Special Health Care Needs for Children and Adolescents

OBJECTIVE

The objective of this Clinical Practice Guideline (CPG) is to provide evidence-based practice recommendations for the Special Health Care Needs for Children and Adolescents. In addition, the CPG outlines the organizations that WellCare aligns with regarding this topic and relevant Measureable Health Outcomes.

OVERVIEW

Children and youth with special health care needs (CYSHCN) are described as individuals under the age of 21 who have or are at increased risk of developing a chronic physical, developmental, behavioral, or emotional condition and require health and related services of a type or amount beyond that usually required by children. Examples of conditions that result in special health care needs include:1

- Asthma
- Chronic Lung Disease (aka Bronchopulmonary Dysplasia)
- Congenital Heart Disease
- Cystic Fibrosis
- Diabetes Mellitus
- Disorders of Speech, Language, Learning, Behavior
- Epilepsy
- Food Allergies
- Genetic Disorders
- HIV/AIDS
- Hypoxic Ischemic Encephalopathy
- Juvenile Idiopathic Arthritis
- Myelomeningocele
- Neuromuscular Disease
- Sickle Cell Disease
- Trauma-Related Injury
- Technology dependent/assisted
- Trauma-Related Injury

CYSHCN include those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. In the United States, over 19 percent of all children age birth to 17 years (over 14 million children) have been diagnosed with a chronic and/or complex health care need. An additional group of children (approximately 3 million) have complex health care needs; estimates of those with the highest levels of need include 320,000 – 560,000 children.2

Medically complex is a subset of CYSHCN with multiple significant chronic health problems that affect multiple organ systems and limit function, and often requires the care of an array of community- and hospital-based providers and medical technology.1

Technology dependent/assisted is a subset of CYSHCN who use technology temporarily or permanently to compensate for loss of function or activity; examples of technology include mechanical ventilation, wheelchairs, facilitated communication, and feeding tubes.1

Special needs and services for CYSHCN may include, but are not limited to:1

- Prescriptions
- Rehabilitative therapies (e.g., occupational therapy, physical therapy, speech therapy)
- Assistive devices/medical technology/durable medical equipment (e.g., wheelchair, insulin pump, supplemental oxygen, orthotics)
- Vision care and/or eyeglasses
- Hearing care and/or hearing aid(s)
- Diapers and other home hygiene supplies (bathing systems, catheters)
- Preventive dental care and dental treatment
- Home health care services (home health aides/home nursing)
- Nutrition therapies (e.g., feeding tubes, speech/swallowing therapy) or special diets
- Referrals for specialty medical services, educational services, or social services
- Behavioral or mental health care
- Respite or hospice care
- Family mental health counseling and family therapy
- Transportation
- Guardianship, power of attorney, and/or support for transition to adult services

### Hierarchy of Support

**GUIDELINE HIERARCHY**

CPGs are updated annually or as necessary due to updates made to guidelines or recommendations by: the Association of Maternal and Child Health (AMCHP), the National Academy for State Health Policy, the Centers for Disease Control and Prevention (CDC), and the American Academy of Pediatrics (AAP). When there are differing opinions noted by national organizations, WellCare will default to the member’s benefit structure as deemed by state contracts and Medicaid / Medicare regulations. If there is no specific language pertaining to the Special Health Care Needs for Children and Adolescents, WellCare will default (in order) to the following:

- National Committee for Quality Assurance (NCQA);
- United States Preventive Services Task Force (USPSTF), National Quality Strategy (NQS), Agency for Healthcare Research and Quality (AHRQ);
- Specialty associations, colleges, societies, etc. (e.g., American Academy of Family Physicians, American Congress of Obstetricians and Gynecologists, American Cancer Society, etc.).

Links to websites within the CPGs are provided for the convenience of Providers. Listings do not imply endorsement by WellCare of the information contained on these websites. NOTE: All links are current and accessible at the time of MPC approval.

WellCare aligns with the organizations below on the topic of Special Health Care Needs for Children and Adolescents. Highlights from their respective publications are noted below.

### ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS & NATIONAL ACADEMY FOR STATE HEALTH POLICY

The Association of Maternal and Child Health Programs and the National Academy for State Health Policy have published *Standards for Systems of Care for Children and Youth with Special Health Care Needs*. The goal of the National Standards is to create a comprehensive, quality system of care for CYSHCN – this includes partnership with state health leaders and other stakeholders such as state Title V CYSHCN programs, health plans, private insurers, state Medicaid and CHIP agencies, pediatricians and family physicians, and families. The National Standards provide an endorsed set of standards that could be used and applied within health care systems to improve quality and outcomes for CYSHCN. Version 2.0 (released in June 2017) includes updates to the critical domains, elements, and standards originally published. In total there are eight core domains.²

The following are essential principles that guided development of the National Standards and are the foundation for all standards in each domain. These principles ensure a comprehensive, quality system of care for CYSHCN:³

1. **Children and families of CYSHCN are active, core partners in decision making in all levels of care.**

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2. Special health care needs
3. Continuity of care
4. Early identification
5. Access to care
6. Special education and rehabilitation services
7. Family support and information
8. Transition services

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Clinical Practice Guideline
2. **All services and supports for CYSHCN are implemented and delivered in a culturally competent, linguistically appropriate, and accessible manner to best serve CYSHCN and their families.** This includes written materials provided to CYSHCN and their families – materials should be culturally appropriate, provided in the primary language of the CYSHCN and their family, and in a manner and format appropriate for children and their parents or caregivers who have limited English proficiency, lower levels of literacy, or sensory impairments.

3. **Insurance coverage for CYSHCN is accessible, affordable, comprehensive, and continuous.**

4. **All care provided to CYSHCN and their families is evidence-based where possible, and evidence-informed and/or based on promising practices where evidence-based approaches do not exist.**

The System Domain and Standard(s) are noted below. For additional information on Identification, Screening, Assessment, and Referral/Follow-Up click [here](#) to view the Standards in their entirety. Related National Principles and Frameworks are also available.²³

- **System Domain: Identification, Screening, Assessment, and Referral**
  - Children are screened early and continuously for special health care needs.

- **System Domain: Eligibility and Enrollment in Health Coverage**
  - Outreach activities
  - A comprehensive member services program
  - Information and materials related to insurance program eligibility and enrollment processes
  - Assurance of continuity of care during periods of enrollment and transition
  - Written policies and procedures:
    - At the system level for transitioning CYSHCN between non-network and network providers (includes communication with the medical home and family); and
    - To allow CYSHCN who are newly enrolled or have recently changed health plans to continue seeing out-of-network providers for up to six months after enrollment.

- **System Domain: Access to Care**
  - Capacity and processes in place to ensure CYSHCN have geographic and timely access to primary and specialty services²
  - Reasonable access requirements and wait times are in place for routine, episodic, urgent, and emergent physical, oral, and mental health and habilitative services.
  - Transportation assistance.
  - Use of satellite programs, electronic communications, and telemedicine.
  - Written policies and procedures that describe how CYSHCN choose and/or are assigned to a primary care provider (PCP) and how they may change their PCP.
  - Pediatric specialists who demonstrate a clinical relationship as the clinical coordinator of the child’s care.
  - A documented process for how to access pediatric specialists (face-to-face or via telemedicine) specified in a child’s plan of care.
  - Coverage of medically necessary services²
  - Comprehensive habilitative services.
  - Authorization processes take consider the unique needs of CYSHCN; processes are simplified to promote access to services.
  - Second opinions are available to families of CYSHCN without restrictions.

² Includes in-network and out-of-network providers; physical, mental and dental health care providers; pediatric primary care and pediatric subspecialists; children's hospitals; pediatric regional centers where available; and ancillary providers.

²² Medically necessary services are defined as services for “the prevention, diagnosis, and treatment of an enrollee's disease, condition, and/or disorder that results in health impairments and disability; the ability for an individual to achieve age-appropriate growth and development; the ability for an enrollee to attain, maintain, and retain functional capacity; and the opportunity for an enrollee receiving long term services and supports to have access to the benefits of community living, to achieve person centered goals, and live and work in the setting of their choice.”
- **System Domain: Medical Home**
  CYSHCN will receive family-centered, coordinated, ongoing comprehensive care within a medical home.
  Sub-categories include:
  - Pediatric Preventive and Primary Care
  - Medical Home Management
  - Care Coordination
  - Pediatric Specialty Care

- **System Domain: Community-Based Services and Supports**
  CYSHCN and their families are provided access to comprehensive home and community-based supports.
  Sub-categories include:
  - Respite Care
  - Palliative and Hospice Care
  - Home-Based Services

- **System Domain: Transition to Adulthood**
  Youth with special health care needs receive the services necessary to make transitions to adult care.
  - **Pediatric Health Care Setting:** includes Transition Policy, Transition Readiness, Transfer of Care, and Transfer of Completion.
  - **Adult Health Care Setting:** includes Young Adult Transition and Care Policy, Orientation to/Integration into Adult Practice, an Initial Visit, and Ongoing Care.

- **System Domain: Health Information Technology**
  1. Electronic health information should be accessible, retrievable, and available across systems and meet meaningful use requirements.
  2. Medical homes have the capacity for electronic health information and exchange, including maintenance of clinical information.
  3. Families have easy access to their electronic health information.
  4. Documented processes exist for exchanging health information across care settings, including an agreement about exchanging information, the types of information to be exchanged, time frames for exchanging information, and to what extent referrals are made electronically.

- **System Domain: Quality Assurance and Improvement**
  1. The state, health plans, providers, and insurers have a specific and ongoing quality assurance (QA) and quality improvement (QI) process in place.
  2. Child medical record reviews include a representative sample of CYSHCN so that the experiences of this population are reflected in QA and QI activities.
  3. The utilization review and appeals processes for CYSHCN includes members of a child’s integrated care team when requested by the family.

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**AMERICAN ACADEMY OF PEDIATRICS (AAP)
CENTERS FOR DISEASE CONTROL & PREVENTION (CDC)**

The American Academy of Pediatrics (AAP) has published resources related to *Children and Youth with Special Needs* (available [here](#)). The Centers for Disease Control and Prevention (CDC) have also published articles [here](#) and [here](#). Nearly 1 in 5 children in the United States has a special healthcare need. When faced with an emergency situation, preparedness is critical. CYSHCN may have difficulty going from one place to another, urgent or constant medical needs, communication difficulties, as well as having difficulty transitioning to different situations. A disaster only compounds the difficulties however, being prepared can help Members and their families calm and safe.

- **Planning and Written Plans.** This includes a written emergency care plan as well as practicing the plan. Including the child, if possible, is also suggested. Providers should work with families of CYSHCN to make sure that needs are addressed in the emergency plan. Also, Providers can assist in identifying support networks and other community and state-wide resources. Discussion and writing down a plan has shown to
increase better outcomes for CYSHCN and their families compared to those families with no plan. Providers can familiarize families who may not be familiar with preparedness planning or they may not consider this a top priority.5

- **Disaster Supply Kit and Emergency Kit Checklist.** Families should be encouraged to create a Disaster Supply Kit. Items important to include for CYSHCN are medication, power supply, and food and supplies. Another important item to plan ahead for is transportation, especially for those requiring special equipment that need a large vehicle.6 The CDC has developed an Emergency Checklist for Families (available here) that contains items specific for CYSHCN and their family. Each kit will be vary depending on the individual needs of the child however this Checklist serves as a guide. Items should be collected before an emergency, stored in a container, and kept in a place that is easily accessible in the event of an emergency. Items include:5
  - Child’s medical information, medications, and general supplies
  - Back-up power and supplies
  - Obtaining emergency medical supplies and medications

- **Coping and Adjustment.** Families of CYSHCN are often focused on meeting the daily needs of their child. Providers can give guidance on how they can start or which actions are a priority for them to take on first. The AAP Promoting Adjustment and Helping Children Cope Web page (here) offers additional information and resources.6 Providers can encourage families to stay as connected as possible with children and with others. This will be helpful during times of emergency (e.g., distracting children to lessen their worries and anxiety). Adults should talk to children about the situation in a manner that they can understand; use simple language while bearing in mind the age of the child and type of disability.5 CYSHCN may require special support services (e.g., medicine, medical equipment) which are not readily available in emergency shelters. Families should contact the local Emergency Medical Services (EMS) and other applicable responders in advance of an emergency.5 Providers may also access the Emergency Information Form (available here) published by American College of Emergency Physicians (ACEP) and the American Academy of Pediatrics (AAP) to help emergency care healthcare professionals administer appropriate care for CYSHCN during an emergency. Safe transportation is also a critical concern during an emergency. More information can be found here in the AAP’s Transporting Children With Special Health Care Needs.5,6

- **After the Disaster.** CYSHCN are at high risk for severe stress during times of emergency. To minimize long-term behavioral health effects, it is important to establish as close to a normal routine and environment as possible.5

### Evidence Based Practice

**AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)**

The Agency for Healthcare Research and Quality (AHRQ) has not published reports on this topic.

### MEASUREMENT OF COMPLIANCE

WellCare is committed to adhering to the measures and standards published by the Centers for Medicare and Medicaid Services (CMS) and the National Committee for Quality Assurance (NCQA). Please reference WellCare’s Clinical Policy Guiding Document titled Quality Improvement.

NOTE: To access Clinical Policy Guiding Documents visit [www.wellcare.com](http://www.wellcare.com) – select the Provider tab, then “Tools” and “Clinical Guidelines”.

### Care Management

Children and Youth with Special Health Care Needs (CYSHCN) require a variety of health and related services depending upon their chronic condition. These needs often are unmet or unrecognized, particularly among CYSHCN.
with more severe limitations. Care coordination provided within a medical home model of care helps to address unmet needs for CYSHCN and their parent/guardian. Special needs and services may include, but are not limited to:

- Technology dependent/assisted (mechanical ventilation, wheelchairs, facilitated communication, and feeding tubes)
- Prescriptions
- Rehabilitative Therapies
- Assistive Devices / Medical Technology / Durable Medical Equipment (e.g., wheelchair, insulin pump, supplemental oxygen, orthotics)
- Vision care and/or Eyeglasses
- Hearing care and/or Hearing aid(s)

- Diapers and Other Home Hygiene Supplies (bathing systems, catheters)
- Preventive Dental Care and Dental
- Home Health Care Services (home health aides/home nursing)
- Nutrition Therapies (e.g., feeding tubes, speech/swallowing therapy) or Special Diets
- Referrals for Specialty Medical Services
- Educational Services
- Social Services

The medical home is the foundation for optimal health care. It is a model of care centered on shared responsibility with the parent/guardian and the community for the complete care of the child. The benefits of a medical home for CYSHCN include streamlined care, efficient use of resources, decreased out-of-pocket expenditures, expanded expertise and competence for the involved providers, establishment of a forum for problem solving, and improved satisfaction for the patient, parent/guardian, and provider. The medical home also provides an effective model for implementing successful transitions for CYSHCN. Transition planning includes both transition to adult-oriented systems and transition from inpatient to outpatient settings. The primary care provider often directs the medical home, but the location may vary depending upon medical complexity, clinical experience, and availability of resources. As examples, for a child with cystic fibrosis, the medical home may be the hospital-based pulmonary clinic; for a child with lymphoma, the medical home may be the oncology clinic.

The goals for Care Management are to support the member's/member’s parent’s/guardian’s ability to self-promote their health, encourage healthy behaviors to minimize risks of disease and/or complications thereof, and remove barriers preventing the member/member’s parent/guardian from achieving those goals. Additional items for assessment and member education are below under “Case Management Objectives”.

**MEASURABLE HEALTH OUTCOMES**

1. The member reports fewer or well-managed symptoms over a specific period after the start of Case Management engagement. Member-specific goals should reference member’s individual symptoms. Compare member’s symptom assessment responses, initial to subsequent assessments.

2. The member experiences no symptoms requiring acute medical care and intervention. Compare pre- and post-engagement utilization frequency. Monitor for ED and inpatient authorization/utilization related to the primary diagnosis. In absence of ED and inpatient utilization, authorizations and claims data, or to otherwise demonstrate less frequent need for acute medical intervention, CM may use Provider and/or Member narrative.

3. The member shows improvement over time in their transition readiness from adolescence to adulthood based on their Transition Age Youth Assessment score. They work with their case manager to create goals for a smooth transition into adulthood.

**CASE MANAGEMENT GOALS**

Case Goals should target specific care gaps and/or adherence issues, and measure the member’s progress towards self-management and adherence, which will lead to the targeted health outcomes above. Examples include:

- Member can describe the use of fall/injury precautions over the last 30 days.
- Member’s treatment demonstrates at least an 80% adherence rate of prescribed medications (verified by claims or member/provider narrative) over last 30 days.
- Member can accurately describe their healthcare needs/disability including the ability to describe signs and symptoms of complications and when to seek care from their PCP or from an urgent / emergent care center.
- Member is aware of the healthcare transition from pediatric to adult provider and is taking steps to find an adult provider.
• Member has an action plan for the steps they need to complete, regarding healthcare and guardianship, before becoming an adult.
• Member obtains Durable Medical Equipment, technology-related items, and/or supplies needed in 30 days.
• Specific for Members Requiring Hospitalization: Member participates in provider follow-up visit within 7 days of hospital discharge.

**CASE MANAGEMENT OBJECTIVES**

Case Management objectives should focus on improving the member’s self-management skills including:¹

- Assess and address safety concerns
- Medication adherence
- Assess and address nutrition
- Coordinate care with PCP/Specialists
- Assess and assist with home healthcare needs
- Behavioral / mental health care
- Respite or hospice care
- Family mental health counseling and family therapy
- Assess for and address transportation needs, safe, accessible transportation
- Guardianship, power of attorney
- Support for transition to adult services
- Assist with developing emergency plan/disaster plan
- Assist with coordinating therapies (Physical, Occupational, Speech)
- Assist with locating community resources and support services
- Assess for and address financial barriers
- Assess and address educational/learning needs
- Assess and coordinate age appropriate preventive care (well child visits, immunizations, dental, vision)

**MEDICAL BEHAVIORAL INTEGRATION**

WellCare has experience in providing Care Management for high-risk groups, such as children with:

- Serious emotional disturbance
- Co-occurring major mental disorders and/or Substance Use Disorders (SUD)
- Involvement in multiple services systems (education, justice, medical, welfare, and child welfare)
- Medical fragility / complex medical conditions requiring significant medical or technological health supports

*Psychosocial and Economic Consequences* ¹

When a child has a chronic illness it can impact the family home and wellbeing of family members. The use of services related to home nursing, therapy, or special equipment may change the home environment; the time dedicated for health care visits, therapies, and hospitalizations can lead to social isolation. For example, parents may have difficulty spending time with siblings of the chronically ill child. Economic hardships may also impact the family due to higher health needs and costs. Those with special health care needs are likely to have public insurance such as Medicaid. In addition, parents may be unable to work as much (or at all) in order to dedicate time to their child's care (e.g., treatments, appointments, etc.).

*Other Considerations* ¹

It is important for Members to have a "medical home" model of care – this benefits CYSHCN and their Providers through streamlining care, efficient use of resources, decreased out-of-pocket expenses, increased expertise for involved Providers, and a place for problem solving and Member satisfaction. Patient- and family-centered care is a key principle of care in the medical home. Patient and family-centered care focuses on the individuality and personality of the child, family needs, and the concerns of health care and service providers with whom the child interacts. The family is involved in shared decision making. The multidisciplinary team ensures care coordination to focus on care planning, team-based care, and supporting the family's goals.
With respect to primary and preventive care for CYSHCN, it is important that Members have routine health care maintenance such as immunizations, screening, dental care, and anticipatory guidance. Also, Providers should give assessment and referral as necessary (e.g., services for early intervention, special education, rehabilitation, home nursing/home health aide as well as behavior therapy, transportation, support and advocacy). Providers can help Members transition to an adult care Provider to help the Member develop self-sufficiency which requires advance planning and preparation.

### MEMBER EDUCATIONAL RESOURCES

WellCare contracts with Krames/StayWell for Member educational materials utilized by Case Managers. Items are available to review with Members to address knowledge gaps. Case Managers verbally educate Members on the topics below related to epilepsy. (Titles may also be sent to the member).

**NOTE:** Links are internal for WellCare Care Management staff.

- Seizures and Epilepsy
- Partial Seizures: Staying Healthy
- Treating Epilepsy: Medicines
- Epilepsy: How Seizures Affect the Body
- Diagnosing Epilepsy
- Partial Seizures: Know What to Do
- Medicines for Partial Seizures
- Coping with Seizures in Children
- Self-Care for Epilepsy
- First Aid: Seizures
- Living Well with Epilepsy
- What Is a Partial Seizure?
- Epilepsy: Safety During a Seizure
- Self-Care for Epilepsy

These materials are in the approval process and will be available for member educational mailing in the future. Providers may wish to research the titles above related to epilepsy that Case Managers utilize with Members.

### Related WellCare Guidelines

In addition to the information contained in this document, the CPGs below include an overview of the specified condition: Congenital Disorders (HS-1055); Epilepsy (HS-1070); Hemophilia (HS-1058); Neonatal and Infant Health (HS-1072); Congenital Metabolic Disorders (HS-1060); and Sickle Cell Anemia (HS-1038);

For information regarding transitioning to adulthood, reference the CPG Diabetes in Children (HS-1004) for information on transition to adulthood.

**NOTE:** Clinical Policies can be accessed by going to [www.wellcare.com](http://www.wellcare.com) – select the Provider tab, then “Tools” and “Clinical Guidelines”.

### References


### Disclaimer
Clinical Practice Guidelines (CPGs) made available by WellCare are informational in nature and are not a substitute for the professional medical judgment of treating physicians or other health care practitioners. CPGs are based on information available at the time and may not be updated with the most current information available at subsequent times. Individuals should consult with their physician(s) regarding the appropriateness of care or treatment options to meet their specific needs or medical condition. Disclosure of a CPG is not a guarantee of coverage and is not intended to be used for Utilization Management Decisions or for claims. Members of WellCare Health Plans should consult their individual coverage documents for information regarding covered benefits. WellCare does not offer medical advice or provide medical care, and therefore cannot guarantee any results or outcomes. WellCare does not warrant or guarantee, and shall not be liable for any deficiencies in the information contained herein or for any inaccuracies or recommendations made by independent third parties from whom any of the information contained herein was obtained. Links are current at time of approval by the Medical Policy Committee (MPC) and are subject to change. Lines of business are also subject to change without notice and are noted on www.wellcare.com. Guidelines are also available on the site by selecting the Provider tab, then "Tools" and "Clinical Guidelines".

Missouri Care ~ "Ohana Health Plan, a plan offered by WellCare Health Insurance of Arizona
OneCare (Carefirst Health Plan Arizona, Inc.) ~ Staywell of Florida ~ ~ WellCare Prescription Insurance ~ WellCare TexanPlus (Medicare – Dallas and Houston markets)
WellCare (Arizona, Arkansas, California, Connecticut, Florida, Georgia, Illinois, Kentucky, Louisiana, Mississippi, Nebraska, New Jersey, New York, South Carolina, Tennessee, Texas)

Medical Policy Committee Approval History

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<tr>
<th>Date</th>
<th>History and Revisions by the Medical Policy Committee</th>
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<tr>
<td>7/30/2019</td>
<td>Approved by MPC. Updated Measurable Health Outcomes and Case Management Goals (CM section).</td>
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<td>1/10/2019</td>
<td>Approved by MPC. New.</td>
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