# The Need for Adequate Health Insurance

Having health insurance is important for all families. Insurance coverage allows families to access needed services, pay for medical equipment and prescriptions, obtain annual physicals, sick care and provides the peace-of-mind that a loved one can get the care they need should an illness or chronic condition occur. Having insurance that will pay for needed services in a manner that is adequate is especially important for families that have children and youth with special healthcare needs. Children and Youth with Special Healthcare Needs (CYSHCN) only make up approximately 15% of the population but utilize 33.6% or more of the healthcare costs associated with children. [1] Because of the nature of their disability or special healthcare need, CYSHCN are the "frequent flyers" of the healthcare system and this often means that their families have a disproportionate share of the costs.

When a child is diagnosed with a disability or chronic healthcare condition, typically families have to access specialty care, attend therapy sessions, pay for specialized equipment or prescription drugs, and carry-out the day-to-day care needs for their child. Often the additional needs of the child require one parent to quit working to insure that adequate care is provided. This can cause financial problems for the family due to decreased wages and increased healthcare costs.

Having adequate private and/or public insurance to pay for needed services for CYSHCN is a core outcome for Title V programs, the Maternal and Child Health Bureau and also is an identified objective in Healthy People 2010 and 2020.[2]

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

According to the National Survey for Children and Youth with Special Healthcare Needs, 22.5% of Nebraska families experienced financial problems due to their child's health needs. While this figure has not increased, it has been a persistent concern over time.

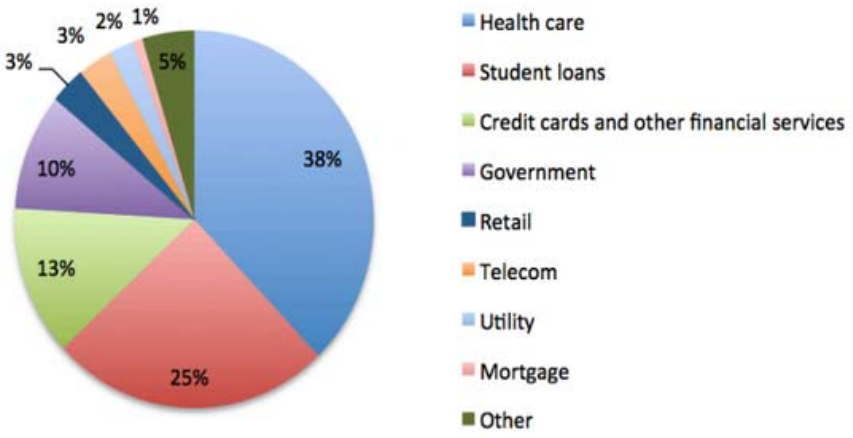
Every year the Community Action Agencies of Nebraska surveys over 10,000 individuals/families across the state. In 2013, more than half of survey respondents reported difficulties finding affordable medical, vision, and dental care. In households with children, access to disability services was a concern for 30%. In addition, respondents reported difficulties accessing mental health care, which increased from 24% in 2010 to 28% in 2013.[3]

In the 2013 Arc Family Support Project funded by the Nebraska Planning Council of Developmental Disabilities, Nebraska families identified the following concerns related to healthcare:

- Therapies too costly
- Income restrictions for Medicaid eligibility
- No longer qualify for needed services
- Insurance won't cover

In 2014, the financial advising company 'NerdWallet'[4] found that medical bankruptcy was the number one cause of bankruptcies in the United States.[5] This was reported by both CNBC

## Types of Debt Collected From Consumers in 2013




NerdWallet analysis of Ernst & Young's analysis of third-party debt collection

News[6] and Fox Business News[7]. The study also noted that having year round health insurance coverage did not protect the family from bankruptcy.

While co-pays and total out-of-pocket amounts can be cost-prohibitive, experts say that the health insurance deductible, which in 2014 averaged $2,000 or more for single coverage for nearly one in five workers and from around $2,000 to $4,500 for families, substantially impacts both the total cost and also deters families from seeking treatment. [8] The authors of the NerdWallet survey reported that having high deductible plans of $5,000 to $10,000 is becoming more common. In these type of plans, since the deductible must be met before the plan will pay, older employees and those with chronic care needs will not benefit.[9]

High-deductible plans started out as offerings by small businesses in order to offer health insurance in an affordable manner. In 2012, nearly a quarter of the workers at companies with fewer than 200 workers were covered by high-deductible health plans, compared with 17 percent of workers at larger firms.[10] Business Day reports that a survey conducted by the National Business Group on Health that in 2015 nearly a third of large employers will offer only high-deductible plans — up from 22 percent in 2014 and 10 percent in 2010.[11] Since about half of the Nebraska's private workforce was supported by small businesses in 2012[12] and health insurance premiums in Nebraska increased 10% between 2014-2015[13], it would seem reasonable to say that the problem of inadequate health insurance is getting worse and that CYSHCN and their families are disproportionately affected.

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

Prior to the passage of the Affordable Care Act (ACA), CYSHCN could be denied access to insurance coverage simply based on their pre-existing condition. In addition, if they met maximum health insurance caps, CYSHCN could be forced out of insurance plans completely. In Nebraska, CYSHCN might be eligible for Medicaid or Children's Health Insurance Program if their family income or their disability met eligibility guidelines. While the ACA, has negated some of these issues, barriers and health disparities still exist. These include caps on certain categories of services offered and the denial of classes of categories. In Nebraska, within the last three years, examples of coverage concerns for CYSHCN include:

- The coverage of cochlear ear implants[14]
- Autism coverage within private health insurance market[15]
- Autism coverage within the state Medicaid program[16]
- Behavioral Health Coverage for Children under the age of 5[17]
- Specialized formulas for CYSHCN with digestive disorders[18]
- Overuse of psychotropic medications for children with behavioral health disabilities[19]
- Concerns related to families' ability to access the Medicaid and other economic assistance programs within the state's 'Access Nebraska' system. [20]

Uninsured families or under-insured families are less likely to:

- be satisfied with the care they receive;
- feel like partners in decision-making;
- have less access to a medical home and community-based services; and,
- be less successful in their transition to adulthood[21]

### *Criterion 3: Strategies Exist to Address the Problem/An Effective Intervention is Available*

The Catalyst Center funded by the federal Maternal Child Health Bureau offers the following strategies to support CYSHN who do not have insurance or adequate coverage:

**Teach Families How to Maximize Their Private Insurance Benefits:**

An effective strategy used by states to reduce underinsurance is to provide support and advocacy for families in understanding and using their health care benefits – either with the state Medicaid program or with their private insurance plan.

- In Illinois, the Title V program has hired former staff members of health insurance companies who travel to regional CYSHCN offices and work with care coordinators, showing them how to help people maximize their private benefits and advocate with Medicaid to pay for needed services.

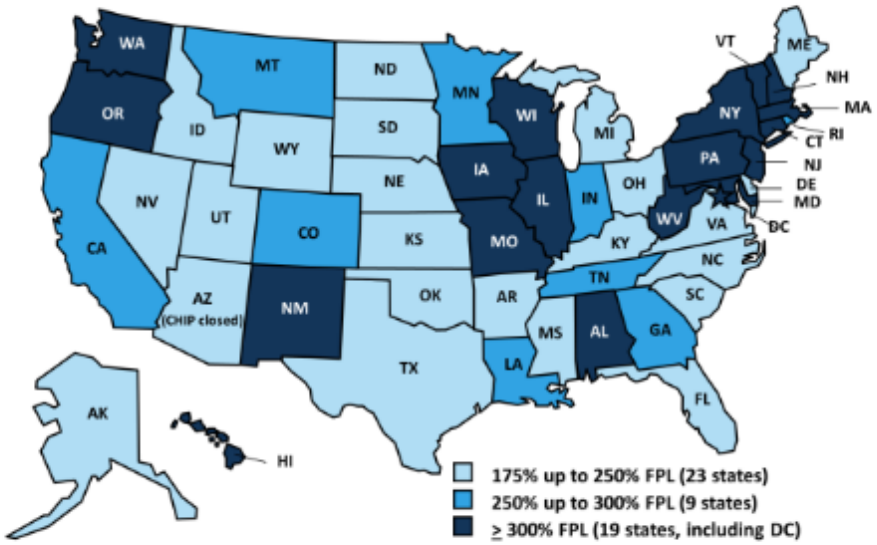
- In Vermont, Title V staff works directly with privately insured families to advocate for coverage of services that are prescribed by a physician or referrals to out-of-network providers that were initially rejected by the insurer.
- Advocacy and Benefits Counseling (ABC) for Health, a Wisconsin-based, nonprofit, public interest law firm, provides direct benefits counseling services to families having problems with health care coverage, adequacy of benefits, or access to services. ABC for Health has developed a model for training culturally competent and family-centered benefits counselors.

**Partner with Medicaid to offer Medicaid buy-in programs, support with co-pays and deductibles, or offer premium assistance programs:**

- For families that have a child with a disability that make too much money to qualify for Medicaid but need coverage, or need additional coverage, they can pay premiums to 'buy-into" the state Medicaid program. Medicaid "Buy-In" Programs are available in Colorado, Texas, and Massachusetts.
- In Tennessee, the Title V program covers co-payments and deductibles for eligible CYSHCN who are privately insured or are required to pay these costs under TennCare, the state Medicaid program.
- Premium assistance programs offer another means by which states can increase the number of CYSHCN with insurance coverage. In premium assistance programs, a state agency pays all or part of a family's health insurance premiums if it is cost effective to do so. While the majority of premium assistance programs are administered by state Medicaid agencies (in at least 23 states by current count), some Title V programs also provide premium assistance for CYSHCN.

Figure 4

**Income Eligibility Levels for Children in Medicaid/CHIP, January 2015**




NOTE: The federal poverty level (FPL) for a family of three in 2014 is $19,790. Thresholds include the standard 5 percentage point of the FPL disregard.
SOURCE: Based on results from a national survey conducted by the Kaiser Commission on Medicaid and the Uninsured and the Georgetown University Center for Children and Families, 2015.

**Expand Eligibility in the Children's Health Insurance Program (CHIP) or Medicaid Program**

The Children's Health Insurance Program (CHIP) program is financed by the federal government and each state. Of the almost five million children enrolled in CHIP, a significant proportion (17% to 25% in studies done from 1999 to 2002) are

estimated to be CYSHCN. Under the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA), states can now offer health insurance coverage to uninsured children in families with incomes above 200% of the federal poverty level (FPL) without facing major penalties. The federal government pays an enhanced matching rate for children in families up to 300% of the FPL and the Medicaid matching rate for children in families over 300% of the FPL. Across states, CHIP eligibility levels range between 160% and 400% of the FPL, with 37 states with income eligibility levels over 200% of FPL.

**Increase the number of slots and eligibility criteria within Nebraska's Medicaid Waiver programs**

Medicaid waivers are a way that states can offer less costly home and community based services to individuals with disabilities. The following chart is a summary of Nebraska's waiver programs compared to surrounding states. Nebraska could expand the number of waiver slots to support CYSHCN and also offer mental health waivers.

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

There are many existing projects and programs in which Title V could partner or support. The following are suggested activities:

**Advertise Existing Programs in Nebraska that Support Families that Have CYSHCN and Provide Training, Education and Outreach on Program Eligibility**

There currently are many programs available to families that have CYSHCN which can help provide for needed services and supports, offset some of the costs, and minimize the financial impact. These include:

- Nebraska's Aged & Disabled Waiver
- Nebraska's Developmental Disabilities Waiver
- Nebraska's Day Services Waiver
- Nebraska Children's' Waiver
- Nebraska's Traumatic Brain Injury Waiver
- Nebraska's Disabled Person and Family Support Program

| Location | ID/DD | Aged | Aged & Disabled | Physically Disabled | Children | HIV | Mental Health | TBI | Total |
|---|---|---|---|---|---|---|---|---|---|
| Nebraska | 4,044 | NA | 6,132 | NA | 323 | NA | NA | 27 | 10,526 |
| Colorado | 7,436 | NA | 18,032 | NA | 2,354 | 80 | 2,539 | 286 | 30,727 |
| Iowa | 10,888 | 12,102 | NA | 3,761 | NA | 57 | NA | 1,163 | 27,971 |
| Kansas | 7,965 | 7,960 | NA | 9,036 | 5,319 | NA | NA | 377 | 30,657 |
| South Dakota | 3,334 | 1,397 | NA | 141 | NA | NA | NA | NA | 4,872 |
| Wyoming | 1,494 | NA | 2,072 | NA | 892 | NA | NA | 176 | 4,634 |

Source: http://kff.org/medicaid/state-indicator/participants-by-hcbs-waiver-type/# (2009)

- The Health Insurance Premium Program (HIPP)
- The Medically Handicapped Children's Program
- Respite Network and Respite Subsidy

However, families often report that they don't know about these programs.[22] Therefore, these programs need to be advertised, services coordinators need to be provided training, and education. In addition, there needs to be on-going outreach on program eligibility to families and professionals across the state and current program eligibility could be broadened to insure that more CYSHCN have coverage.

**Support and Build the Capacity of the Aging and Disability Resource Center (ADRC)**

An Aging and Disability Resource Center is supposed to be a single entry/no wrong door into systems. It is supposed to be a clearinghouse of information for individuals who are aging or who have disabilities and their families. These resources are provided virtually, through the phone, and also through a network of options-counselors. Title V could support the existing efforts of creating Nebraska's ADRC to have a specific focus on CYSHCN and their families. A legislative bill supporting Nebraska's ADRC is expected to be successful this session.

**Collaborate with the federally-funded Navigator grant program**

Under the Affordable-Care Act, each federally-facilitated health insurance exchange program operates a grant program with 'Navigators' who can assist individuals and families in applying for and purchasing health insurance coverage. These Navigators also assist individuals in accessing Medicaid coverage or the Children's Health Insurance Program (CHIP). In Nebraska, the network of Community Action Agencies currently have the grant to run this program. Title V could collaborate with this program to insure that the 'Navigators' have knowledge of the Title V Programs and other programs that support CYSHCN. In addition, translators could be supported and employed to insure non-English speaking individuals have knowledge of and access to insurance coverage. Medicaid reimbursement for translation and interpretation services is available to states through a 75% matching program.[23]

**Collaborate with the Nebraska Medicaid Program to maximize programs available to support CYSHCN**

As illustrated in the section above, there are several existing strategies that could be utilized to support CYSHCN and their families to insure adequate coverage. These include:

- Teaching families to maximize their private insurance benefits
- Medicaid buy-in programs
- Premium assistance programs
- Assistance with deductibles and co-pays
- Expanding Medicaid and/or CHIP Eligibility
- Expanding Medicaid Waiver slots or Waiver Programs
- Employ and expand availability of translators

### *Criterion 5: Severity of Consequences*

Children with special healthcare needs who experience inconsistent, inadequate, or do not have health insurance are more likely to suffer

consequences from their health conditions. When they cannot obtain needed treatments and obtain specialist care, they cannot maintain their health. Often the inability to access needed services can be dire. The lack of access to insurance coverage, or inadequate coverage often leads to a higher cost for both the family and society. Christina Bethel and colleagues analyzed data from the 2008 Medical Expenditure Panel Survey and determined that the average annual health care expenditures for CSHCN were four times higher than those for other children-$3,392 compared to $856.[24]

Children who experience developmental delays who cannot get needed medical interventions do not progress or experience further delays compared to their peers. When the family cannot pay for the needed medical interventions, crisis care is necessary-often which is accessed through an Emergency Room and at a cost much higher than had the intervention or prescription or equipment needs been provided to begin with.

There are also many indirect cost for families having CYSHCN. Several studies indicate that having a child with disabilities increases the likelihood that the mother (and less often the father) will either curtail hours of work or stop working altogether. Researchers also find that having a child with disabilities can affect a mother's own health and put substantial strains on the parents' relationship.[25] Several studies cite the higher divorce rate for families that have CYSHCN. In addition, siblings of CYSHCN are also impacted. Studies indicate siblings are often forced into caregiving roles at early ages and are asked to "help out" more than their peers. They also may feel ignored by their parents whose time is often required by the child who has a special healthcare need or disability. These siblings subsequently are more likely to have emotional and behavioral problems and are often found to have "psychosomatic" illnesses in order to get attention from their parents.[26]

Often health insurance coverage and adequacy of coverage are related to under-lying social factors such as family income or unemployment. Children dealing with these issues are often faced with greater stress and adversity (Data Resource Center for Child & Adolescent health, 2013) Children who have chronic healthcare concerns often experience further complications if their conditions are not treated and cannot be ameliorated. This in turn impacts health outcomes and most likely CYSHCN's workforce participation and productivity as adults.

As noted previously, families that have CYSHCN face obstacles that typically are not faced by families that do not have CYSHCN. Having adequate health insurance can relieve some of the stressors faced by these families and improve the health and well-being of the child with the disability or special healthcare need.

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