it is unknown how many children are currently in need of supports.

Our family had Medicaid waiver services in another state for several years and we moved to NE. I was able to call and ask for help in finding out about the waiver in NE, someone came to my house to assess, but no real help, direction or assistance in almost 2 years. There was no real communication to help me even know where we stand with services...I was still placed on a waiting list. I do think this is a promise of hope for parents who do not know the system and expect help.

Funding for the Autism Waiver was mentioned by several respondents. In 2010 Nebraska received approval from the Center for Medicare and Medicaid Services for a waiver to provide behavioral support for children with autism. However, statutory language required private financing which was withdrawn prior to implementation.

²¹ Division of Developmental Disabilities Updates. December 31, 2012. Nebraska Department of Health and Human Services report to the legislature.

Many families were left without the means to access behavioral therapies for their children. The current legislative session, 2014, passed legislation requiring insurance coverage for treatment related to Autism Spectrum Disorders which may provide some assistance to these families.

The lack of professionals in rural areas was difficult for families. The Nebraska Rural Health Advisory Commission reported health shortages in nearly every specialty in every rural community in Nebraska in 2013²². Families reported traveling long distances to see a specialty physician which was costly and stressful to the family.

We must travel to Omaha to see our 6.5 year old's specialists for bladder and neurological conditions. Last week we traveled 6 hours total, only to have our Doctor called away to an emergency. We needed to see another Doctor because I was unwilling to "reschedule" as the office requested. It's a LONG day for a 6.5 year old to travel 6 hours and wait for a Doctor...not to mention a missed day of school.

Unmet Family Needs

Tolstoy begins his novel Anna Karenina with the statement that all happy families resemble one another but all unhappy

²² Nebraska Rural Health Advisory Commission, State Designated Shortages Areas Medical and Mental Health. Available at <http://dhhs.ne.gov/publichealth/Documents/MED%20MH%20LISTING%20FINAL2013.pdf>

families are unhappy in its own way²³. Families who participated in the survey were no different. While unique in reporting the supports they needed to help maintain the integrity of their families some common themes emerged.

Families identified assistance with child care as central to their ability to participate in their economic communities and to maintain stability. Access to child care particularly in the summer was mentioned 19 times. This is particularly concerning because for children who participate in the A & D Waiver childcare was included in the supports they could receive. However, in the late summer of 2013 the Division of Medicaid and Long Term Care notified families that the childcare covered by the waiver was not in compliance with federal standards and the support provided would be reduced to the specific costs of childcare related to the child's disability. Typical childcare costs would no longer be provided.

Working families had to find the funds to pay for child care and maintain employment. Many were able to access assistance from the Child Care Subsidy. However, the income assessment to qualify for this program are based on family income including the Supplemental Security Insurance payment that the child may be receiving while the Medicaid income assessment is based only on the child's income. Therefore many families who could access Medicaid Waiver programs are unable to access the Child Care Subsidy program.

²³ Tolstoy, L. (1963). *Anna Karenina*. New York: Random House

The need for respite care was mentioned 42 times in the comments that respondents made. Respite is a support that is offered to caregiving families to allow them to have a provider care for their family member with a disability while they tend to other matters. Many of the programs of support to families offer respite services.

The Nebraska Respite Network helps connect families with respite providers. The Network has Respite Coordinators in each of the 6 DD Council regions of the state. The Coordinators maintain a list of respite providers that families can contact to find the appropriate person to assist them.

Families, however, commented that while there are respite providers available, it was difficult to find good providers who were willing to work with children who have behavioral challenges and intense medical needs. In addition, for families living in rural areas of the State, they encountered problems with finding providers who would drive long distances without mileage reimbursement or paid drive time.

I am very happy with the Respite program and we have been fortunate to use qualified people for our caregivers. But, they are difficult to find. Our one caregiver is 82 and it has been a challenge to find someone to replace her; which I am still looking. Thank you for trying to improve this system.

Respite reimbursement is paid for face-to-face support and is paid at a minimal hourly rate. In addition, families using the Lifetime Respite Subsidy Program

have a \$125.00 monthly cap. Focus group participants commented about a “use it or lose it” clause meaning that if the program is not used in a given month then the family is removed from the program and must make application again. Arrangements can be made in advance and efforts are being made to enable families to bank the unused amounts to pay for planned activities that may require more time paid to the respite provider than would be allowed. For example, a caregiver who is scheduled for surgery and would require several days of respite care for an individual with a disability.

Training was mentioned several times. Parents wanted training support to allow them to assist their children. Many commented that knowledge of the therapies their children were receiving would help them to assist and maintain consistency of treatment. Behavior therapy was identified as a need for many of the families of children with autism and families reported that better understanding of the techniques would be of benefit to them.

Respondents also cited the need for general economic and household assistance in keeping their families together. The added costs and commitments involved in raising a child with a disability can be overwhelming. Families were not asking for someone to take over those, rather they expressed appreciation for whatever help they could receive.

In my granddaughters case we are very lucky to have doctors and teachers that really care. We work as a team and give her the best care possible. Her IEP is

very much a group effort with all of us making suggestions and goals. In this she is lucky that we don't have to go looking for extra support services. But at the same time there are extras like recreation services or help with home modifications that would make a world of difference for her and us. These things aren't cheap and honestly we just can't afford most of them. So finding out about special services would help ALOT!

Discussion and Recommendations

Families in Nebraska with children who have disabilities struggle to meet the needs of all of their children. As the respondent said in the quote that started this report, they are just asking for a little help. The family is the core social unit of our society and helping to maintain strong families is beneficial for everyone in the state.

As a single mother, it is frustrating when trying to better me and my family and not able to receive assistance due to my income. I have been told several times I should drop my work hours or have more children and I would qualify. I am trying to get out of a hole not create more potential problems. That's not the advice I would expect to hear from case workers

Nebraska has a number of programs to support families and children with disabilities; however, strict income limitations, narrowly defined eligibility requirements, and a confusing application process make accessing these

programs difficult. This report is intended to shed a little light on what families need to meet the challenges of daily life and maintain the integrity of their families.

The advisory committee and workgroups met after the completion of the survey and the following recommendations were suggested:

Strengthen the Aging and Disability Resource Center Program (ADRC)

Many respondents to the survey commented that they were unaware of what was available. Families criticized the State for a lack of outreach activities that would increase awareness of the programs that exist. Strengthening and expanding the Aging and Disability Resources Centers could help families find the information they need.

Aging and Disability Resource Centers (ADRC) is a collaborative program with the U.S. Administration on Community Living and Centers for Medicare and Medicaid Services. The intent of this program is to create a single point of contact for information about services and supports to the aged and disabled populations.

In Nebraska the program has focused on extensive websites, Answers4Families, Nebraska 211, and the Nebraska Client Assistance Program. Report by the Center for Health Policy at the University of Nebraska Medical Center found that Nebraska was not a recipient of a grant for up to \$500,000 of grant money for Aging and Disability

Resource Centers in the Affordable Care Act²⁴.

Personnel at the Department of Health and Human Services reported that Nebraska chose not to participate in the 2012 funding opportunity²⁵. Nebraska applied for and received grants in 2009 and again in 2010 for development and improvements to the ADRC program. Funds remained from the earlier grant and work was continuing on a website that will be called Nebraska Directions.

A grant application will be prepared for the upcoming period to continue to enhance this program. As the state moves forward in developing the ADRC program, consideration needs to be given for the needs of the people who require this assistance. Respondents made it very clear through their comments that what they need is personal contact with people who know what is available and can help them access those supports.

People are missing out on services available to them because they are unknown to the family needing them. Because of only internet or phone services and no longer having case workers available to help explain services. There are families who do not have a support system and have frustrations that can and do become a negative influence and stressful in living their lives: Programs that are there to help them, support groups that can help

²⁴ Shaw-Sutherland, K., Wang, Y., & Stimpson, J. Health Reform Funding in Nebraska. Omaha, NE: UNMC Center for Health Policy; 2013 available at: http://www.unmc.edu/publichealth/docs/2013_Shaw-Sutherland_Health_Reform_Funding.pdf

²⁵ Conversation with P. Clark ARDC Coordinator Nebraska Health and Human Services on May 7, 2014.

them, a breathing person available to talk to face to face who understands. But to some this is lost because of either the unavailability of internet access to apply and access but more importantly a case worker whom they can speak to and offer suggestions of services available to the family (which the computer cannot do).

Increase reimbursement rates and income eligibility for child care

With recent changes to the Aged & Disabled Waiver regarding child care reimbursement families are struggling to find and afford qualified and accessible child care for their children with disabilities. Previously, children on the A & D Waiver were covered for child care when parents were working or attending school full time in the pursuit of a degree. In the late summer of 2013 the Division of Long Term Care, in an attempt to bring the waiver into compliance with federal guidelines moved to cover only specific disability related child care activities. Typical child care activities would be covered by families. The intention was that the Child Care Subsidy Program would be available to help families who could not manage the increase costs.

Many families found that they did not qualify for the Child Care Subsidy. Income eligibility for children on the A & D Waiver considers only the income of the child, which is typically Supplemental Security Income. Eligibility for the Child Care Subsidy Program considers all household income including SSI payments made to a child. This difference left many families

struggling to find affordable child care for their children.

A report by the Women's National Law Center on state child care assistance policies²⁶ shows Nebraska at the lowest levels of income eligibility. The report shows Nebraska income eligibility limits for families of 117% of poverty in 2013. The Economic Policy Institute estimates that an average family of three requires an income that is at least 200% of the federal poverty level to meet its basic needs which include housing, food, child care, transportation, health care, and other essentials²⁷.

Currently, the Nebraska child care reimbursement program eligibility is \$2,193.93 monthly for a family of three²⁸. Respondents throughout the survey commented that they struggled to make ends meet yet were over income for many of the programs that would assist them.

²⁶ Schulman, K. & Blank, H. (2013) Pivot Point: State Child Care Assistance Policies 2013. Washington DC: National Women's Law Center. Available at: <http://www.nwlc.org/resource/pivot-point-state-child-care-assistance-policies-2013>

²⁷ Gould, D., Wething, H, Sabadish, N., & Finio, N. (2011) What Families Need to Get By: The 2013 Update of EPI's Family Budget Calculator. (Washing DC: Economic Policy Institute) available at: <http://www.epi.org/publication/ib368-basic-family-budgets/>

²⁸ Nebraska Department of Health and Human Services Non-Transitional (sliding fee) Child Care. Available at: http://dhhs.ne.gov/publichealth/Pages/chs_chc_csubsyapa03.aspx

Financial guidelines for programs make it hard for struggling working families to get any help.

Adding to the concerns of families, reimbursement rates for the Child Care Subsidy make finding qualified day care difficult as well. Currently, Nebraska reimburses child care at 50% of market rates for child care. Seventy-five percent of market rate is recommended by the federal government and three states reimburse at higher rates: South Dakota, North Dakota and New York. In 2001, 22 states were paying higher than 75%.

Some states allow child care providers to charge the difference between their rates and the rate that the subsidy will reimburse. Nebraska is not one of those states. Providers can receive additional reimbursement for disability related care for children who use the A & D Waiver.

Fund services for intensive therapy during the first three years

Parents who have children younger than three who have been identified as at risk of developing a developmental disability or who have a diagnosis of a specific disability and have been referred to the Early Development Network find that the assistance they receive adequate but lacking an intensity that they feel would be beneficial for their children. Families reported that they have had to pay out-of-pocket for therapies they felt would benefit their young children. Families in the focus groups reported bankruptcy as a result of getting their children the supports they felt they needed.

Currently in Nebraska, children younger than three are generally not considered eligible for intensive therapy as it is determined to not have a medical benefit. However, research has shown that intense therapy including behavioral, speech and occupational improves children's outcomes in social skills and communication as they age²⁹.

For two sessions, the Nebraska legislature has debated legislation that would require health coverage for Autism Spectrum Disorder. During the 2014 legislative session, legislation was passed mandating coverage by insurance plans for services related to individuals diagnosed with Autism Spectrum Disorder³⁰. Unfortunately, children on the Autism Spectrum are typically not diagnosed until the age of four.

As Nebraska moves toward a managed care model of health care delivery, the state must consider the needs of its non-typical citizens. The issuance of request for proposals relating to long-term care was postponed until September 1, 2015³¹

²⁹ Mazurek, M.O., Kanne, S. M., & Miles, J. H. (2012). Predicting improvement in social-communication symptoms of autism spectrum disorders using retrospective treatment data. *Research in Autism Spectrum Disorders*, 6 535-545

³⁰ Nebraska Legislature, 103rd Legislature. LB245, A bill to eliminate a termination date for insurance coverage for anticancer medication and provide insurance coverage for autism spectrum disorder and funding for amino acid based elemental formulas. Text of bill available at: <http://uniweb.legislature.ne.gov/FloorDocs/Current/PDF/Final/LB254.pdf>

³¹ Nebraska Legislature, 103rd Legislature. LB854, an act relating to long-term care; relating to requests for proposals. Text of bill available at: <http://www.nebraskalegislature.gov/FloorDocs/Current/PDF/Final/LB854.pdf>

to allow for meaningful input from stakeholders. Understanding the importance of early and intense therapy for young children will be necessary for effective health care delivery to children with developmental delays.

Apply for the Community First Choice Option through a 1915(k) state plan and waiver case management

Nebraska has made available to children with disabilities and their families a wide array of services to help them meet their needs and become productive adults. Throughout the survey, families reported that, while they qualified for services, they were unable to access them because they had been placed on a waiting list. They also commented that some of the supports that were offered were not exactly what they needed.

Common sense is missing from policies. Families with children who have disabilities spend way too much time, money, energy and mental faculties trying to meet the needs of their families because of red tape and regulations. Policies try to place round pegs into square holes, so to speak. Two children who have the same diagnosis can have completely different needs. It is difficult to generalize.

The Community First Choice Option is a program offered by CMS and authorized by the Social Security Administration under a 1915 (k) waiver. Under this option states can offer specific services that are determined after an independent

assessment of the individual's needs and the development of a person-centered plan to meet those needs³². Services that are required include:

- services that assist the individual with activities of daily living,
- instrumental activities of daily living which includes skills that assist an individual to live independently within the community,
- health-related tasks through hands-on assistance, supervision, or cueing;
- services for the acquisition, maintenance, and enhancement of skills necessary for individuals to accomplish activities of daily living and instrumental activities of daily living and health related tasks
- voluntary training on how to select, manage, and dismiss direct care workers
- backup systems (such as beepers or other electronic devices) to ensure continuity of services and supports.

Access to the Community First Choice Option cannot be determined by slots that are available thereby eliminating a waiting list for services. The Federal Medical Assistance Percentage (FMAP) for states that adopt this program will be increased by 6% with no sunset clause.

³² Center for Medicare and Medicaid Services, Community First Choice Option Section 1915 (K) Fact sheet. Retrieved from <http://www.cms.gov/apps/media/press/factsheet.asp?Counter=4350&intNumPerPage=10&checkDate=&checkKey=2&srchType=2&numDays=0&srchOpt=0&srchData=community+first&keywordType=All&chkNewsType=6&intPage=&showAll=1&pYear=&year=0&desc=&cboOrder=date>

CMS has determined that the additional funding will be needed to support independent assessment and person-centered planning activities³³.

Individuals accessing this program will need to meet income eligibility requirements, as well as institutional level of care standards assessed annually. It will not be a panacea for all of the issues identified by respondents however, it will go a long way to helping families shape supports that meet the individualistic needs of their children. As the Division of Long-term Care develops the State Plan over the next year, consideration of the Community First Choice Option needs to be on the table.

Conclusion

The enthusiasm shown number of responses this project generated and the thoughtfulness of the comments offered, indicates that Nebraska families are interested in helping policy makers improve services for children with disabilities. The following comment sums up the general feelings expressed throughout the project: Families want help to stay intact and while the state remains fiscally sound. They are willing to contribute their thoughts on how this might be accomplished.

I served as a work group member on this project and during our focus group meeting there were programs and

services that I was not even aware existed - and I work in the field of disability advocacy! Other professionals around the table didn't know about certain programs. Our state needs to address the need to inform parents, educators, and professionals, about potential supports available for families in need. It won't cost much to improve the networking. Funds do need to be increased to help families who have youth struggling with behavioral and mental health in order to prevent youth from entering the system as wards of the state or into group homes. It does save the state much more money to keep families in tact and youth with DD/ID in their homes. I have seen great improvement over the years within NE Special Education...it is time for the other services to catch up!

³³ The Henry J. Kaiser Family Foundation State Health Facts, Section 1915 (k) Community First Choice State Plan Option. Available at: <http://kff.org/medicaid/state-indicator/section-1915k-community-first-choice-state-plan-option/>

Appendix B

Federal and State Statutory and Regulatory Authority for Programs

Children's DD Waiver

Federal Statutes	Federal Regulations	State Statutes	State Regulations
Title XIX of the Social Security Act	42 CFR 440.180 and part 441 Subpart G	Neb. Rev. Stat. §§ 83-1201 to 83-1226 (1997)	404 Neb. Admin. Code 10 (2011)
Section 1915(c) Medicaid HCB Waiver		Neb. Rev. Stat. §§ 68-901 to 68-949 (2012)	Nebraska Department of Health and Human Services – Developmental Disabilities Division, Interim Policies, August 1, 2011
		Neb. Rev. Stat. §§ 81-3110 to 81-3124 (2007)	

Disabled Person's and Family Support Program

Federal Statutes	Federal Regulations	State Statutes	State Regulations
Not Applicable	Not Applicable	Disabled Persons and Family Support Act Neb. Rev. Stat. §§ 68-1501 to 68-1521	472 Neb. Admin. Code 1-000 to 472 Neb. Admin. Code 4-004

Aged & Disabled Waiver

Federal Statutes	Federal Regulations	State Statutes	State Regulations
Title XIX of the Social Security Act	42 CFR 441.300	Medical Assistance Act, Neb. Rev. Stat. §§ 68-901 to 68-974	480 Neb. Admin. Code ch. 5 (1998)
section 1915(c) (Medicaid HCB Waiver)		Neb. Rev. Stat. § 81-2229(3)	
		Neb. Rev. Stat. § 81-2268	

Katie Beckett Program

Federal Statutes	Federal Regulations	State Statutes	State Regulations
Title XIX of the Social Security Act	42 CFR 435.225	Neb. Rev. Stat. § 68-1018	471 Neb. Admin. Code 12-014.07

Personal Assistance Services

Federal Statutes	Federal Regulations	State Statutes	State Regulations
Sec. 1102 of the Social Security Act (42 U.S.C. 1302)	42 CFR 440.167	Neb. Rev. Stat. § 68-1021.	471 Neb Admin. Code 15-000
Chapter V CMS Subchapter C Part 440			

Child Care Subsidy

Federal Statutes	Federal Regulations	State Statutes	State Regulations
Child Care and Development Block Grant Act	45 CFR Parts 98 and 99	Neb. Rev. Stat. Section 43-2602	392 Neb. Admin. Code 1-000

Nebraska Medical Assistance Program (NMAP) also referred to as Medicaid

Federal Statutes	Federal Regulations	State Statutes	State Regulations
Title XIX of the Social Security Act	42 CFR - Title 42— Public Health	Neb.Rev.Stat. §68-1018	471 Neb. Admin. Code
			480 Neb. Admin. Code
			482 Neb Admin. Code

Health Insurance Premium Payment Program (HIPP)

Federal Statutes	Federal Regulations	State Statutes	State Regulations
Title XIX of the Social Security Act.		Neb. Rev. Stat. § 68-910.	471 Neb. Admin. Code 30-000.

Medically Handicapped Children’s Program

Federal Statutes	Federal Regulations	State Statutes	State Regulations
Public Law 97-35, Subtitle D, Section 501(a)(4)	42 U.S.C. §§ 701-731.	Neb. Rev. Stat. §§ 43-522, 68-309, & 68-717.	467 Neb. Admin. Code 5-000.
Social Security Act Title V Maternal and Child Health Services Block Grant			

Lifespan Respite Subsidy Program

Federal Statutes	Federal Regulations	State Statutes	State Regulations
Not Applicable	Not Applicable	Neb. Rev. Stat. §§ 68-1520 through 1528 and 71-76114.04	464 Neb. Admin. Code 2-000

Disabled Children’s Program (SSI-DCP)

Federal Statutes	Federal Regulations	State Statutes	State Regulations
Title XIX of the Social Security Act	42 U.S.C. §§ 701-731.	Neb. Rev. Stat. §§ 43-522, 68-309, & 68-717.	467 Neb. Admin. Code 6-000

Home and Community-Based Waiver Services for Children with Autism Spectrum Disorder

Federal Statutes	Federal Regulations	State Statutes	State Regulations
Title XIX of the Social Security Act,	42 CFR 440.180	Neb. Rev. Stat. §§ 68-962 to 68-966	480 Neb. Admin. Code 11-000 (2010).
Section 1915(c) (Medicaid HCB Waiver)			

Early Development Network

Federal Statutes	Federal Regulations	State Statutes	State Regulations
Disabilities Education Act (IDEA) , Part H	34 CFR Part 303.	The Nebraska Early Intervention Act Neb. Rev. Stat. §§ 43-2501 through 2516 Neb. Rev. Stat. §§ 79-3301 through 79-3365, R.R.S., 1943	92, Neb. Admin. Code , Chapter 55
Family Educational Rights and Privacy Act of 1974 (FERPA)	34 CFR 99	Nebraska Medical Assistance Program Neb. Rev. Stat. §§ 68-1018 to 68-1025, R.R.S., 1943	92, Neb. Admin. Code , Chapter 51

Special Education

Federal Statutes	Federal Regulations	State Statutes	State Regulations
20 U.S.C. 1401.	34 CFR Part 300.	Neb. Rev. Stat. §§ 79-1110 through 79-1178 (1996, Cum. Supp. 2000, and Supp. 2001)	92 Neb. Admin. Code 51 (2010).

Appendix C

Respondent's Experience with Programs

Disability	Children's DD Waiver					
	N	Unaware	Applied	Denied	Receiving	N/A
Autism	107	61	14	8	5	30
Brain Disorder	13	6	1	1	2	4
Cerebral Palsy	19	6	2	2	5	5
Developmental Delay	28	17	1	0	2	12
Down Syndrome	47	31	4	3	0	13
Intellectual Disability	25	11	2	0	2	11
Multiple Disorders	10	4	2	2	0	3
Seizure Disorder	7	4	1	1	1	2
Speech and Hearing Disorder	11	5	0	0	2	5
Other Disorder	22	7	2	1	1	11
Totals	338	179	30	19	20	118

Disability	Disabled Persons and Family Supports Program					
	N	Unaware	Applied	Denied	Receiving	N/A
ADHD	19	13	0	0	0	6
Autism	107	74	2	6	1	32
Brain Disorder	13	11	1	0	1	4
Cerebral Palsy	19	14	0	2	1	2
Developmental Delay	28	16	1	0	3	9
Down Syndrome	47	38	1	2	2	9
Intellectual Disability	25	15	0	1	1	9
Learning Disability	20	10	0	1	0	9
Mental Illness	10	7	1	0	0	2
Multiple Disorders	10	6	1	0	0	4
Seizure Disorder	7	6	1	0	0	2
Speech and Hearing Disorder	11	6	0	0	0	6
Other Disorder	22	11	1	1	1	8
Totals	338	227	10	13	10	102

Aged and Disabled Waiver

Disability	N	Unaware	Applied	Denied	Receiving	N/A
Autism	107	59	3	7	2	43
Brain Disorder	13	7	2	0	2	5
Cerebral Palsy	19	6	4	4	6	4
Developmental Delay	28	13	2	1	2	10
Down Syndrome	47	30	4	5	1	13
Intellectual Disability	25	11	1	0	2	10
Mental Illness	10	4	1	1	0	4
Multiple Disorders	10	3	1	1	1	5
Seizure Disorder	7	4	1	0	1	3
Speech and Hearing Disorder	11	3	0	0	2	7
Other Disorder	22	5	2	3	4	10
Totals	338	164	22	22	23	134

Katie Beckett Program

Disability	N	Unaware	Applied	Denied	Receiving	N/A
ADHD	19	14	0	0	0	6
Autism	107	76	0	4	0	34
Brain Disorder	13	13	0	1	0	3
Cerebral Palsy	19	9	1	2	0	8
Developmental Delay	28	15	1	0	1	11
Down Syndrome	47	36	0	4	0	13
Intellectual Disability	25	12	0	0	0	12
Learning Disability	20	9	0	0	0	11
Mental Illness	10	7	0	0	0	3
Multiple Disorders	10	4	0	2	0	5
Seizure Disorder	7	6	0	0	0	3
Speech and Hearing Disorder	11	7	0	0	0	5
Other Disorder	22	12	0	2	0	8
Totals	338	220	2	15	1	122

Personal Assistance Program

Disability	N	Unaware	Applied	Denied	Receiving	N/A
Autism	107	73	2	5	1	33
Brain Disorder	13	14	0	0	0	3
Cerebral Palsy	19	10	2	2	0	5
Developmental Delay	28	13	1	0	1	13
Down Syndrome	47	37	1	1	0	13
Intellectual Disability	25	14	0	1	0	10
Learning Disability	20	9	1	0	0	10
Mental Illness	10	6	1	0	0	3
Multiple Disorders	10	5	0	0	0	6
Seizure Disorder	7	6	0	0	1	2
Speech and Hearing Disorder	11	6	0	0	0	6
Other Disorder	22	11	1	2	1	9
Totals	338	217	10	11	4	119

WIC

Disability	N	Unaware	Applied	Denied	Receiving	N/A
ADHD	19	2	3	2	0	12
Autism	107	12	5	17	5	74
Brain Disorder	13	1	1	2	0	11
Cerebral Palsy	19	2	1	2	2	13
Developmental Delay	28	2	1	3	2	19
Down Syndrome	47	3	7	7	3	33
Intellectual Disability	25	3	1	0	1	19
Learning Disability	20	0	1	1	2	16
Mental Illness	10	0	1	2	0	7
Multiple Disorders	10	1	0	2	1	7
Seizure Disorder	7	1	0	0	0	8
Speech and Hearing Disorder	11	0	1	2	3	6
Other Disorder	22	2	0	2	1	17
Totals	338	29	22	42	20	242

		Child Care Subsidy					
Disability	N	Unaware	Applied	Denied	Receiving	N/A	
ADHD	19	5	0	3	1	10	
Autism	107	41	2	11	6	51	
Brain Disorder	13	10	0	0	1	6	
Cerebral Palsy	19	8	1	1	0	9	
Developmental Delay	28	9	1	2	3	13	
Down Syndrome	47	25	2	5	0	19	
Intellectual Disability	25	7	1	1	1	14	
Learning Disability	20	2	1	2	0	15	
Mental Illness	10	1	1	1	0	7	
Multiple Disorders	10	3	0	2	1	5	
Seizure Disorder	7	2	0	0	0	7	
Speech and Hearing Disorder	11	4	0	2	1	5	
Other Disorder	22	3	2	1	3	15	
Totals	338	120	11	31	17	176	

		Medicaid					
Disability	N	Unaware	Applied	Denied	Receiving	N/A	
ADHD	19	1	4	1	5	9	
Autism	107	9	13	29	32	32	
Brain Disorder	13	0	4	3	6	3	
Cerebral Palsy	19	0	6	5	7	4	
Developmental Delay	28	3	1	3	12	8	
Down Syndrome	47	7	9	10	9	14	
Intellectual Disability	25	1	2	2	8	11	
Learning Disability	20	1	3	4	3	10	
Mental Illness	10	0	2	1	3	3	
Multiple Disorders	10	0	2	1	5	2	
Seizure Disorder	7	1	1	3	0	1	
Speech and Hearing Disorder	11	0	3	2	6	1	
Other Disorder	22	0	6	4	9	8	
Totals	338	23	56	68	105	106	

HIPP						
Disability	N	Unaware	Applied	Denied	Receiving	N/A
ADHD	19	9	0	1	0	10
Autism	107	67	1	8	2	29
Brain Disorder	13	9	1	1	0	5
Cerebral Palsy	19	9	2	1	3	5
Developmental Delay	28	17	0	0	0	11
Down Syndrome	47	38	2	2	1	6
Intellectual Disability	25	9	3	0	2	10
Learning Disability	20	8	0	1	0	11
Mental Illness	10	6	0	0	0	3
Multiple Disorders	10	4	0	1	2	3
Seizure Disorder	7	3	1	0	0	2
Speech and Hearing Disorder	11	6	0	1	1	3
Other Disorder	22	10	3	1	3	8
Totals	338	195	13	17	14	106

Medically Handicapped Children's Program						
Disability	N	Unaware	Applied	Denied	Receiving	N/A
Autism	107	58	8	7	3	35
Brain Disorder	13	9	2	2	1	2
Cerebral Palsy	19	7	5	6	1	2
Developmental Delay	28	15	1	0	3	9
Multiple Disorders	10	2	2	1	1	4
Seizure Disorder	7	3	1	0	1	1
Speech and Hearing Disorder	11	4	0	1	0	6
Other Disorder	22	5	2	3	0	13
Totals	338	158	28	26	16	120

Lifespan Respite Subsidy Program						
Disability	N	Unaware	Applied	Denied	Receiving	N/A
ADHD	19	10	1	2	0	6
Autism	107	59	6	8	12	26
Brain Disorder	13	10	2	0	0	3
Cerebral Palsy	19	10	1	1	1	6

Developmental Delay	28	16	1	1	0	10
Down Syndrome	47	32	2	3	0	11
Intellectual Disability	25	10	3	0	1	11
Learning Disability	20	4	1	0	0	15
Mental Illness	10	3	0	1	1	4
Multiple Disorders	10	6	1	0	0	3
Seizure Disorder	7	3	1	0	0	2
Speech and Hearing Disorder	11	6	2	0	1	3
Other Disorder	22	7	1	1	0	13
Totals	338	176	22	17	16	113

Nebraska Respite Network

Disability	N	Unaware	Applied	Denied	Receiving	N/A
ADHD	19	9	1	1	1	7
Autism	107	49	11	9	13	27
Brain Disorder	13	6	4	1	2	3
Cerebral Palsy	19	5	6	1	4	3
Developmental Delay	28	13	1	1	2	11
Down Syndrome	47	25	4	3	2	13
Intellectual Disability	25	12	4	0	1	9
Learning Disability	20	4	1	0	1	14
Mental Illness	10	2	0	2	1	4
Multiple Disorders	10	3	2	0	1	5
Seizure Disorder	7	2	0	0	1	3
Speech and Hearing Disorder	11	4	1	0	1	5
Other Disorder	22	5	3	0	1	14
Totals	338	139	38	17	32	118

Disabled Children's Program (SSI-DCP)

Disability	N	Unaware	Applied	Denied	Receiving	N/A
ADHD	19	9	1	0	0	9
Autism	107	53	8	16	13	21
Brain Disorder	13	8	1	2	3	1
Cerebral Palsy	19	5	3	5	3	5
Developmental	28	14	3	2	2	7

Delay						
Down Syndrome	47	33	4	3	3	7
Intellectual	25	10	3	1	1	9
Disability						
Learning	20	7	0	0	0	13
Disability						
Mental Illness	10	3	0	1	1	4
Multiple	10	3	1	0	2	4
Disorders						
Seizure Disorder	7	5	0	0	0	1
Speech and	11	6	1	0	1	4
Hearing Disorder						
Other Disorder	22	8	3	3	2	9
Totals	338	164	28	33	31	94

Early Development Network

Disability	N	Unaware	Applied	Denied	Receiving	N/A
ADHD	19	4	1	1	1	12
Autism	107	28	8	6	15	52
Brain Disorder	13	2	1	1	2	9
Cerebral Palsy	19	3	5	0	2	10
Developmental	28	8	3	0	5	12
Delay						
Down Syndrome	47	7	8	0	13	20
Intellectual	25	6	0	0	2	16
Disability						
Learning	20	2	1	0	3	14
Disability						
Mental Illness	10	2	0	0	0	7
Multiple	10	2	1	0	1	6
Disorders						
Seizure Disorder	7	1	2	0	0	3
Speech and	11	2	0	0	2	7
Hearing Disorder						
Other Disorder	22	2	7	0	6	11
Totals	338	69	37	8	52	179

Special Education

Disability	N	Unaware	Applied	Denied	Receiving	N/A
ADHD	19	2	2	2	8	6
Autism	107	9	19	4	75	10
Brain Disorder	13	0	2	0	14	1
Cerebral Palsy	19	1	6	0	9	4
Developmental	28	1	1	2	21	3
Delay						
Down Syndrome	47	6	7	1	20	14

Intellectual Disability	25	1	2	1	14	8
Learning Disability	20	2	4	0	12	3
Mental Illness	10	2	3	0	3	2
Multiple Disorders	10	1	1	0	6	2
Seizure Disorder	7	0	3	0	3	1
Speech and Hearing Disorder	11	1	1	0	7	2
Other Disorder	22	1	2	1	10	10
Totals	338	26	53	11	202	65

Appendix D

Themes and Categories for Narrative Responses

Challenges for families	Total: 163
Therapies too costly	26
Can't get Medicaid	49
Don't qualify anymore	10
Insurance won't cover	14
Out of pocket costs too high	14
Too many points of contact	9
Unaware of services available	41

Service Responsiveness	Total: 122
Lack of access to assistive devices	4
Lack of service consistency statewide	33
Lack of accountability	11
Lack of transition supports	18
IEP meeting advocacy	7
No Outreach	49

System Barriers	Total: 99
Waiting lists	8
Application process inaccessible	18
Professionals not knowledgeable	11
Lack of funding	27
Inadequate behavioral health services	28
Insufficient medical professionals in community	7

Unmet Family needs	Total: 157
Respite	42
Child Care	19
Parent training support	17
Transportation	9
Household assistance	5
Economic Assistance	15
Educational Supports	18
Social Skills Training	32