



# Identifying and Supporting Members with Special Health Care Needs

Medical Grand Rounds

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# Disclosure

I have no actual or potential conflict of interest in relation to any product or service mentioned in this program or presentation.



# Learning Objectives

1. Define a member with special health care needs (MSHCN)
2. Understand the importance of identifying MSHCN
3. Knowledge to provide patient and family centered coordination and support for children and adults with special health care needs
4. Knowledge of resources available to support MSHCN



# Did you know....

- 1 out of every 5 children (14.1 million) in the U.S. has a special healthcare need
- More than 1 in 4 households with children had at least one child or young adult with SHCN
- In Texas, 55% of CSHCN caregivers report feeling isolated because of their child's disability. Over a third do not feel a sense of belonging to their community.
- Studies have shown that parents of children with SHCN experience more marital distress than other parents.
- Adults with special health care needs have more mental distress.
- 1 in 4 women with SHCN will more likely experience intimate partner violence.



# Why is this important?

Require greater diversity, intensity and coordination of services.

The diverse needs of SHCN cannot be adequately served unless identified.

MSHCN account for most health care costs.



# What is a child with special health care needs?

MCHB defines CYSHCN as children and youth ages 0–21 years that “have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond than required by children generally.”

# Components of identification

The National Survey of Children's Health (NSCH) identifies CYSHCN through a validated 5-item screener that asks parents/caregivers if their child has any of the following service needs or limitations due to a health condition that has lasted or is expected to last 12 months or longer:

- Need or use of prescription medication(s)
- Elevated need or use of medical care, mental health, or education services
- Functional limitation(s) (that limit daily activity)
- Need or use of special therapies (e.g., physical, occupation, or speech therapy)
- Emotional, developmental, or behavioral problem for which treatment or counseling is needed



# Disability can be:

- Related to conditions that are present at birth and may affect functions later in life, including cognition (memory, learning, and understanding), mobility (moving around in the environment), vision, hearing, behavior, and other areas. These conditions may be
  - Disorders in single *genes* (for example, [Duchenne muscular dystrophy](#));
  - Disorders of *chromosomes* (for example, [Down syndrome](#)); and
  - The result of the mother's exposure during pregnancy to infections (for example, rubella) or substances, such as alcohol or cigarettes.
- Associated with developmental conditions that become apparent during childhood (for example, [autism spectrum disorder](#) and [attention-deficit/hyperactivity disorder or ADHD](#))
- Related to an injury (for example, [traumatic brain injury](#) or [spinal cord injury](#)[external icon](#)).
- Associated with a longstanding condition (for example, [diabetes](#)), which can cause a disability such as vision loss, nerve damage, or limb loss.
- Progressive (for example, [muscular dystrophy](#)), static (for example, limb loss), or intermittent (for example, some forms of [multiple sclerosis](#)[external icon](#)).





# The Dimensions of Disability

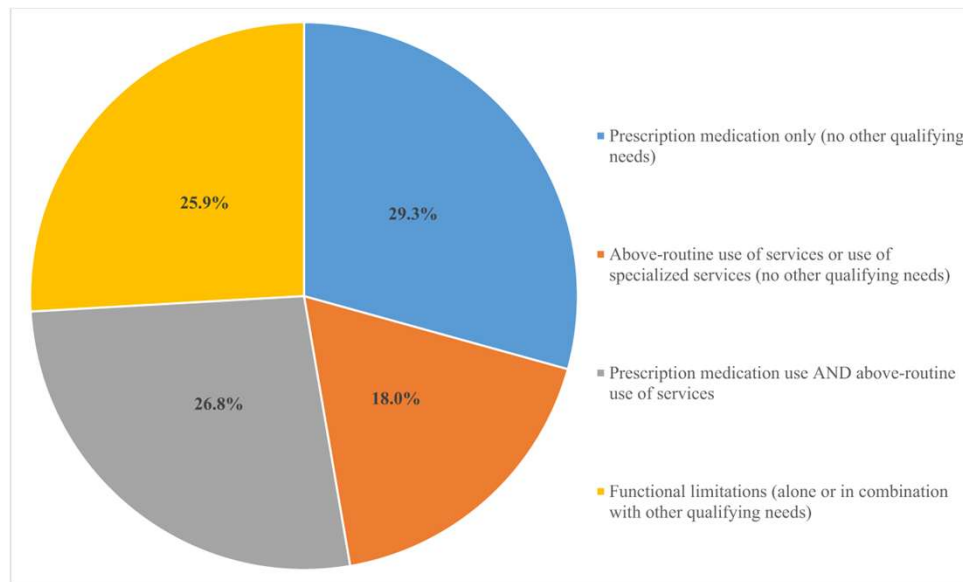
According to the World Health Organization, disability has three dimensions:<sup>1</sup>

- 1. Impairment** in a person's body structure or function, or mental functioning; examples of impairments include loss of a limb, loss of vision or memory loss.
- 2. Activity limitation**, such as difficulty seeing, hearing, walking, or problem solving.
- 3. Participation restrictions** in normal daily activities, such as working, engaging in social and recreational activities, and obtaining health care and preventive services.





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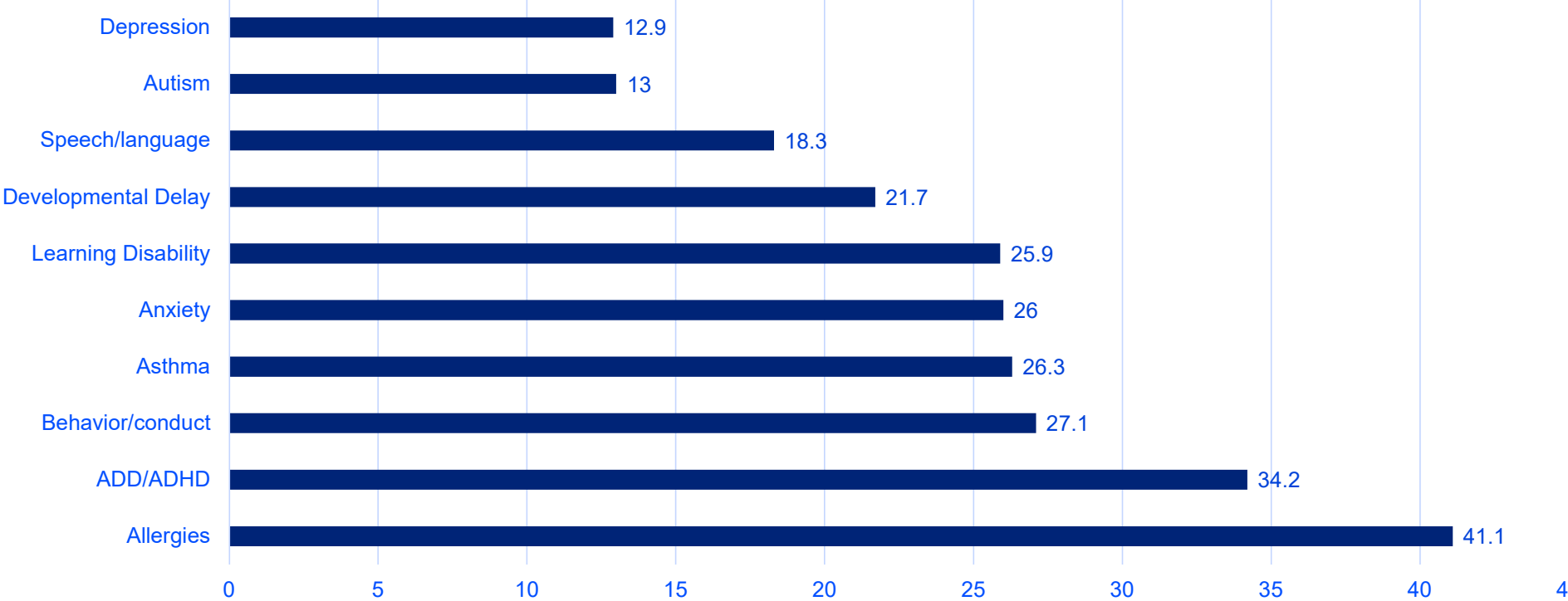


**Figure Legend:**

Prevalence of children and youth with special health care needs, by number and type of qualifying criteria among CYSHCN ages 0 to 17 from the National Survey of Children's Health 2016 to 2019.



# Health Conditions of CSHCN



# What does Special Healthcare Needs Look Like?

- Autoimmune Disorders
- Blood Disorders
- GI Diseases
- Genetic Disorders
- Kidney Diseases
- Metabolic Conditions
- Neurocognitive and Behavior Disorders
- Neurological Conditions

# Risks for Children with SHCNs

Bullying

Abuse

Injuries

Missed school days

Unmet healthcare needs

Mental and behavioral health issues

# Impact on Family

- Link between parent wellbeing and parenting a child with SHCN
- Marital distress
- Social isolation
- Siblings

# The importance of this topic

- Today's experiences and exposures influence tomorrow's health. This is true for individuals as well as across generations. Our health risk factors accumulate across our lifespan and can impact our children and grandchildren.
- Our future health is particularly affected during sensitive periods in our lives, specially during childhood. At these early developmental stages, health promotion interventions can have the greatest benefit.
- Our community environment affects our capacity to be healthy. Environment is more than the physical spaces where we live, learn, work, and play. Safe housing, nutritious foods, and clean air are parts of the equation, but environment also includes social and economic factors, such as poverty, racism, job opportunities, violence, and culture.
- One's genetic make-up offers both protective elements and risk factors for disease, and we often make lifestyle choices that do not guide us down the path to ideal health. However, external factors, such as those mentioned above, contribute greatly to health disparities.

# What is your role in identifying and supporting MSHCN?



Complete health risk assessments



Listen



Educate



# Early Identification and Continuous Screening

- Referral and communication between all providers
- Early intervention programs
- Well-child checks (for metabolism, vision, hearing, development, behavior, and mental health) and Immunizations
- Education: Nutrition, physical activity, gun safety
- School adjustment

# Culturally Competent Care

- Provide interpreter services
- Provide member a service coordinator with same background

# Access to Services

- Appropriate
- Timely
- Easy to access
- Transition of services from pediatric to adult

# Resources and Support



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# Thank You

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“To make a difference in someone’s life you don’t have to be brilliant, rich, beautiful or perfect. You just have to care.”





# Q&A

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• Thank you!



# Leading Causes of Death and Disability

Heart Disease

Cancer

Chronic Lung Disease

Diabetes

Stroke

Alzheimer's Disease

Chronic Kidney Disease

