Clinical Practice Guideline
Children with Special Health Care Needs

Definition

Children and youth with special health care needs (CYSHCN) are defined by the Department of Health and Human Services, Health Resources and Service Administration, Maternal and Child Health Bureau as: “those who have or are at increased risk for a chronic physical, developmental, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”  


<table>
<thead>
<tr>
<th>Health Issue Identified*</th>
<th>Prevalence by Percentage Among CSHCN**</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADD/ADHD</td>
<td>32.2</td>
</tr>
<tr>
<td>Asthma</td>
<td>30.2</td>
</tr>
<tr>
<td>Learning Disability</td>
<td>27.2</td>
</tr>
<tr>
<td>Speech Problems</td>
<td>15.6</td>
</tr>
<tr>
<td>Developmental Delay</td>
<td>14.7</td>
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<tr>
<td>Behavioral Problems</td>
<td>13.6</td>
</tr>
<tr>
<td>Anxiety Problems</td>
<td>13.4</td>
</tr>
<tr>
<td>Depression</td>
<td>8.5</td>
</tr>
<tr>
<td>Autism, Asperger’s, ASD</td>
<td>8.0</td>
</tr>
<tr>
<td>Bone, Joint or Muscle Problems</td>
<td>7.7</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>4.8</td>
</tr>
<tr>
<td>Hearing Problems</td>
<td>4.2</td>
</tr>
<tr>
<td>Vision Problems</td>
<td>3.2</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>3.1</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1.4</td>
</tr>
<tr>
<td>Brain Injury</td>
<td>1.1</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>1.0</td>
</tr>
<tr>
<td>Tourette Syndrome</td>
<td>0.2</td>
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</table>

*The NS-CSHCN is a telephone survey conducted by the National Center of Health Statistics at the Centers for Disease Control under the direction and sponsorship of the Federal Maternal and Child Health Bureau. Randomly sampled telephone numbers are called to find households with children ages 0-17. In each household, one child is randomly selected to be the subject of the interview. Survey results are weighted to represent the population of non-institutionalized children ages 0-17 who are classified as having one or more special health care needs (CSHCN) nationally and in each state. Condition prevalence in 2011/12 was asked using two questions: prevalence of conditions ever or currently. Survey of Prevalence of Special Healthcare Conditions https://mchb.hrsa.gov/chscn/pages/prevalence.htm

**CSHCN-Children with Special Healthcare Needs

AAP Developmental Surveillance and Screening Algorithm
Developmental Surveillance and Screening Using the American Academy of Pediatrics Algorithm

Algorithm may be found at: http://pediatrics.aappublications.org/content/118/1/405.full.pdf

— Contact Rocky Mountain Health Plans if assistance is needed. —
1. Developmental concerns should be included as one of several health topics addressed at each pediatric preventive care visit throughout the first 5 years of life.5

2. Developmental surveillance is a flexible, longitudinal, continuous, and cumulative process whereby knowledgeable health care professionals identify children who may have developmental problems. There are 5 components of developmental surveillance: eliciting and attending to the parents' concerns about their child's development, documenting and maintaining a developmental history, making accurate observations of the child, identifying the risk and protective factors, and maintaining an accurate record and documenting the process and findings.

3. The concerns of both parents and child health professionals should be included in determining whether surveillance suggests the child may be at risk of developmental delay. If either parent or the child health professional express concern about the child's development, a developmental screening to address the concern specifically should be conducted.

4. All children should receive developmental screening using a standardized test. In the absence of established risk factors or parental or provider concerns, a general developmental screen is recommended at the 9-, 18-, and 30-month visits. Additionally, autism-specific screening is recommended for all children at the 18-month visit.

5a and 5b. Developmental screening is the administration of a brief standardized tool aiding the identification of children at risk of a developmental disorder. Developmental screening that targets the area of concern is indicated whenever a problem is identified during developmental surveillance.

6a and 6b. When the results of the periodic screening tool are normal, the child health professional can inform the parents and continue with other aspects of the preventive visit. When a screening tool is administered as a result of concerns about development, an early return visit to provide additional developmental surveillance should be scheduled even if the screening tool results do not indicate a risk of delay.

7-8. If screening results are concerning, the child should be scheduled for developmental and medical evaluations. Developmental evaluation is aimed at identifying the specific developmental disorder or disorders affecting the child. In addition to the developmental evaluation, a medical diagnostic evaluation to identify an underlying etiology should be undertaken. Early developmental intervention/early childhood services can be particularly valuable when a child is first identified to be at high risk of delayed development, because these programs often provide evaluation services and can offer other services to the child and family even before an evaluation is complete. Establishing an effective and efficient partnership with early childhood professionals is an important component of successful care coordination for children.40

9. If a developmental disorder is identified, the child should be identified as a child with special health care needs and chronic condition management should be initiated (see No. 10 below). If a developmental disorder is not identified through medical and developmental evaluation, the child should be scheduled for an early return visit for further surveillance. More frequent visits, with particular attention paid to areas of concern, will allow the child to be promptly referred for further evaluation if any further evidence of delayed development or a specific disorder emerges.

10. When a child is discovered to have a significant developmental disorder, that child becomes a child with special health care needs, even if that child does not have a specific disease etiology identified. Such a child should be identified by the medical home for appropriate chronic condition management and regular monitoring and entered into the practice's children and youth with special health care needs registry.41
Addressing Needs of Children and Families

- Consider referral to PT, OT, ST, or a Behavioral Health Specialist, as necessary based on diagnosis
- Health Departments in geographical areas are able to assist with proper referrals to community programs. Contact RMHP for case manager assistance with coverage, programs, transportation assistance

Develop a Care Plan

The Center for Medical Home Improvement and the National Institute of Children’s Healthcare Quality medical home learning collaborative published essentials of “Comprehensive Care Planning” based on the premise that children with special health care needs, their families, physicians, practice teams and community providers will benefit from having a clear, written medical summary, emergency treatment plan and plan of care. These components of the plan can be combined or developed separately. When combined, the Medical Summary, Emergency Treatment Plan, and Working Care Plan are the components of a Comprehensive Care Plan.

The medical summary/care plans serve multiple purposes, which are:

- An available source of information for parents to provide to the medical, educational and other care teams.
- A quick reference for medical emergencies that includes essentials about the child.
- An action plan that the entire care team, including the family and patient develop, use to prioritize, assign tasks, implement and assess care.

The working care plan is a written framework combining the goals of the patient/family/team with the treatment plan. Uncomplicated, small steps work best in the beginning. The major components of the comprehensive care plan include a medical summary with an emergency treatment plan and a working care plan.

<table>
<thead>
<tr>
<th>Plan</th>
<th>Summary</th>
<th>Specific Components</th>
<th>Example Tools/ Reference Materials</th>
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</table>
| Medical Summary           | Short synopsis of child’s current diagnosis, problem list, treatment including medications and recurrent problems, past medical history and community based care | Family contact (including emergency contact)  
Allergies and Medications  
Diagnosis and Active Problem List  
Consultants and their contact information  
Transport/Equipment Needs  
Past History  
Review of Systems  
Coverage Concerns/Recurrent Problems  
Hospitalizations  
Assets and challenges unique to individual child | Using a documentation template can be an effective mechanism to collect and organize medical summary information. Many electronic medical records (EMR) also include comprehensive medical summary templates. Building A Medical Home Care Coordination includes examples: [https://www.medicalhomeportal.org/clinical-practice/building-a-medical-home/care-coordination#d16382e594](https://www.medicalhomeportal.org/clinical-practice/building-a-medical-home/care-coordination#d16382e594) |
| Emergency Treatment Plan  | The medical summary may include components of emergency treatment and in some cases may be substantial enough to serve as both the summary and emergency plan. Consider creating a separate Emergency Treatment Plan for the child with multiple, complex conditions and/or recurrent life threatening events. | Primary Care and Specialty Contact Numbers  
Diagnosis, Past Medical History and Most Recent Exam  
Allergies: Medications and Foods to be avoided  
Procedures to be avoided  
Immunizations  
| Working Care Plan         | This plan aids the focus/role of a practice-based care coordinator. | Prioritized list of main concerns/goals  
Current clinical, educational, and social information pertinent to the concern/goal  
Current plan/intervention for that concern/goal  
Person(s) responsible for that intervention  
Due date for the intervention | Hitchcock Clinic Concord- Care Plan Parts I & II  
Chronic Condition Management in Primary Care  
Building A Medical Home Care Coordination includes examples: [https://www.medicalhomeportal.org/clinical-practice/building-a-medical-home/care-coordination#d16382e594](https://www.medicalhomeportal.org/clinical-practice/building-a-medical-home/care-coordination#d16382e594) |
Helpful Resources and References:

American Academy of Pediatrics main website: [www.aap.org](http://www.aap.org)


Medical Home Portal: [https://www.medicalhomeportal.org/clinical-practice/building-a-medical-home/care-coordination#d16382e594](https://www.medicalhomeportal.org/clinical-practice/building-a-medical-home/care-coordination#d16382e594)

Clinical guidelines adopted by RMHP are based on clinical evidence at the time of publication. New information, evidence and practice standards may be available; therefore, always use best judgment in their interpretation.

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