APPENDIX A- CAHMI CYSHCN SCREENER

The CAHMI CYSHCN Screener: A Non-Condition Specific, Consequences-Based Approach

The **CAHMI CSHCN Screener** was designed in 1998-2000 by the Child and Adolescent Health Measurement Initiative (CAHMI) (now at Oregon Health & Science University).

- Developed through a national process involving physicians, state leaders, families, methods experts, and policymakers
- Tested with parents of 36,000+ children during development phase. Several versions tested, leading to final screener, which takes **1 minute** for parents to complete
- Data for more than 1 million children has been analyzed since 2000. The CAHMI CSHCN Screener has been included in 3 national/state surveys and CAHPS CCC.

The CAHMI CSHCN Screener evaluates children on the following **health consequences** which must be due to a medical, behavioral or other health condition AND has lasted or expected to last for at least 12 months:

- Limited or prevented in ability to function
- Prescription medication need/use
- Specialized therapies (OT, PT, Speech)
- Above routine use of medical care, mental health or other health services
- Counseling or treatment for on-going emotional, behavioral or developmental problem

Implementation Considerations

The following questions are important to consider before implementing any CYSHCN screener.

- ***How will you administer the screener?***
  - After trying various methodologies, most T-CHIC practices in the Oregon project opted to administer the screener on paper at the time of visit. The screener has been used as a phone survey as well. Choose what works best given the context within your practice.
- ***How will you introduce the screener to the parent/patient?***
  - Setting the appropriate context is vital. Use inclusive wording like “in order to better partner with you for your child’s health” rather than “assessing your child for special needs”
- ***At which visits will you administer the tool?***
  - It is important to consider early on what the periodicity will be given different age ranges. Currently there is not a recommended periodicity given by CAHMI, but benefit has been seen in distributing the survey once a year until of school age and then every other year after that.
    - Also consider how to administer the screener with the adolescent population: who should answer the screener questions?
  - Consider how many tools parents are being asked to complete at a visit. If you have visits at which other screening questionnaires are typically administered, such as standardized developmental screeners, autism screeners, or screening for maternal depression, consider the burden to the parent and identify methods to reduce burden and stagger parent-completed tools. Many of these screening tools accurately identify children at risk for having specific special health needs (for example, developmental screening tools, if positive, indicate that a child has special health care needs). At these visits, a second screening tool is not likely necessary.
  - Younger aged children (particularly less than a year of age) are less likely to have an established diagnosis or increased need that a provider is not already aware of (such as prematurity, congenital abnormalities, etc.).

- ***How will the screener be used in the practice?***
    - The results of the screener are valuable for population management and care coordination, but they are also an important communication tool for providers. How will the completed screener fit into the flow of the visit?

Sample PDSA Cycle to Implement the CAHMI CSHCN Screener

Scenario: *A pediatric practice of 5 providers has decided to implement the CAHMI CYSHCN Screener to identify CYSHCN. This is the first* ***PDSA (Plan-Do-Study-Act)*** *cycle they design to begin the work of effectively implement this process within the flow of their practice.*

- **PLAN**
    - Pilot overview
        - With one provider at next 10 well visits
        - To be administered by front desk staff with other paperwork, introduced separately verbally and with a handout
            - Be clear about why and how it will be used!
        - Scored by the MA
        - Provider to discuss briefly with family
        - Assess charting of the screener and hand off to care coordinator in future PDSA cycles
- **DO**
    - Carry out the pilot as planned
- **STUDY**
    - Huddle with QI team and review measurement questions
- **ACT**
    - What questions came up during the pilot?
    - What adjustments need to be made in the process?
    - **Next steps:**
        - Start another short pilot with adjustments?
        - Conduct a PDSA cycle on another aspect of the process: care coordinator involvement, documentation, or tracking?

After working out your process for these additional steps, you would then plan for spread and sustainability.

CAHMI

The Child and Adolescent Health Measurement Initiative

THE CHILDREN WITH SPECIAL HEALTH CARE NEEDS (CSHCN) SCREENER©

Developed in Collaboration with:

BACKGROUND

The Children with Special Health Care Needs (CSHCN) Screener© was developed through the efforts of the Child and Adolescent Health Measurement Initiative (CAHMI), a national collaboration coordinated by FACCT—The Foundation for Accountability. Beginning in June 1998, the CAHMI brought together federal and state policymakers, health care providers, researchers and consumer organizations into a task force for the purpose of specifying a method to identify children with special health care needs. During the course of this project, the task force met in person six times and more than a dozen times by teleconference.

The CSHCN Screener© is a five item, parent survey-based tool that responds to the need for an efficient and flexible standardized method for identifying CSHCN. The screener is specifically designed to reflect the federal Maternal and Child Health Bureau definition of children with special health care needs:

> "Children who have special health care needs are those who have…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.[1]"

The CSHCN Screener© uses non-condition specific, consequences-based criteria to identify children with special health care needs for purposes of quality assessment or other population-based applications. Children are identified on the basis of experiencing one or more current functional limitations or service use needs that are the direct result of an ongoing physical, emotional, behavioral, developmental or other health condition.

The non-condition specific approach used by the CSHCN Screener© identifies children across the range and diversity of childhood chronic conditions and special needs, allowing a more comprehensive assessment of health care system performance than is attainable by focusing on a single diagnosis or type of special need. In addition, the relatively low prevalence of most childhood chronic conditions and special health care needs often makes it problematic to find adequate numbers of children with a specific diagnosis or type of special need. A non-condition specific approach makes it possible in many cases to identify enough children to allow statistically robust quality comparisons across health care systems and/or providers.

The CSHCN Screener© is currently being used in several national surveys, including the National Survey of Children with Special Health Care Needs and as part of the CAHPS®[2] survey items in the Medical Expenditure Panel Survey (MEPS). The Agency for Healthcare Research and Quality (AHRQ) has included the screener as an integral part of the new CAHPS 2.0 Child Survey. The Screener is also formally integrated into the CAHPS 2.0H Child Survey to identify the Children with Chronic Conditions Measurement Set, a component of the National Committee for Quality Assurance's Health Plan Employer Data and Information Set (HEDIS®).[3] English and Spanish versions of the CSHCN Screener© are available.

[1]McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. Pediatrics. 1998; 102:137-140.
[2]CAHPS® is a registered trademark of the Agency for Healthcare Research and Quality (AHRQ).
[3]HEDIS® is a registered trademark of the National Committee for Quality Assurance (NCQA).

For more information on the development, testing and application of the CSHCN Screener:

Bethell CD, Read D, Stein REK, Blumberg SJ, Wells N, Newacheck PW. Identifying children with special health care needs: development and evaluation of a short screening instrument. Ambulatory Pediatrics. 2002;2:38-47.

Bethell CD, Read D, Neff J, Blumberg SJ, Stein REK, Sharp V, Newacheck P. Comparison of the children with special health care needs screener to the questionnaire for identifying children with chronic conditions–revised. Ambulatory Pediatrics. 2002;2:49-57.

Van Dyck P, McPherson M, Strickland B, Nesseler K, Blumberg SJ, Cynamon M, Newacheck, PW. The national survey of children with special health care needs. Ambulatory Pediatrics. 2002;2:29-37.

For scoring programs or other technical support for the CSHCN Screener and its applications:

Christina Bethell, Director
CAHMI—The Child and Adolescent Health Measurement Initiative
Telephone: 503.494.1930
email: cahmi@ohsu.edu

For technical support for the CAHPS 2.0 Child Survey, please contact:
The CAHPS Survey User Network
800.492.9261 or www.cahps-sun.org

For technical support on the CAHPS 2.0H© Child Survey*, please contact:
NCQA Policy Clarification Support
hedis@ncqa.org

User's Form:
There is no cost to use the CSHCN Screener; however, we ask that you complete the enclosed User's Form. Your input helps us to develop an understanding of our key users and to provide updates.

Please submit the User's Form via fax (503.494.2475) or email (cahmi@*ohsu.edu*).
We look forward to hearing from you!

*The National Committee for Quality Assurance has incorporated a version of the CAHPS 2.0 survey into the HEDIS measurement set. The version of the survey required for HEDIS is referred to as the "CAHPS 2.0H Survey."

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Children with Special Health Care Needs (CSHCN) Screener©
(mail or telephone)

1. Does your child currently need or use **medicine prescribed by a doctor** (other than vitamins)?
   - ☐ Yes → Go to Question 1a
   - ☐ No → Go to Question 2

   1a. Is this because of ANY medical, behavioral or other health condition?
   - ☐ Yes → Go to Question 1b
   - ☐ No → Go to Question 2

   1b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

2. Does your child need or use more **medical care, mental health or educational services** than is usual for most children of the same age?
   - ☐ Yes → Go to Question 2a
   - ☐ No → Go to Question 3

   2a. Is this because of ANY medical, behavioral or other health condition?
   - ☐ Yes → Go to Question 2b
   - ☐ No → Go to Question 3

   2b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

3. Is your child **limited or prevented** in any way in his or her ability to do the things most children of the same age can do?
   - ☐ Yes → Go to Question 3a
   - ☐ No → Go to Question 4

   3a. Is this because of ANY medical, behavioral or other health condition?
   - ☐ Yes → Go to Question 3b
   - ☐ No → Go to Question 4

   3b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

4. Does your child need or get **special therapy**, such as physical, occupational or speech therapy?
   - ☐ Yes → Go to Question 4a
   - ☐ No → Go to Question 5

   4a. Is this because of ANY medical, behavioral or other health condition?
   - ☐ Yes → Go to Question 4b
   - ☐ No → Go to Question 5

   4b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

5. Does your child have any kind of emotional, developmental or behavioral problem for which he or she needs or gets **treatment or counseling**?
   - ☐ Yes → Go to Question 5a
   - ☐ No

   5a. Has this problem lasted or is it expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

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Scoring the Children with Special Health Care Needs (CSHCN) Screener©

The CSHCN Screener© uses consequences-based criteria to screen for children with chronic or special health care needs. To qualify as having chronic or special health care needs, the following criteria must be met:

a) The child currently experiences a specific consequence.
b) The consequence is due to a medical or other health condition.
c) The duration or expected duration of the condition is 12 months or longer.

The first part of each screener question asks whether a child experiences one of five different health consequences:

1) Use or need of prescription medication.
2) Above average use or need of medical, mental health or educational services.
3) Functional limitations compared with others of same age.
4) Use or need of specialized therapies (OT, PT, speech, etc.).
5) Treatment or counseling for emotional or developmental problems.

The second and third parts* of each screener question ask those responding "yes" to the first part of the question whether the consequence is due to any kind of health condition and if so, whether that condition has lasted or is expected to last for at least 12 months.

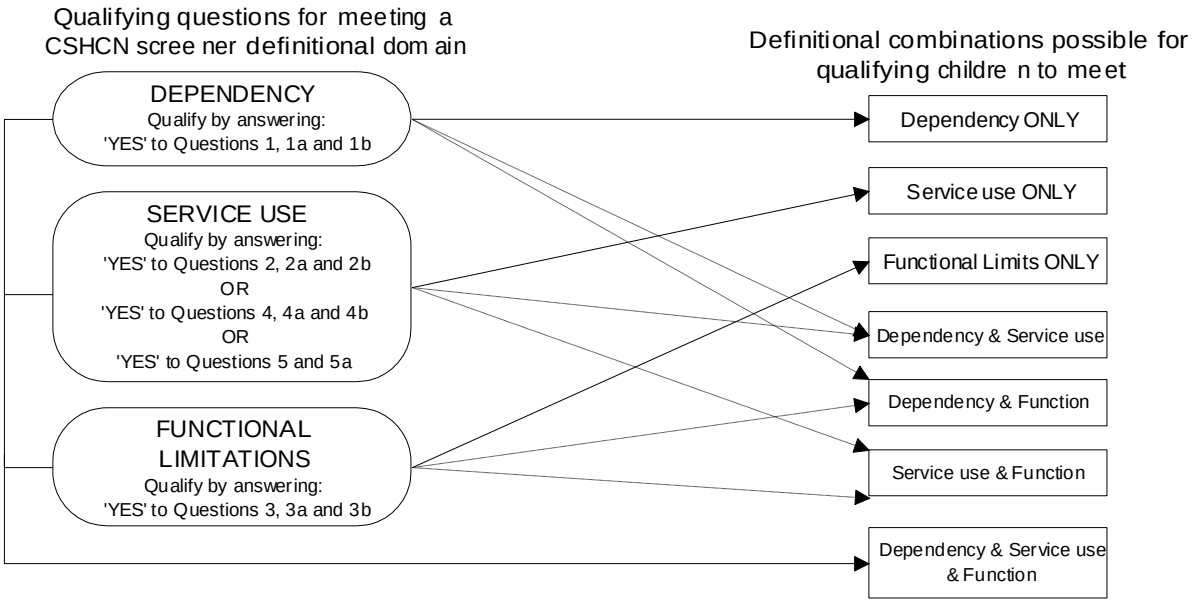
*NOTE: CSHCN screener question 5 is a two-part question. Both parts must be answered "yes" to qualify.

All three parts of at least one screener question (or in the case of question 5, the two parts) must be answered "yes" in order for a child to meet CSHCN Screener© criteria for having a chronic condition or special health care need.

The CSHCN Screener© has three "definitional domains:"

1) Dependency on prescription medications.
2) Service use above that considered usual or routine.
3) Functional limitations.

The definitional domains are not mutually exclusive categories. A child identified by the CSHCN Screener© can qualify on one or more definitional domains (see diagram).



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APPENDIX B- USING ICD-9 CODES TO IDENTIFY CYSHCN

Please see the attached Excel Spreadsheet for the List of Specific ICD-9 codes that can be used to identify CYSHCN. These codes are based on the following sources:

1. **Deaths Attributed to Pediatric Complex Chronic Conditions by Feudner, et al**. This list represents a modified list of codes used in a retrospective longitudinal study of mortality patterns in Washington State - which was based on studies of hospitalization patterns of children with costly illnesses and congenital defects. The authors modified the list to include epilepsy and by expanding the range of ICD-9 codes for the subcategories of: mental retardation; central nervous system degeneration and disease; and malignancy.
2. **Center for Infants and Children with Special Needs Care Coordination Toolkit.** These codes were contributed by the providers who participated in Carl Cooley's 2001 Learning Collaborative, Building a Medical Home: Improvement Strategies in Primary Care for Children.
3. **Cincinnati Children's *Children with Special Health Care Needs Identification Project*** (155 pediatricians/38 practices) which identified that 30% of patients have at least one chronic condition when they completed data claims runs (hospital and practice-based). Hypothesizing that this was an over-estimation of children needing focused care management; the providers reviewed the patient list and refined it based on 15 factors (i.e. multiple chronic conditions or one chronic condition that was not well-controlled). This resulted in an average of 15% of the patient panel being identified as needing care management. From there the providers divided list into two categories – always included and conditional, meaning only conditional patients needed chart reviews.
4. **Adoption and Foster Care Analysis and Coding System: AFCARS Disability/Special Needs Table.** This table lists several medical/emotional conditions that may be mapped to AFCARS data elements for foster care and adoption. It is not an exhaustive list of all conditions that states may used for reporting; it is also important to note that AFSCARS does not utilize ICD-9 codes, but rather utilizes diagnosis groups.
5. **New Codes as noted in Coding for Pediatrics 16th Edition of American Academy of Pediatrics.** The International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) for 2011 identified more than 150 new codes, revisions and deletions effective October, 2011.

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APPENDIX C- PROVIDER GESTALT

A number of practices start first with identifying children and youth for whom the provider knows that they have exceptional health care needs and would be benefit from an enhanced medical home and care coordination. The literature has documented that the provider recall about patients with special health care needs is often narrow to specific, high-complexity patients that they have recently encountered and/or for whom a negative e event occurred. In asking providers to identify patients, it is important to clarify **WHY** they are identifying the patient and **HOW** the information will be used:

- For example, providers will identify a different groups of patients when asked to identify patients that would benefit from care coordination versus identify a population for which you might want to assess their health needs and whether proactive care planning might be helpful.

- In asking providers to identify CYSHCN, it may be helpful to ask them to identify:
    - Patients who meet the MCHB definition of special health care needs:

      *"Children with special health care needs are those who **have or are at 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."*

A helpful way to operationalize this definition is to consider children who are experiencing the following consequences and are expected to have these consequences for at least year:

- ✓ Limited or prevented in ability to function
- ✓ Prescription medication need/use
- ✓ Specialized therapies (OT, PT, Speech)
- ✓ Above routine use of medical care, mental health or other health services
- ✓ Counseling or treatment for on-going emotional, behavioral or developmental problem

    - Consider patients who have special health care needs because of the complexity of the needs of the family and value of enhanced support and coordination of the practice team with their family.

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References

1. Maternal and Child Health Bureau, July 1998
2. Davidoff, Health Services Research, 2004
3. Mathematica Policy Research, Inc., November 2004
4. U.S. Department of Health and Human Services, National Survey of Children's Health (2007),
5. Klitzner et al., 2010, Journal of Pediatrics
6. Gordon et al., 2007, Archives of Pediatrics & Adolescent Medicine)

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