CYSHCN Mental Health Needs

Mental Health is important to overall health. Mental disorders (for example, attention-deficit/hyperactivity disorder (ADHD), Tourette syndrome, behavior disorders, mood and anxiety disorders, autism spectrum disorders, substance use disorders, etc.) are chronic health conditions often times continue through the lifespan. Without early diagnosis and treatment, children with mental disorders have problems at home, in school, and problems forming friendships. (CDC 24/7:CDC Features, 2015) Children and youth who have intellectual disabilities or developmental disorders are at higher risk of mental health issues or behavioral problems.

Just over a third of Nebraska's youngest children are screened for developmental delays during the first 3 years, when interventions are most effective and least costly. Only 35 percent of infants and toddlers in Nebraska receive developmental screenings, often resulting from parent-reported concerns about their children's physical, linguistic, and social-emotional growth. Developmental screening are effective at identifying health or behavioral problems in young children, and better enable families to apply for and receive early intervention services that can make a difference in the life trajectories of infants and toddlers at risk. (David Murphey, 2015)

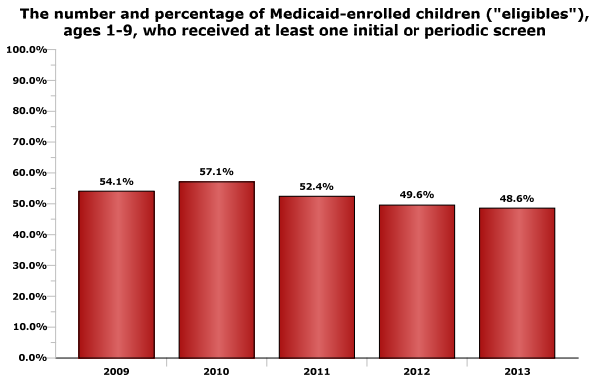
Criterion 1: The Problem is Worse than the Benchmark or Increasing

The U.S. Centers for Disease Control and Prevention (CDC) define childhood mental disorder as all mental disorders that can be diagnosed and begin in childhood (for example, ADD/ADHD; behavior disorders, mood and anxiety disorders, autism spectrum disorders). A total of 13%-20% of children in the U.S. experience a mental disorder in a given year. Surveillance during 1994-2011 has shown the prevalence of these conditions to be increasing. (Centers for Disease Control and Prvention, 2015)

1 in 5 children has a diagnosable mental disorder but factors that predict mental health problems can be identified in the early years. Babies and toddlers have limited number of responses to stress and trauma, unlike adults. Mental health disorders in infants and toddlers can be shown as physical symptoms (poor weight gain, slow growth and constipation), overall delayed developments, inconsolable crying, sleep problems, aggressive or impulsive behavior, or fears. (Zero to Three, 2012)

Periodic developmental and behavioral screen during early childhood is essential to identify possible delays in growth and development. These screenings are required for all children enrolled in Medicaid through the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT). Children are also covered if they are enrolled in Children's Health Insurance Program (CHIP). The number and percentage of Medicaid-enrolled children ages 1-9, who received at least one initial or periodic screen, has declined over the past five years.

Figure 1



81.9% of CYSHCN ages 2-17 in Nebraska received all the mental health care or counseling that they needed, but almost 20% did not.

The prevalence of mental health disorders is much higher than generally recognized among children and youth with intellectual disability, estimated to be between 30-50%. (Einfeld, 2011) Co-occurring conditions for example, anxiety and attention deficit/hyperactivity disorder are very common in children with autism spectrum disorders.

Parents describe time-consuming and painful searches for appropriate assessments, and medical evaluations

About 1 in 68 children (or 14.7 per 1,000 8 year olds) in the U.S. were identified with Autism Spectrum Disorder (ASD) (need reference, including the year for these data). This new estimate is roughly 30% higher than the estimate for 2008 (1 in 88), about 60% higher than the estimate for 2006 (1 in 110), and about 120% higher than the estimates for 2002 and 2000 (1 in 150). Yet, fewer than half of children identified with ASD were evaluated for developmental concerns by the time they were 3 years old. In fact, most children identified with ASD were not diagnosed until after age 4, even though children can be diagnosed as early as age 2 and earlier diagnosis is significantly predictive of better outcomes. (Centers for Disease Control and Prevention)

In Nebraska, 6.5% of children (2-17) were diagnosed with Autism or Autism Spectrum Disorder for 2009/2010 up considerably from 2006 (2.2%).

Research has shown that a diagnosis of autism at age 2 can be reliable, valid, and stable. (Kozlowski AM, Matson JL, Horovitz M, Worley JA, Neal D., 2011). On average, children identified with ASD were not diagnosed until after age 4. Studies have shown that parents of children with ASD typically notice a developmental problem before their child's first birthday. Concerns about vision and hearing were more often reported in the first year, and differences in social, communication, and fine motor skills can be evident from 6 months of age. (Kozlowski AM, Matson JL, Horovitz M, Worley JA, Neal D., 2011) (Centers for Disease Control and Prevention, 2015)

More than one-half of school-aged children with ASD use at least one psychotropic medication to meet their developmental needs. Almost one-third of school-aged children with ASD use stimulant medications, one-quarter use anti-anxiety or mood-stabilizing medications and one-fifth use antidepressants. (Beverly A. Pringle, Ph.D.; Lisa J. Colpe, Ph.D., M.P.H.; Stephen J. Blumberg, Ph.D.; Rosa M. Avila, M.S.P.H.; and Michael D. Kogan, Ph.D., 2012) 73.8 % of children with ADD or ADHS used ADHD medication in the last week (Your Data...Your Story, 2009/10).

Common co-morbidities of children and youth with ASD include epilepsy (19.44%); schizophrenia (2.43%); inflammatory bowel disease (0.83%); SNS/cranial anomalies (12:45%); diabetes mellitus type I (0.79%) muscular dystrophy (0.47%); sleep disorders (1.12%) with each category being higher than children and youth without ASD. (Kohane, Isaac et al, 2012) One factor linked to increased impairment beyond core ASD symptoms is the presence of anxiety. Up to 80% of children with ASDs experience clinically significant anxiety, with high comorbidity rates for social phobia (30%), generalized anxiety disorder (35%), obsessive-compulsive disorder (37%) and separation anxiety disorder (38%). Anxiety comorbidity is associated with greater ASD

symptom severity and concomitant impairments in psychosocial functioning. (Nadeau, Joshua et al, 2011)

Averages of 38.8% of Nebraska children ages 6-17 are reporting that they were experiencing anxiety or depression (2009/2010). There is no data for ages 0-5 years.

Studies show that between 30 & 50% of individuals with ASD manifest ADHD symptoms (particularly at pre-school age), and similarly, estimates suggest two-thirds of individuals with ADHD show features of ASD. Recent findings from the Autism Treatment Network (ATN) database suggest that co-occurrence of ADHD and ASD is associated with a lower quality of life and poorer adaptive functioning than in any one of these conditions. (Leitner, 2014)

ADHD is one of the most common children's mental health disorders. ADHD doesn't just happen suddenly when a child reaches school age. Most children are not diagnosed with ADHD until past the age of 6, although younger children can be diagnosed.

In Nebraska, an estimated 27.2% of CYSHCN (ages 2-17) were diagnosed with ADD/ADHD (2009/2010).

Criterion 2: Disparities Exist Related to Health Outcomes

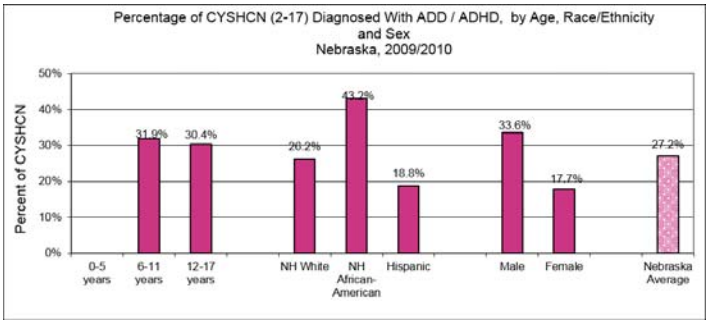
Significant mental health problems can and do occur in young children. Children can show characteristics of anxiety disorders, mood disorders, ADD/ADHD, and autism at a very early age.

Research has shown that infants and young children have mental health needs, which when left untreated can cause life- long developmental problems. Often, adolescents receiving mental health services had observable behavioral and emotional problems at preschool age, but they were left untreated until years later.

The estimated 27.2% of CYSHCN (2-17) in Nebraska diagnosed with ADD/ADHD is non-significantly lower than the U.S. estimate of 30.2%. Looking at the breakdown by race/ethnicity in Nebraska, 43.2% of African-American CYSHCN (2-17) have been diagnosed with ADD/ADHD compared to 26.2% of WhiteWhite and 18.8% Hispanic CYSHCN. However, the small samples included in the National Survey data lead to large confidence intervals around the racial estimates, and the differences among them are not statistically significant.

According to the National Resource Center on AD/HD, 9.8% of African-American have been diagnosed with ADHD nationally. African-American children are diagnosed and medicated less frequently than White children with ADD/ADHD.

Figure 2.



The number of children ages 2-17 diagnosed with Autism or Autism Spectrum Disorder has shown an increase from 2006 (2.2%) to 2009/2010 (6.5%) in Nebraska. Nebraska falls below the national average (7.9%).

28% of children and youth (3-17) CYSHCN in Nebraska, have on-going emotional, developmental and/or behavioral conditions according to the Nebraska Title V 2015 Needs Assessment compared the 31.9% nationally. (2009-2010) Only10.8% are age 0-5 compared to the 6-11 (32.6% and 12-17 years of age (31.1%)

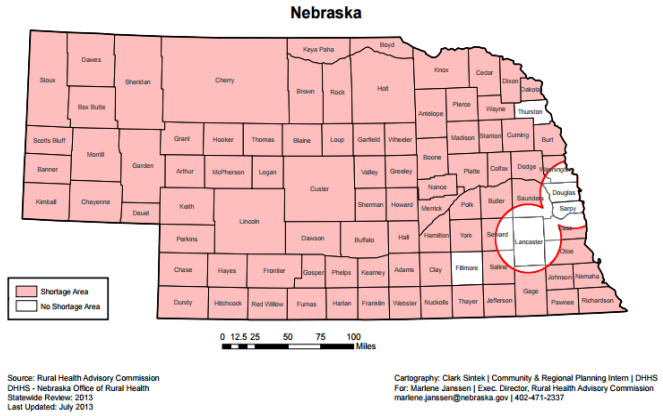
For those CYSHCN experiencing difficulty with feeling anxious or depressed in Nebraska ages 12-17 show the most difficulty (13.8%), compared to younger children (6-11 year olds; 4.5%).

The greatest opportunity for prevention is among young people but you must have the resources to provide prevention and treatment.

Parents describe time-consuming and painful searches for appropriate assessments, and/or medical evaluations. Often times they are turned away from agency to agency because their child have the "wrong diagnosis" or the "wrong IQ (either too high or too low), or they have the "wrong insurance". A comprehensive interdisciplinary evaluation is essential and requires professionals with specific expertise in co-occurring disorders. (Georgetown National Technical Assistance Center for Children's Mental Heatlh)

Below is Nebraska's Designated Shortage Area for Psychiatry and Mental Health. The pink colored indicate the shortage area. As you can see the metropolitan areas of Lincoln and Omaha do not have a shortage.

Figure 3



Criterion 3: Evidence-based Strategies Exist to Address the Problem/An Effective Intervention is Available

Nebraska has multiple sources of evidence-based strategies to address the prevention of mental health concerns for children with special health care needs. These programs have been shown to improve public health outcomes. These include:

- Prevent Child Abuse Nebraska offers PCIT - Parent-Child Interaction Therapy & Circle of Security
- Nebraska Children Foundation offers the Sixpence Program
- Early Head Start
- N-MIECHV – Home Visiting Program
- First Five – building a child's ability to learn
- Nebraska Early Development Network

Nebraska also has resources to address mental health needs of children and families or communities. These include:

- Nebraska Federation of Families for Children's Mental Health

- CHI Health Mental Health Services Child/Adolescent Care
- Nebraska DHHS Behavioral Health Regions - Family Navigator/Family Peer Support Services and Nebraska Family Helpline
- Behavioral Health Education Center of Nebraska
- LB556 Provide for tele-health services for children's behavioral health – currently in a pilot project with three sites involved.
- LB603 created the Children and the Family Behavioral Health Support Act, which created several programs to help families and children. It also created the Behavioral Health Workforce Act, which established the Behavioral Health Education Center (BHECN), to be administered by the University of Nebraska Medical Center. The BHECN Mission is to enhance the behavioral health of the people of Nebraska by improving the numbers, accessibility and competence of the Nebraska

Criterion 4: Societal Capacity to Address the Problem

Nebraska's support systems for the mental health of children with special health care needs are growing. Communities are recognizing the need for mental health care and making attempts to de-stigmatize mental illness. The Nebraska Network of Care is a resource for individuals, families and agencies concerned with mental health. It provides information about behavioral health services, laws and related news, as well as communication tools and other features. (Nebraska Department of Health and Human Services)

Newborn Screening Program (Nebraska Department of Health & Human Services) requires testing for 29 disorders some of which can lead to mental health problems if not detected and treated.

LB505 - Provides requirement for insurance coverage of autism spectrum disorders. This assists families to get the treatment and interventions in Nebraska that will improve the lives of children with autism.

The SAMHSA Behavioral Health Treatment Services Locator (Behavioral Health Treatment Services Locator) provides information on mental health services within 50 miles of any location in Nebraska.

Answers4Families (Answers4Families.org) provides resources for families of children with special health care needs.

Nebraska Resource & Referral System (Nebraska Resource and Referral System) provides a search of thousands of community agencies to find the needed resources.

Nebraska DHHS School Health Program (Nebraska Department of Health & Human Services) helps schools provide for the health needs of children with special health care needs while the children are attending school.

Criterion 5: Severity of Consequences

Mental illness is treatable and the best outcomes occur with early identification and intervention. Tragic and costly consequences of unidentified and untreated mental illness in children can be prevented or at least mitigated by taking action.

13% of youth aged 8-15 live with mental illness severe enough to cause significant impairment in their day-to-day lives. This figure jumps to 21 percent in youth aged 13-18. Half of all lifetime

cases of mental illness begin by age 14 and three quarters by age 24.

There is often a delay of several years before a family seeks mental health care for their child with special health care needs. 1 in 4 parents find it difficult to obtain specialized mental health services for their child and waiting lists can be 3 months to a year.

Approximately 50% of students aged 14 and older with mental illness drop out of high school—the highest dropout rate of any disability group. 90% of those who die by suicide have a mental illness. Suicide is the third leading cause of death for youth aged 15-24.

70% of youth in state and local juvenile justice systems have mental illness, with at least 20% experiencing severe symptoms. At the same time, juvenile facilities fail to adequately address the mental health needs of youth in their custody. (Coalition Partners ..., 2013)

The National Survey of Children with Special Health Care Needs found the following consequences for the child:

•The use of or need for prescription medication;

•The use of or need for more medical care, mental health services, or education services than other children of the same age;

•An ongoing emotional, behavioral, or developmental (EBD) problem that requires treatment or counseling;

•A limitation in the child's ability to do the things that most children of the same age do;

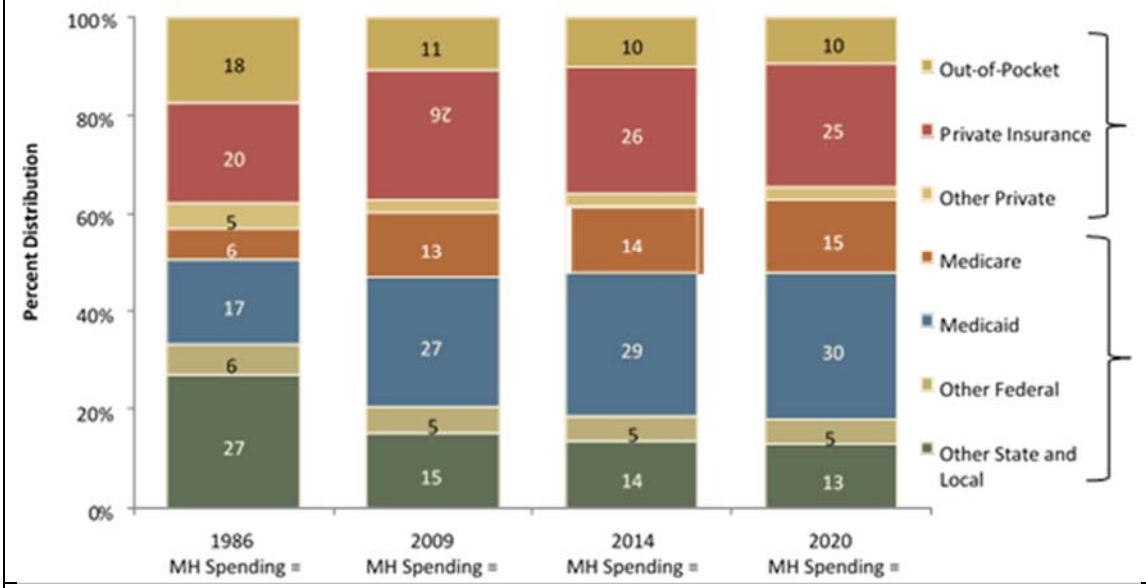
•The use of or need for special therapy, such as physical, occupational, or speech therapy.

(Consequences of Special Needs, 2009-2010)

SAMHSA is the Substance Abuse & Mental Health Services Administration and is the agency within the U.S. Department of Health and Human Services that leads public health efforts to advance the behavioral health of the nation. SAMHSA's mission is to reduce the impact of substance abuse and mental illness on America's communities.

The SAMHSA chart below on Spending Estimates shows the approximate spending increases for treatment of mental health disorders.

Figure 4



Source: SAMHSA Spending Estimates (SAMHSA , 2014)

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