Measures that Matter Data Brief:
Children and Youth with Special Health Care Needs in Minnesota

Autism Spectrum Disorders: Findings from the National Survey of Children with Special Health Care Needs 2009/2010

Background

Autism spectrum disorders (ASDs) are a group of developmental disabilities that can cause significant social, communication and behavioral challenges. ASDs affect each person in different ways, and can range from very mild to severe.[i]

The National Survey of Children with Special Health Care Needs 2009/2010 (NS-CSHCN) looks at the health and functional status of children with special health care needs in the United States — their physical, emotional and behavioral health, along with critical information on access to quality health care, coordination of services, access to a medical home (often referred to in Minnesota as health care home), transition services for youth, the impact of chronic condition(s) on the child's family and demographic characteristics.[ii] More than 3,500 Minnesota households with children were contacted and more than 7,000 children were screened for a special health care need. Parents or guardians were asked five screening questions about each child:

- The use of prescription medications
- The need for more medical, mental health or education services than other children
- Having a limitation in functional abilities
- The need for special therapies
- Having emotional, developmental or behavioral difficulties requiring treatment or counseling.

An affirmative response to any of the screening questions (and associated follow-up questions regarding relation of the need area to a health condition and duration of more than a year) would qualify the child as having a special health care need. Families of 750 children and youth with special health care needs (CYSHCN) in Minnesota then participated in an in-depth interview.

Based on the survey, there are an estimated 179,000 CYSHCN under age 18 in Minnesota (14.3%).[iii] More than one in five families in Minnesota with children has at least one child with a special health care need.

ASD Prevalence among CYSHCN

As part of the survey, parents were read a list of health conditions, and asked if a doctor or other health care provider ever told them that their child had the condition, even if he or she does not have the condition now. For each health condition with a "yes" response, parents were then asked if their youngster *currently* had the health condition. Table 1 lists the health conditions included in the survey, and the estimated percentage of CYSHCN in Minnesota who currently have the condition.

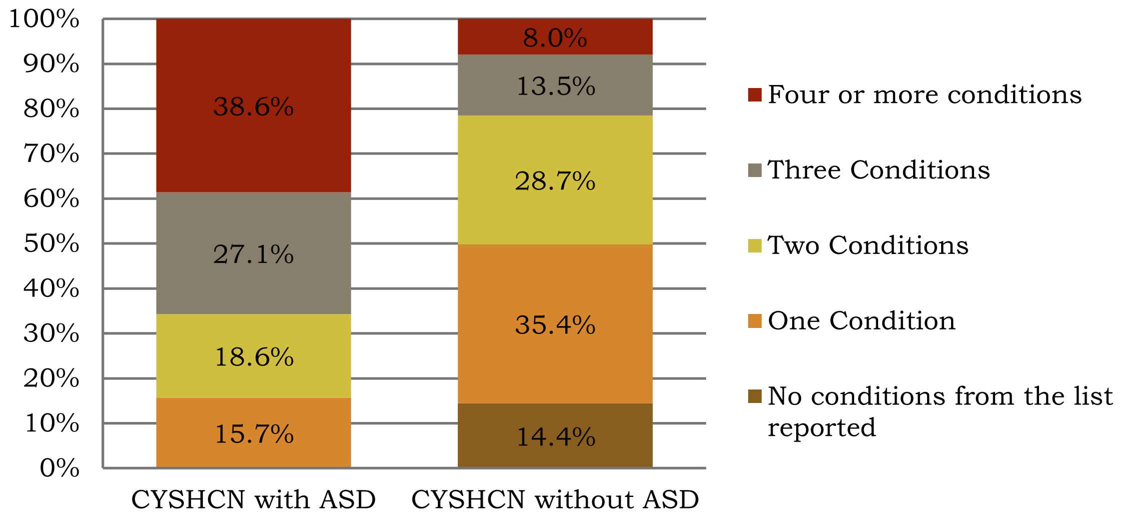
Table 1. Current Health Conditions Among CYSHCN aged 2–17 years, Minnesota, NS-CSHCN 2009/2010

Condition	Currently have condition (weighted percentage)	Condition	Currently have condition (weighted percentage)
Allergies	45.1		
Food allergies	9.9	Depression	12.9
Asthma	36.3	Behavior / conduct problems	11.2
Attention deficit / hyperactivity disorder (ADHD)	30.1	Migraines or frequent headaches	10.0
Anxiety problems	19.7	Autism / Asperger's / PDD	9.4
Developmental delay affecting learning	14.3	Intellectual disability	3.2
Health conditions with an estimated percentage below 3%: Diabetes, heart problems, cerebral palsy, epilepsy, head injury/traumatic brain injury, arthritis, Down syndrome, blood problems, cystic fibrosis, muscular dystrophy			

Parents of CYSHCN aged 2–17 were asked if their child currently had autism, Asperger's Disorder, pervasive developmental disorder (PDD) or other ASD. Approximately 9.4% of the Minnesota survey respondents indicated that their child currently has an ASD. This corresponds to a weighted estimate of 15,600 CYSHCN over age 2 in Minnesota with an ASD (95% confidence interval 11,000 – 20,000). This is slightly higher than the estimated percentage of CYSHCN nationally with an ASD, but the difference is not statistically significant.

CYSHCN with an ASD often have additional health conditions. Among the 20 health conditions asked about in the survey, 65.7% of CYSHCN who have an ASD have three or more health conditions (including ASD), compared with 21.5% of CYSHCN without an ASD (Figure 1).

Figure 1. Number of Current Health Conditions Reported Among CYSHCN with and without ASD aged 2-17 years, Minnesota, 2009/2010 NS-CSHCN



Demographics of CYSHCN with ASD

CYSHCN in Minnesota with an ASD are much more likely to be boys than girls; 80.5% of the CYSHCN with an ASD are boys. This is similar to the gender differences seen nationally.

Approximately 72% CYSHCN aged 2–17 currently diagnosed with ASD in Minnesota live with two biological or adoptive parents, compared with 60% of CYSHCN without an ASD. Nationally, 61% of CYSHCN aged 2–17 who currently have an ASD live in two-parent families, compared with 55% of those without an ASD.

In Minnesota, 83% of CYSHCN who currently have an ASD, and 79% of those without an ASD, live with at least one adult who has more than a high school education. Nationally, 76% of CYSHCN who currently have ASD, and 69% of those who never have been diagnosed with an ASD, live with at least one adult who has more than a high school education.

While in Minnesota there does not appear to be a difference in prevalence between racial groups, nationally CYSHCN with an ASD are more likely to be white.

Among CYSHCN with an ASD in Minnesota, 91.4% live in families with incomes above the federal poverty level (FPL). There is a higher proportion of CYSHCN with an ASD in the 100-199% FPL income group than would be expected if the prevalence of ASD were evenly distributed across levels of family income in Minnesota. Nationally, there are no significant differences in ASD prevalence among CYSHCN by family income. (Figure 2)

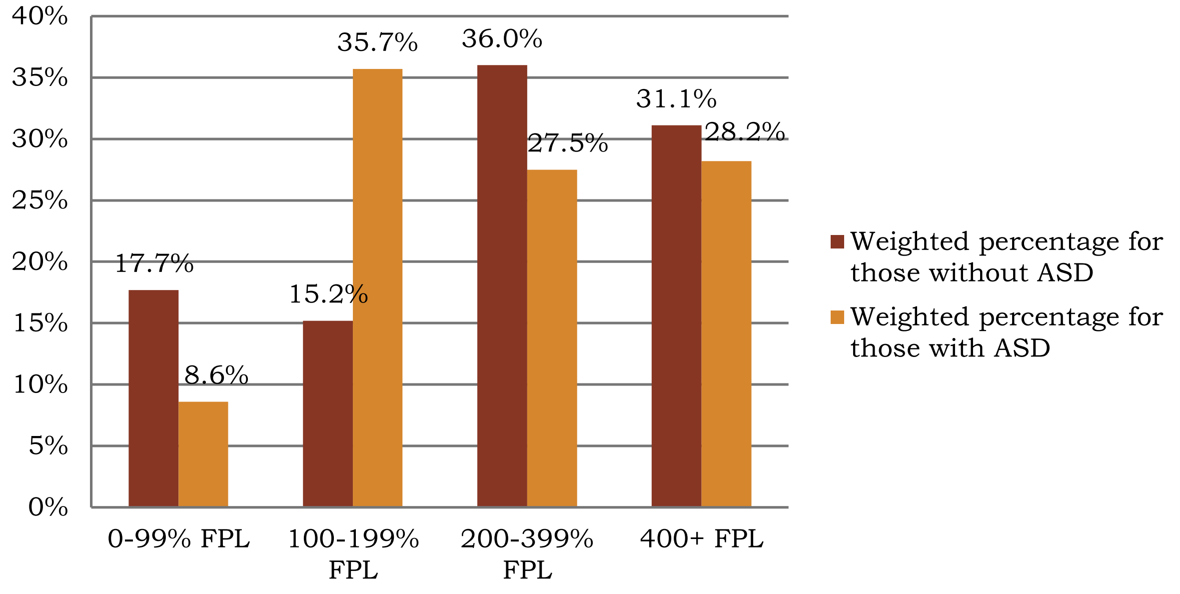


Figure 2. Poverty levels of CYSHCN in Minnesota with and without ASD

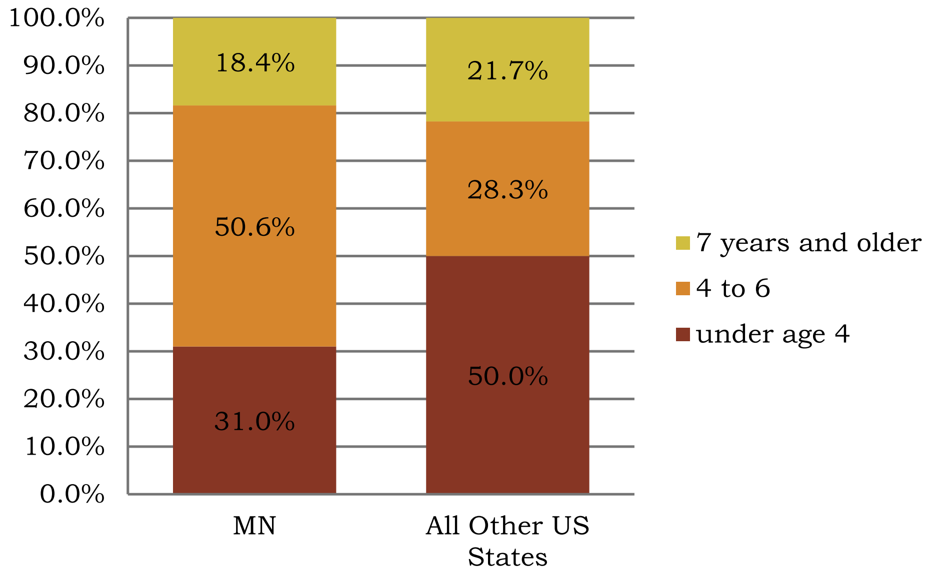
Developmental Screening and Age at ASD Diagnosis

Early identification of health and developmental needs is critical so that appropriate intervention can begin as early as possible. CYSHCN are at particularly high risk for experiencing developmental delays and therefore ongoing developmental monitoring is essential to identifying any new concerns or secondary conditions.[iv,v]

Nearly 70% of CYSHCN aged 1 to 5 years, without regard to specific health conditions, had a developmental screening in the past year in which parents filled out a questionnaire about their specific concerns or observations about their child's development, communication or social behavior. These screening elements together address the core-defining features of ASDs. Minnesota is second only to Massachusetts in the percentage of CYSHCN who had a developmental screening in the past year. Nearly all CYSHCN in Minnesota between the ages of 2 and 5 years (98%) who had been screened in the last year were asked specifically about parent concerns about how the child behaves and gets along with the parent and others.

Despite the positive results related to developmental screening, less than one third of CYSHCN in Minnesota aged 2-17 who currently have ASD were diagnosed before they were 4 years old. By comparison, approximately half of CYSHCN with ASD in all other states were diagnosed by the time they were 4 years old (Figure 3).

Figure 3. Age at First ASD Diagnosis Among CYSHCN with ASD aged 2 - 17 years, Minnesota vs. All Other US States



Condition Severity and Impact on the Child

Parents were asked about the severity of their child's ASD. Minnesotans whose children have an ASD are more likely to rate its severity as mild (69%) compared with the rest of the United States (49%). Only 5% of Minnesota parents rate the severity of their child's ASD as severe compared with 14% of parents of children with ASDs in the other states. The higher percentage of parent-rated mild severity of ASD cases in Minnesota compared with other states may contribute to the higher percentage of Minnesota children with an ASD being diagnosed at age 4 or older. Further study is needed to confirm this.

Parents were asked how often their child's health condition affected his or her ability to do things other children his or her age typically do. In Minnesota, 57% of CYSHCN currently with ASD, compared with 8% of children without an ASD, were usually or always affected in their ability to do age-appropriate activities.

Parents were provided with a list of ways children might experience difficulties related to their health condition. Nearly all Minnesota CYSHCN with an ASD (98.8%) experienced at least one of these difficulties (Table 2).

Table 2. Percentage of CYSHCN with ASD aged 2-17 Who Experience Difficulties Due to Their Health Condition(s), Minnesota, 2009/2010 NS-CSHCN

Type of Difficulty	Percent	Type of Difficulty	Percent
Speaking, communicating or being understood	86.0	Coordination - moving around	41.6
Making/keeping friends (age 3-17 years only)	82.6	Respiratory	31.6
Learning, understanding, paying attention	92.3	Swallowing, digesting food, metabolism	29.3
Feeling anxious or depressed	78.1	Chronic pain	25.9
Behavior problems	70.1	Seeing (even when wearing glasses or contact lenses)	24.9
Caring for self (age 3-17 years only)	58.5	Hearing (even when using hearing aid or other device)	10.3
Using hands	44.2	Blood or circulation	3.7

Impact on Families

Having a child or adolescent with a special health care need can affect a family's finances and employment. The demands on families may require that parents reduce work hours or give up a job, at the same time that they may face burdensome out-of-pocket health care costs.[vi] The severity of a child's condition and his or her level of dependency influence the time and intensity of the care parents provide at home. More than half (55.4%) of families of CYSHCN provide at least some type of health care at home. Minnesota families of CYSHCN with an ASD are somewhat more likely to provide care at home (41.6%) than those without an ASD.

Employment

Nearly half of families of CYSHCN with an ASD (47.7%) have members who have cut back work hours because of the child's health condition(s), compared with 14.3% of families of CYSHCN without an ASD. Nearly one-third (32.1%) of families of CYSHCN with an ASD have had someone stop working because of the child's health condition(s), compared with 11.4% of families whose CYSHCN do not have an ASD. Nearly half of the families of CYSHCN with an ASD (47.6%) are afraid to switch jobs due to insurance concerns, compared with 20% of families of CYSHCN without an ASD.

Insurance and Out-of-Pocket Costs

In Minnesota, CYSHCN with an ASD are more likely to have both public and private insurance to pay for health care services than those without an ASD, and are less likely to have private insurance alone (Table 3).

Table 3. Types of Insurance Coverage, Minnesota CYSHCN aged 2-17 with and without ASD, 2009/2010 NS-CSHCN

Insurance Type	Current ASD (percent)	No ASD (percent)
Private only	54.2	62.8
Public only	28.5	25.3
Both public and private	13.7	6.2
Uninsured	0.0	2.0

Note: Shaded areas indicate a small number of survey respondents, and therefore results should be viewed with caution.

For purposes of the national survey, a child is considered to have adequate health insurance coverage if:

- The child is currently insured;
- The child had no gaps in coverage for 12 months;
- The child's insurance offers benefits that usually or always meet his or her needs;
- Non-covered charges are usually or always reasonable;
- Insurance usually or always allows the child to see needed providers.

By this definition, there is no significant difference in insurance adequacy between CYSHCN with ASD and without ASD – approximately 60-62% of both groups have adequate health insurance coverage.

The national survey also asked families about the amount of money paid during the last 12 months for medical care. Families were asked to *exclude* insurance premiums and costs reimbursed by another source. They were asked to *include* payments for co-payments, dental or vision care, medications, special foods, adaptive clothing, durable equipment, home modifications and any kind of therapy. Half (50.5%) of the families of CYSHCN with an ASD had out-of-pocket expenses exceeding $1,000 for the 12 months preceding the survey, compared with 28.7% of families of CYSHCN without an ASD (Figure 4).

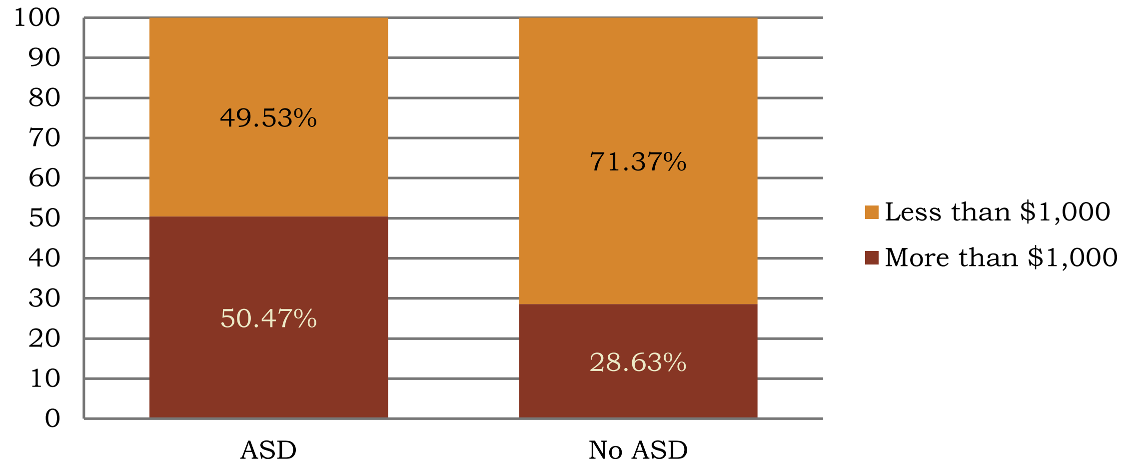


Figure 4. Percentage of Families Paying More and Less than $1,000 in out-of-pocket medical expenses: Minnesota CYSHCN aged 2-17 with and without ASD, 2009/2010 NS-CSHCN

Health Care and System Quality Measures

The effective promotion of health and health services for CYSHCN requires a system of care that is integrated, comprehensive, coordinated, family centered, and consistent throughout the life course (or lifespan). Advancing integrated systems of care for CYSHCN and their families is a national mandate under Public Law 101-239 and is a priority reflected in the Healthy People goals set forth by the U.S. Department of Health and Human Services from 2000 to 2020. To help determine progress towards these goals, the Federal Maternal and Child Health Bureau established the following six core outcomes that are key measures of integrated systems of care for CYSHCN[vii]:

- Parents as Partners in Decision-Making
- Having a Medical Home
- Adequate Health Insurance
- Early and Continuous Screening
- Ease of Access to Needed Services
- Transition to Adulthood.

Adequate Health Insurance and Early and Continuous Screening were addressed earlier in this brief. The other four core outcomes are discussed below.

Parents as Partners in Decision-Making

A partnership between a child's family and their health care providers allows for an open and intentional dialogue about his or her unique health needs. This leads to individualization of care and the ability to identify factors that may negatively affect his or her health. It also gives children and their families the support they need during critical periods of development.[viii] The NS-CSHCN 2009/2010 uses a composite of four questions to measure the extent to which doctors or other health providers work with the family to make decisions about health care services and treatment. These questions concern whether doctors or other providers:

- Discuss a range of treatment options for the family to consider
- Encourage the family to ask questions or raise concerns
- Make it easy for the family to ask questions or raise concerns
- Consider and respect health care and treatment choices the family feels would be best for the child.

In Minnesota, 67% of parents of CYSHCN with an ASD feel that they are partners with their child's health care providers in decision making, compared with 77% of CYSHCN without an ASD.

Having a Medical Home

Medical home is an approach to primary care where primary care providers, families and patients work in partnership to improve quality and value in the health care system, and improve health outcomes for individuals with chronic health conditions and disabilities. In Minnesota, the term most often used is "health care home."

The national survey assesses the following components of a medical home:

- A usual source of routine sick and preventive care
- A personal doctor or nurse
- No problems obtaining needed referrals for specialty care
- The child and family receive needed care coordination
- The care provided is family-centered.

Without regard to age or health condition, approximately 48% of CYSHCN in Minnesota have primary care meeting the medical home criteria. Children with more complex needs (which includes CYSHCN with functional limitations, those who need more than routine health services and those who need medications *and* more than routine health services) have been found to be less likely to have a medical home than those whose health care needs are managed by medications alone.[ix] CYSHCN with an ASD in Minnesota are significantly less likely to have a medical home than CYSHCN without an ASD (25.2% vs. 50.0%).

Ease of Access to Needed Services

CYSHCN have complex needs that are usually not addressed solely through a single doctor's office. They and their families often require services from multiple providers, as well as schools and other community based organizations. Table 4 shows the percentage of CYSHCN with an ASD who needed each of 14 services. Approximately 66% of Minnesota's CYSHCN with an ASD have no unmet needs for the specific services listed.

Table 4. Service Needs Among CYSHCN with ASD aged 2-17, Minnesota, 2009/2010 NS-CSHCN

Service	Percentage Needing Service	Service	Percentage Needing Service
Preventive Medical Care	85.4	Eyeglasses/Vision Care	36.1
Specialist Care	59.9	Substance Abuse Treatment (children 8-17 only)	<1%
Preventive Dental Care	88.9	Home Health Care	<10%
Other Dental Care	19.4	Hearing Aids/Care	<10%
Prescription Medications	75.6	Mobility Aids (children 3-17 only)	<5%
Physical, Occupational, or Speech Therapy	64.5	Durable Medical Equipment	<5%
Mental Health Care	47.2	Communication Aids (children 3-17 only)	<10%

Integrated and accessible services allow CYSHCN and families to connect with the resources they need to grow and develop optimally. Ideally, families of CYSHCN can easily navigate such a system, leading to positive experiences seeking care and interacting with service providers.[x]

The NS-CSHCN 2009/2010 considers two factors in measuring whether services are organized so they are easy for families to use. The first factor is whether there are difficulties or delays getting services; the second is the extent of frustration parents experience during the process of obtaining services. Services are considered to be easy to use if there were no delays or difficulties getting services during the last year, and if parents were never or only sometimes frustrated during the process of getting services for their child.

Among families of CYSHCN with an ASD in Minnesota, 54.6% report having easy access to needed services, while 70.0% of those without an ASD report easy access to services.

Transition to Adulthood

Adolescence is a period of significant transition involving biological, psychosocial, and cognitive development. During adolescence, young people become increasingly independent and begin assuming adult roles and responsibilities, a process that continues as they transition to young adulthood. Given a nurturing environment, with policies and positive community environments that support young people and their families, most adolescents make a successful transition into young adulthood, in which they are healthy, productive, and meaningfully engaged in society. Young people need support from many sectors during this period.

Certain populations of adolescents require additional support, including adolescents with special health care needs.[xi] Understanding one's health needs and taking responsibility for managing one's health to the extent possible are among the developmental tasks of adolescence. Moving from pediatric to adult health providers and different payment sources for health care services are concerns that need to be addressed as adolescents with special health care needs move toward adulthood.

Several questions in the NS-CSHCN 2009/2010 contribute to our understanding of the extent to which these concerns are addressed.

- Has the youth's doctor discussed changing health needs as the youth becomes an adult?
- Has the doctor discussed transitioning to doctors who treat adults and how to maintain health insurance?
- Does the doctor encourage the youth to take age-appropriate responsibility for managing his or her own health needs?

Together, these questions form a composite indicator of successful transition to adulthood. Both locally and nationally, youth with an ASD were less likely than other CYSHCN to have a successful transition (21.1% vs. 41.3%).

Conclusions

The National Survey of Children with Special Health Care Needs 2009/2010 provides insight into the lives of children with special needs and their families from the perspective of the families themselves.

Autism is one of several conditions experienced by children and youth with special health needs. In Minnesota, approximately 15,600 children over 2 years old have an ASD. It is uncommon for CYSHCN with an ASD to have ASD alone (15.7%); two-thirds of CYSHCN with an ASD have three or more health conditions.

Nearly all the children with an ASD experience health-related functional difficulties – among them difficulties not typically thought of as being associated with an ASD such as respiratory difficulties or difficulties with chronic pain. Despite these difficulties, Minnesota families are more likely to rate their child as being mildly affected by their ASD diagnosis than parents of children with ASDs in other states.

In addition to the impact an ASD can have on CYSHCN experiencing the condition, having a child or youth with a special health care needs can have consequences for the family as well. The need to provide health care at home, and decreasing the number of hours of employment or leaving the workforce altogether, affect parents of children with an ASD in higher percentages than families of CYSHCN without an ASD.

Families of CYSHCN in Minnesota are more likely than families in nearly every other state to have out-of-pocket expenses exceeding $1,000 per year; a higher percentage (50.5%) of Minnesota families of CYSHCN with an ASD have expenses exceeding

$1,000 per year than other Minnesota families (28.6%). On measures of insurance adequacy, CYSHCN with an ASD in Minnesota are as likely as peers without an ASD to have adequate insurance.

CYSHCN with an ASD in Minnesota are less likely than their peers without ASD to experience quality health care as measured by having a medical home and parents who are decision-making partners with professionals. It also appears children with ASD are less likely to be prepared for a successful transition to adult services than their peers without an ASD, and their families are less likely to find that the community-based service system is easy to use.

About Measures that Matter

“Measures that Matter: The Status of Children with Special Health Care Needs in Minnesota” is a joint effort of the Minnesota Department of Human Services and the Minnesota Department of Health to identify, track and report on health indicators regarding children and youth with or at high risk for chronic illnesses and disabilities and their families. Additional Measures that Matter data briefs are available at www.dhs.state.mn.us/MeasuresThatMatter.

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[i] Centers for Disease Control and Prevention. Autism Spectrum Disorders “Signs and Symptoms” webpage, last updated 5/13/2010. www.cdc.gov/ncbddd/autism/signs.html Accessed 09/11/12.

[ii] Child and Adolescent Health Measurement Initiative (CAHMI). National Survey of Children with Special Health Care Needs 2001, 2005/06 and 2009/10 Indicator Data Sets. Data Resource Center for Child and Adolescent Health. www.childhealthdata.org www.childhealthdata.org

[iii] ibid

[iv] MN Dept of Human Services, "Measures that Matter Data Brief: Developmental Delay, 6/13/12.

[v] Delgado, CE, Vagi, SJ, Scott, KG, Identification of Early Risk Factors for Developmental Delay, Exceptionality, 15 (2), 119-136, 2007.

[vi] U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2005–2006.* Rockville, Maryland: U.S. Department of Health and Human Services, 2008,

[vii] Data Resource Center for Child and Adolescent Health, "Families are Partners in Decision Making", November 2011.

[viii] ibid

[ix] MN Dept of Human Services "Measures that Matter Data Brief: Medical Home", 6/12/12.

[x] Data Resource Center for Child and Adolescent Health, Outcome #5 Community-based service systems are organized for ease of use, November 2011.

[xi] Park, M., Adams, S., Irwin, C., "Health Care Services and the Transition to Young Adulthood: Challenges and Opportunities", Academic Pediatrics, Vol 11, Issue 2, March-April 2011, pages 115-122.