

## *Unmet Needs for Family Support (Knowledge of Programs)*

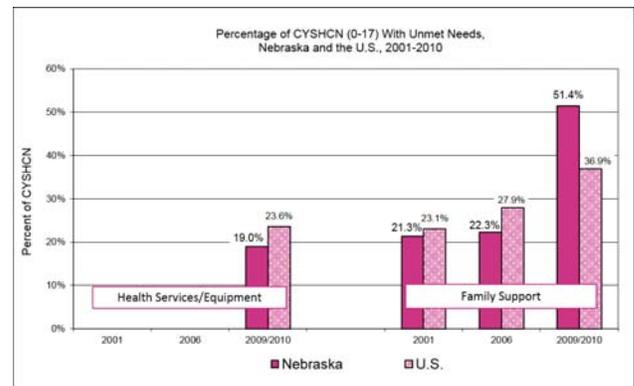
For families raising children with special health care needs, navigating through complex systems of care and support is often overwhelming and confusing. Many of these Nebraska families have unmet family support needs as reflected in findings from the Nebraska Title V Needs Assessment, the 2013-2014 Family Support Project survey assessment completed by The Arc of Nebraska (2013. Fischer-Lempke, M. and Cottingham, P.), and the “State of the States in Intellectual and Developmental Disabilities” 2011 & 2013 reports (Braddock et. al., 2011, 2013). Although the “State of the States” needs assessment is primarily focused on individuals with I/DD, family support needs between the two groups overlap to the extent that these data are pertinent to families with CYSHCN. It is also important to note that assessing this need is difficult, as families having unmet needs for family support are often unaware and unable to identify what supports they may be lacking. Regardless, research has shown families with unmet needs endure stress, anxiety, financial hardships, caregiver burnout, and discouragement and frequently lack for basic material concerns. (2008. Parish, S. L., et al.)

According to the Centers for Disease Control (CDC), approximately 62 million (30%) of Americans experience either some difficulty with “basic” movement, or cognitive, sensory, or emotional impairments. About 14% of people experience “complex activity limitations” in their ability to participate in society, including maintaining a household, working, and pursuing hobbies. (2014. Yee, S.) The Nebraska Title V Needs Assessment estimates that there were 61,071 children and youth with special health care needs living in Nebraska in 2009 and 2010. These data mean that 13.7% of children and youth in the state have special health care needs; slightly lower than the national estimate of 15.1%. The reality, however, is that there remains significant gaps in services and supports to help these children and youth and their families thrive. (2013. Fischer-Lempke, M. and Cottingham, P.)

### *Criterion 1: The Problem is Worse than the Benchmark or Increasing*

Data from the National Survey on Children with Special Health Care Needs estimate that 51.4% of Nebraska families have one or more unmet needs in family support services, compared to the national average of 36.9%. The data also confirm that Nebraska’s indicator is has been growing worse since 2001.

In addition, Nebraska ranked 49th out of 50 states in the provision of family support expenditures in the 2011 “State of the States in Intellectual and Developmental Disabilities” report. (Braddock et. al., 2011) In the 2013 “State of the States in Intellectual and Developmental Disabilities” Nebraska ranked 41<sup>st</sup> in family support expenditures. (Braddock et. al., 2013) These alarming statistics prompted the Nebraska Developmental Disabilities Planning Council (DD Council) to meet with Nebraska legislators to seek their collaboration in remedying this for



Nebraska’s families. Based on their recommendations, the DD Planning Council subsequently initiated funding for a project directly addressing these concerns (2014 Gordon, M.)

In 2013, the Nebraska Developmental Disability Council awarded the grant to The Arc of Nebraska to conduct the study of family support concerns in Nebraska for families with children with special healthcare needs and/or disabilities. This was initiated by obtaining input from regional workgroups of families and advocates located

across the state. A survey tool was developed and disseminated (451 completed surveys were returned.) The survey data was aggregated, and recommendations were developed. The study was completed in May 2014. Four themes emerged from the analysis: specific challenges for families; service responsiveness; systems barriers, and unmet family needs. The primary concern identified was the lack of information available to families about programs and services that could assist families who have children and youth with special healthcare needs and disabilities.

### Family Support Survey Results

Please tell us who you are. (Check all that apply.)		
Answer Options	Response Percent	Response Count
Parent of one child with an intellectual/developmental disabilities or a chronic healthcare condition	59.1%	270
A professional who provides services or care	27.6%	126
Parent of more than one child with an intellectual/developmental disabilities or a chronic healthcare condition	14.4%	66
Family member or care-giver who is legally responsible	3.7%	17
Grandparent	2.4%	11
Sibling	2.0%	9
Non-relative guardian	1.5%	7
Other (Please describe your relationship to a child with a developmental disability.)	3.5%	16
N=		457

How would you describe the race or ethnic makeup of your family?(check all that apply)		
Answer Options	Response Percent	Response Count
White	91.5%	430
Latino or Hispanic	11.1%	52
Black or African American	6.0%	28
American Indian or Alaskan Native	3.0%	14
Asian	1.9%	9
Native Hawaiian or other Pacific Islander	0.0%	0
Other (please specify)		12
N=		470

### *Specific Challenges for Families (noted by Family Support Study):*

- Therapies too costly
- Income restrictions for Medicaid eligibility
- No longer qualify for needed services
- Insurance won't cover
- Out of pocket costs too high
- Too many points of contact
- Lack of awareness

### *Service Responsiveness:*

- Lack of access to assistive devices
- Lack of service consistency statewide
- Lack of accountability
- Lack of transition supports
- Inadequate supports for families at IEP meetings
- No outreach to families; lack of awareness of services available

### *System Barriers:*

- Waiting lists for needed services
- Eligibility paperwork is burdensome
- Paperwork is lost
- Service Coordinators unknowledgeable
- Inability to fund the Autism Waiver
- Behavioral Health Services inadequate or unavailable
- Lack of access to medical professionals in the community
- Limited knowledge of services that could be used; inadequate resources regarding increased awareness

### *Unmet Family Needs:*

- Respite services not adequate or available
- Lack summer child care
- Lack parent training supports
- Transportation barriers
- Lack household assistance
- Inadequate economic assistance
- Inadequate educational supports

- Lack social skills training for children with autism

Staff from Munroe-Meyer Institute for Genetics and Rehabilitation also document the need for a one-stop referral source for families with CYSHN. Annually their staff handle in excess of 200 phone calls from families/professionals searching for supports.

### **Healthy People 2020 Comparisons**

The Healthy People 2020 Disability and Health objectives highlight areas for improvement and opportunities for children and youth with special healthcare needs and disabilities to:

- Be included in public health activities.
- Receive well-timed interventions and services.
- Interact with their environment without barriers.
- Participate in everyday life activities.

Without these opportunities, CYSHN and with disabilities, the comparisons indicate they will continue to experience health disparities compared to the general population. The 2020 objectives were developed with extensive input from disability communities, and this partnership between the public health and disability communities must continue over the decade in order to meet the Healthy People 2020 objectives. (healthypeople.gov.)

### ***Criterion 2: Disparities Exist Related to Health Outcomes***

Currently, 645 birth-age 17 children and youth are served under the Nebraska Aged and Disabled Medicaid Waiver (children meeting nursing home level of care). There is currently no waiting list. The Children's Developmental Disabilities Waiver currently serves 238 children (but has had an extensive waiting list). Both waivers comprise the only two comprehensive, state-funded programs that include family support services in Nebraska; examples of services provided include homemaker services, respite, access to Medicaid, in-home support, services coordination, etc. (2015. Personal

communication with the Nebraska Department of Health and Human Services.)

As noted earlier, according to the Nebraska Title V Needs Assessment there are 61,071 children identified with Special Healthcare needs in the state. Given 51.4% of families with CYSHCN have at least one unmet family support need per the data, a significant shortage of services can be inferred.

The largest set of U.S. health data for CYSHN and people with disabilities, DATA2010, measures health at the population level. These data highlight improvements in health over the previous decade and clearly reveal specific health disparities for CYSHN and people with disabilities. Compared with people without special healthcare needs or disabilities, people with these conditions are more likely to:

- Experience difficulties or delays in getting the health care they need.
- Not have had an annual dental visit.
- Not engage in fitness activities.
- Use tobacco.
- Be overweight or obese.
- Have high blood pressure.
- Experience symptoms of psychological distress.
- Receive less social-emotional support. (healthypeople.gov)

Given the numbers cited previously, and given the fact also, previously noted, that families with unmet needs endure stress, anxiety, financial hardships, caregiver burnout, and discouragement. (Parish et al), disparities in health outcomes within Nebraska families with children with Special Healthcare Needs is exacerbated by a lack of family support services to affected families.

### ***Criterion 3: Strategies Exist to Address the Problem***

States participating in CMS federally funded grant programs known as "Balancing Incentives Program" (BIP) have reported they are making great strides bringing improvements that benefit

families with CYSHN, including developing a “No Wrong Door/Single Entry Point” system, conflict-free case management, and the development and use of a standardized assessment instrument. The overall goal of “Balancing Incentives Programs” is to increase access to community-based services and supports for eligible individuals and families. BIP grant funding provides participating states with enhanced match funds.

The Nebraska Balancing Incentive Program (BIP) in Nebraska was made possible with funding from a federal grant with CMS that from the NE DHHS Division of Medicaid and Long-term Care in partnership with the Division of Developmental Disabilities. The Nebraska Department of Health and Human Services applied for and secured the grant after legislation (LB690) passed in 2014. The BIP would have provided the state with \$8.1 million dollars of enhanced match funds. An advisory council was established to develop the infrastructure necessary to implement BIP and strengthen access to long-term services and supports statewide.

Unfortunately the Nebraska Department of Health and Human Services recently discontinued the Balancing Incentive Program (BIP) project on March 2, 2015. This was due to concerns within the Department over the extremely limited timeframe for Nebraska’s program to produce a successful project through the BIP grant. See information under Criterion 4.

Nationally, Aging and Disability Resource Centers provide an evidence-based strategy to help individuals with special healthcare needs and/or disabilities as well as families with CYSHN and/or disabilities access services and supports. With the stated goal to be a true “one-stop” system, the ADRC must be designed so that the consumer only has to go one place or make one phone call to access all appropriate services. Through that one contact, the consumer should either directly receive all the information or services they need or be seamlessly connected with a resource which would provide the information and services they need. There are many ways to design a system so that the consumer has the

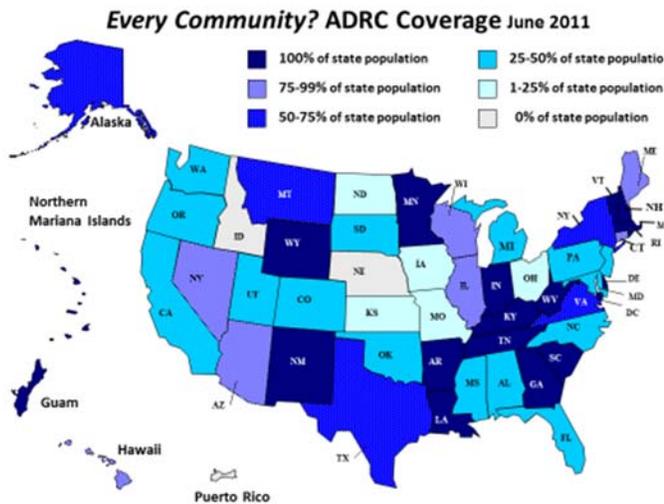
“one-stop” experience. One of those ways is to build an integrated/centralized system so that all the functions and services for all the populations served (e.g. aging and disability populations) are offered by one organization in a service area. A consumer from any of the ADRC target populations can call or walk into this one organization and get all the information and services they need from staff in that one organization. (2007, Blakeway, C.)

The federal ADRC initiative began in 2003 with three core functions: awareness, assistance, and access. These ADRC core expectations now include: information, referral, and awareness, options counseling, advice, and assistance, streamlined eligibility determinations for public programs, and intervention in critical pathways to institutionalization, person-centered transitions, and quality assurance and continuous improvement. (“Aging and Disability Resource Centers, ‘Just the Facts’; National Aging and Disability I&R Symposium, June 2011, Carrie Blakeway, Senior Consultant, The Lewin Group)

The national vision for ADRCs is to have Aging and Disability Resource Centers in every community serving as highly visible and trusted places where people of all incomes and ages can turn for information on the full range of long-term support options and a single point of entry for access to public long-term support programs and benefits.

Current ADRCs across our nation report high levels of consumer satisfaction with responsiveness, objectivity, comprehensiveness of information and assistance. (2011 Blakeway.)

The map below reflects areas in the United States where ADRC coverage exists. Nebraska’s current status as noted in the legend demonstrates the need for a functioning state ADRC system.



**Figure 1:**  
<http://www.nasud.org/documentation/IR/2011-Symposium/ADRC-Just%20the%20Facts.pdf>

Based on the findings from The Arc of Nebraska’s Family Support Project, the following recommendations were made: strengthen the Aging and Disability Resource Center Program (ADRC); increase reimbursement rates and income eligibility for child care and respite; fund services for intensive therapy during the first three years; and apply for the Community First Choice Option through a 1915(k) state plan and waiver case management.

Additional recommendations included: fund and implement the autism waiver, expand Medicaid, expand income eligibility for respite and child care subsidies, strengthen the Nebraska Respite Network and other sources of outreach and information, and promote an independent case management model that separates case management from the funding source. Other suggestions included: require collaboration between the Department of Education and local school districts to develop and present training prior to each school year for Special Education Educators and Parents on the roles, responsibilities, and legal requirements of IEP team members, and expand the Nebraska Loan Repayment Program. Any and all of these recommendations have been demonstrated to alleviate the strains imposed on families with

children with special healthcare needs. (2011. Murphy, N. & Carbone P.)

**Criterion 4: Societal Capacity to Address the Problem**

Senator Kate Bolz introduced legislation: LB 320. This legislation will continue the systemic goals of BIP including a “no wrong door/single point of entry” system and standardized assessments. This legislation has been shown in other states to be cost effective and contributes positively to the key goals of promoting home and community based care and linking people to the right service at the right time. It creates Aging and Disability Resource Centers, as noted as an evidence-based preventative strategy shown to be effective under Criterion 3. These resource centers would serve as an information clearinghouse for Nebraskans who are aging, disabled, and/or family members of aging and disabled Nebraskans. Information and services provided would include, but is not be limited to: information and referral, options counseling, streamlined eligibility determination for public programs, person-centered transition support when moving from one setting to another (such as when an individual moves from a hospital back into a home setting,) strategic partnerships with providers, and quality assurance.

The new health care law of 2010, the Affordable Care Act (P.L.111-148), promotes the central importance of person- *and* family-centered care in the design and delivery of new models of care to improve the quality and efficiency of health care, including assessment of the family caregiver’s experience of care. Family-centered care is an effective strategy to help families gain insight and knowledge to address some of their unmet needs.

By providing adequate funding for respite programs, the state of Nebraska can provide families with CYSHN significant support in the form of caregiving breaks for refreshment and renewal. Lifespan respite programs assist caregivers in gaining access to needed respite services, train and recruit respite workers and volunteers, and enhance coordinated systems of

community-based respite services. Unfortunately the Lifespan Respite Care Act is inadequately funded at only \$2.5 million in FY 2011. (2011, Feinberg et al)

In 2014, the Nebraska Legislature passed legislation requiring insurance coverage on the part of private employers of autism spectrum disorders (Nebraska Revised Statute 44-7,106.) The legislation requires private employee insurance coverage for evidence-based applied behavior analysis and other Autism spectrum disorder treatments. Private employee insurance plans in Nebraska must provide coverage for Autism screening, diagnosis, and treatment provided by a board certified behavior analyst or licensed psychologist. Disease specific and self-funded employee plans are exempt from this legislation. The new legislation requires annual coverage amounts to include a maximum of 25 hours a week until the insured person reaches age 21. The insurer may request a review every six months of the treatment being received. The new legislation is not applicable to qualified health care plans in individual and small group markets sold through and outside the state's health insurance exchange that are required to include the essential health benefits under the federal Affordable Care Act. This legislation represents a significant step forward in addressing a significant unmet need for Nebraska families who have children on the Autism Spectrum.

#### **Criterion 5: Severity of Consequences Criterion**

The problem of unmet family support needs can be a life threatening condition, but is more often significantly disabling to the child or youth, their family and their community. These concerns were addressed by Congress in the Developmental Disabilities Act of 2000 in Title II of the Act. However, Title II has to date not been funded. Without proper supports, families become overwhelmed (2013 Nebraska Department of Health and Human Services: Efficiency and Effectiveness of ACCESS Nebraska.) and consider extreme measures such as giving their children up as wards of the state in order to obtain needed services. Children and youth with special health care needs whose families have unmet needs

regarding family support services are at more risk of abuse, neglect, and out of home placement. To avoid severe negative outcomes, Nebraska must develop strategies to bridge the gap of unmet family support needs. Without a significant effort, families of children with special healthcare needs will be consigned to face specific risks that may be beyond their capacity with which to successfully cope (2013 Burke, M. & Fujiura, G.)

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