Identification of Children and Youth with Special Health Needs (CYSHN)
(Nickel, 2011)

Identification of children and youth with special health needs (CYSHN) is a critical part of an office's care coordination program and medical home transformation. Identification of CYSHN enables practices to work with children and families to proactively plan for the child's care which will result in the following outcomes:

- improved child health,
- improved office practice efficiency,
- improved provider and family satisfaction,
- for many CYSHN, decrease in the cost of care by reduction in ER visits and hospital days,
- and may support improved reimbursement rates for the practice.

The systematic identification of CYSHN also will provide office staff with valuable information about the overall characteristics of the children in their practice, for example % with a special health care need as well as the # with complex chronic conditions (Gillespie, 2012). This information will help determine office personnel needs and may contribute to improved reimbursement. Planning for the identification of CYSHN is best accomplished as part of the practice's ongoing Quality Improvement program. It will require the following steps:

Create an office quality improvement team that includes a family member or youth with special health needs.

Resources:

1. Medical Home Practice-Based Care Coordination (McAllister, Presler & Cooley, 2007), www.medicalhomeimprovement.org/pdf/MHPracticeBasedCC-Workbook_7-16-07.pdf

Conduct a baseline self-assessment. How does your practice currently identify CYSHN, plan for office appointments, and assess child and family needs?

Resources:

1. Medical Home Practice-Based Care Coordination (McAllister, Presler & Cooley, 2007), www.medicalhomeimprovement.org/pdf/MHPracticeBasedCC-Workbook_7-16-07.pdf

Select a definition of CYSHN and consider development of a patient registry. Ultimately, use an overall "functional" definition of CYSHN such as the CAHMI CSHCN Screener or the Questionnaire for Identifying Children with Chronic conditions– Revised (QuiCCC-R), and also record the child's chronic condition (ICD-9 code). A "functional" definition is based on a child's increased utilization of services and limitations in skills or community participation compared to other children the same age.

Your first step in developing a definition of CYSHN for your office, however, may be use of a brief checklist based on current service needs, a short list of ICD-9 codes, or a list of children who have required multiple hospitalizations and ER visits in the last year (high utilization of care). This latter group primarily represents children with complex chronic conditions (children with CCC), although currently there is no generally accepted definition for this group. Another

approach is to start with children who have 3 or more positive items on the CAHMI Screener. This identifies about 85% of children who medically qualify for Supplemental Social Security benefits due to their disability.

Once you have decided how to identify CYSHN, create a patient registry. Patient or disease registries are a searchable list of all patients with a particular chronic condition(s) that often interface with an electronic medical record. Registries, to date, have focused on conditions such as diabetes and asthma. Some practices may start with a patient registry for a single condition, however, consider subsequent development of a patient registry based on a "functional" definition of CYSHN. This will allow tracking the progress of CYSHN as a whole as well as children with specific conditions. The importance of a registry is that it allows timely identification of high-risk sub-populations permitting monitoring of care outcomes and care needs. Registries vary from simple spreadsheets to very complex databases. Individual practices can maintain a "homemade" registry using Excel, Access, or C-DEMS (Gillespie, 2011).

Resources:

1. Care Coordination Toolkit: Proper Use of Coordination of Care Codes with Children and youth with Special Health Care Needs (CYSHCN), Center for Infants and Children with Special Needs, Cincinnati Children's Hospital Medical Center & the National Center of Medical Home Initiatives, www.medicalhomeinfo.org/downloads/pdfs/CareCoordinationToolkit06.pdf
2. Care Coordination for Primary Care (Gillespie, 2011).
3. Supporting Spread: Lessons from the California Improvement Network, (CHCF, 2011), www.chcf.org/publications/2011/06/supporting-spread-lessons-cin
4. CAHMI CSHCN Screener, a 5 item parent-completed questionnaire, cahmi.org/ViewDocument.aspx?DocumentID=115
5. QuiCCC-R, a 16 item interview, www.neserve.org/neserve/pdf/NES%20Publications/QUiCCC_R.PDF
6. Checklist for Determination of CSHCN (from Medical Home Care Coordination Measurement Tool, Antonelli), included in www.medicalhomeinfo.org/downloads/pdfs/CareCoordinationToolkit06.pdf, Appendix II.
7. Brief checklists:
   a. "Uncomplicated" = no more than one or two straight forward chronic conditions; sees no more than one or two consultants; and is taking no more than one or two chronic medications, (Berkowtiz, Children's Hospitals and Clinics of Minnesota, 2008).
   b. CYSHN = Child sees 2 or more specialists, is taking 2 or more chronic medications, and has had 2 or more hospitalizations or multiple ER visits in the last year.
8. List of ICD-9 Codes:
   a. Asthma, ADHD and Autism (the 3 A's)

   b. Exeter Pediatrics – biological, psychological, cognitive and other, included in www.medicalhomeinfo.org/downloads/pdfs/CareCoordinationToolkit06.pdf, P. 23.
   c. Center for Medical Home Improvement's common ICD-9 codes, included in www.medicalhomeinfo.org/downloads/pdfs/CareCoordinationToolkit06.pdf, p. 24.

9. Some practices include children at "risk" of a chronic condition based on biologic (for example, prematurity, intra-ventricular hemorrhage and periventricular leukomalacia) or social risk factors (for example, children living in poverty; in a foster home; with parents or guardians who are alcohol or drug dependent; with parents who have significant mental health disorders such as maternal depression, bipolar disorder and schizophrenia; or with parents who have an intellectual disability).
10. Another step in the identification of CYSHN is to regularly screen the development and behavior of all children in the practice. Review American Academy of Pediatrics' recommendations for developmental screening for young children, aappolicy.aappublications.org/cgi/content/abstract/pediatrics;118/1/405

Apply the definition of CYSHN and flag charts. The initial implementation of the definition may be by remembrance of selected children by office staff, recognition at the time of an office appointment, or by a computer generated list of children based on ICD-9 codes or utilization data from your practice's EMR, health plans or your state's Medicaid agency (these lists may be incomplete). Make sure the paper chart and/or office EMR clearly identifies the child's status as CYSHN, the child's primary diagnosis of a chronic condition (ICD-9 code), and whether the child and family are eligible for the office's enhanced care coordination services (see below). This can be done with color-coded labels for paper charts and specific symbols for electronic records.

Notify families of the office care coordination/management program. This may include development of an office brochure regarding identification of CYSHN and the office's care coordination program. Families should be allowed to request or to refuse participation in the care coordination program.

Resources:

1. Medical Home Practice Brochure for Parents, template at www.pedmedicalhome.org

Complete pre-visit planning for each CYSHN. Pre-visit planning will assist office staff to proactively plan and meet the child's and family's needs for a successful health care appointment. For example, the family can bring copies of school reports or specialty clinic evaluations. The family also can mention any special issues for the appointment such as noise level, lighting and a busy waiting room. They may mention strategies that have worked for their child such as the time of day and length of the appointment, limited time in the waiting room, bringing special toys from home, and use of picture schedules and social stories.

Resources:

1. Family-Centered Care Coordination Tool included at www.pediatricmedhome.org
2. Pre-visit Contact form included at www.pediatricmedhome.org

3. Tips for a Successful Health Care Visit for CYSHN and their Families included in www.ohsu.edu/xd/outreach/occyshn/programs-projects/upload/OCCYSHN_MATRIX_CareCoordinationToolkit_2011_1117.pdf

Use a complexity scale or similar method to determine the need for enhanced care coordination services. The complexity scale should consider the status of the child's chronic condition as well as family and social factors. Some practices may choose to use *utilization data* such as number of office or ER visits and hospital days instead of a formal complexity scale. *Each CYSHN who receives enhanced care coordination services should be introduced to the office care coordinator and should receive a comprehensive child and family needs assessment, a written care plan created and updated regularly in collaboration with the child and family, and additional care coordination services as needed by each individual child and family*. Many CYSHN and their families will not need an enhanced level of services from the office.

Resources:

1. CAHMI CSHCN Screener. It does not directly address family and social factors. If the office chooses to offer enhanced care coordination services to children who are rated positive for 3 or more items on the Screener, staff should identify additional family and social criteria (social risk criteria, for example, parents with drug/alcohol problems or serious mental health disorders, or parents with limited health literacy based on cultural and language factors).
2. Hirsch Complexity Index, it does not consider family and social factors, internet.dscc.uic.edu/forms/medicalhome/HirschComplexityIndex.pdf
3. Exeter Pediatric "HOMES" complexity index, internet.dscc.uic.edu/forms/medicalhome/ExeterComplexityScale.pdf
4. Bob's Levels of Support Scale (BLSS), www.ohsu.edu/xd/outreach/occyshn/programs-projects/upload/ComplexityScale.pdf

***Measure success*.** Patient registries facilitate patient care as well as program evaluation. Program evaluation should include *outputs* or activities needed to accomplish your goals as well as *outcomes*.

Outputs

- # QI meetings
- People participating in QI meetings
- The definition of CYSHN that is adopted by your practice
- Criteria for enhanced Care Coordination that is adopted by your practice
- Methods adopted for implementing identification of CYSHN based on your definition (both retrospective and prospective identification of CYSHN)
- Pre-visit Planning Tool adopted

Short-Term Outcomes

- # Children identified
- # Children missed by your definition of CYSHN
- # New needs identified by Pre-visit Planning
- # CYSHN who require enhanced Care Coordination services
- # families who refuse participation
- # and type of Care Coordination services provided (e.g. # CYSHN with a written Care Plan)

Long-Term Outcomes

- # Office and ER Visits
- # Hospital Days
- Over-all Cost of Care
- Family Satisfaction
- Staff Satisfaction

Resources:

1. Medical Home Care Coordination Measurement Tool (Antonelli) in Care Coordination Toolkit: Proper Use of Coordination of Care Codes with Children and youth with Special Health Care Needs (CYSHCN), Center for Infants and Children with Special Needs, Cincinnati Children's Hospital Medical Center & the National Center of Medical Home Initiatives.
2. The Promoting Healthy Development Survey (PHDS) developed by the Child and Adolescent Health Measurement Initiative (CAHMI), see cahmi.org/pages/Sections.aspx?section=8
3. The Child Primary Care Questionnaire, demo.westat.com/cahps-sun/cahps2005/cahpskit/files/353a_Child_Prim_Eng.htm of the Consumer Assessment of Healthcare Providers and Systems (CAHPS), Agency for Healthcare Research and Quality (AHRQ).