Topic: Caring for Children with Special Health Care Needs (CSHCN)

Learning Objectives:

Upon completion of these materials, viewers will be able to:

1) Define “special health care needs” as it applies to children.
2) Describe the medical home and the aspects which contribute to better outcomes for CSHCN.
3) Identify disability laws and educational rights as they apply to CSHCN.
4) Strategize ways to prepare CSHCN for transition to adult health care.

(Original module prepared by Dr. Shaikh, December 2005; Revised by Mary E. Brown, MD, April 2008; revised by Dr. Shaikh, March 2011 revised Stacey Cook 2017)

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Case

You have a 17-year-old new patient scheduled in your continuity clinic today, with a note that he has “special needs”. As you mentally prepare for the visit, you think about what his special needs might be.

Question 1. What is the working definition of children with special health care needs (CSHCN)? What percentage of children in the US have a special health care need?
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The Maternal and Child Health Bureau has implemented a definition for children with special health care needs (CSCHN):

"Children with special health care needs are 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."

According to the National Survey of Children with Special Health Care Needs (NS-CSHCN) in 2009,

- approximately **14% of all US children** under 18 years of age had some type of special health care need.
- almost **22% of US households** with children have at least one child with a special health care need.

In the NS-CSHCN, children were identified as having a SHCN if their parents indicated that they:

1) used more medical care, mental health services, or educational services than is usual for most children of the same age;
2) used specialized therapies, mental health counseling, or prescription drugs; and/or
3) were limited or prevented in any way in his or her ability to do things that most children of the same age can do because of a medical, behavioral, or other health condition that is expected to last at least 1 year.

Question 2. What kinds of special health care needs do these children and their families have?
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According to the 2009 NS-CSHCN, the most common special needs that patients report having are:

- Prescription medications (86%)
- Specialty medical care (52%)
- Vision care (33%)
- Mental health care (25%)
- Specialized therapies (23%) – including PT, OT, speech, etc.
- Durable medical equipment (11%) – including wheelchairs, ventilators, feeding pumps, nebulizer machines, etc.

16% of patients report having at least 1 unmet need, the most common unmet need being dental care.

According to the 2009 NS-CSHCN, families of CYSHCN report having the following needs:

- Family counseling and support (12%) – to deal with the impact that having a child with special health care needs has on the family members
- Genetic counseling (6%) – for families with children with genetic conditions which may affect other family members or may influence future pregnancies
- Respite care (4%)

5% of parents of CSHCN report having at least 1 unmet need. Additionally, financial burdens are common in families with CSHCN. 80% of pediatric health care expenditures are for CSHCN.

Case (con’t)

Your new patient, Jayden, arrives with his mother. He is a 17-year-old with a mild intellectual disability (formerly referred to as mental retardation*); ADHD; mild hearing loss accommodated with hearing aids; and well-controlled mild persistent asthma. He and his mother moved here 1 month ago from out of state. His mother states that her sister told her to make sure Jayden had a medical home, but she is not really sure what a medical home is.

* Please note that the terminology for mental retardation has recently changed. Rosa’s Law, signed into effect by Barak Obama on October 5, 2010 changes references in Federal law from mental retardation to intellectual disability, and references to a mentally retarded individual to an individual with an intellectual disability.

Question 3. What can you tell her about the principles of the medical home?
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The Medical Home is not a literal “home,” but an approach to providing health care for children and families, especially those with special health care needs. It emphasizes comprehensive, coordinated care for children and families.
The AAP published a policy statement in 2002 (reaffirmed May 2008) about the Medical Home. The AAP statement highlights the following principles of the medical home:

**Family centered**
- The medical home physician is known to the child and family.
- Families and youth are supported to play a central role in care coordination.
- Families, youth, and physicians share responsibility in decision making.
- The family is recognized as the expert in their child’s care, and youth are recognized as the experts in their own care.

**Continuous**
- The same primary pediatric health care professionals are available from infancy through adolescence and young adulthood.
- Assistance with transitions, in the form of developmentally appropriate health assessments and counseling, is available to the child or youth and family.
- The medical home physician participates to the fullest extent allowed in care and discharge planning when the child is hospitalized or care is provided at another facility or by another provider.

**Comprehensive**
- Ambulatory and inpatient care for ongoing and acute illnesses is ensured, 24 hours a day, 7 days a week, 52 weeks a year.
- Preventive care is provided that includes vaccinations, anticipatory guidance and tracking of development and nutrition.
- The physician advocates for the child, youth, and family in obtaining comprehensive care.
- The child’s and family’s medical, educational, developmental, psychosocial needs are identified and addressed.
- Information is made available about insurance, including Supplemental Security Income, Medicaid, the State Children’s Health Insurance Program, waivers, early intervention programs, and Title V State Programs for Children With Special Health Care Needs.
- Extra time for an office visit is scheduled for children with special health care needs, when indicated.

**Coordinated**
- A plan of care is developed in collaboration with the family and is shared with other providers.
- Care among multiple providers is coordinated through the medical home.
- A central record or database containing all pertinent medical information is maintained at the practice.
- The medical home physician shares information among the child or youth, family, and consultant and provides specific reason for referrals.
- Families are linked to family support groups, parent-to-parent groups, and other family resources.
- The plan of care is coordinated with educational and other community organizations to ensure that special health needs of the individual child are addressed.
Community based

- Services based in the community, including health care providers – both primary care and specialty, early intervention, developmental services, education, community organization programs, etc.

Some of the possible benefits of the medical home include:
- Increased patient and family satisfaction because of improved communication between families and providers
- Improved coordination of health care and related services for CSHCN and their families
- More comprehensive care
- More efficient use of health care and community resources
- Fewer ED visits and hospitalizations
- Overall reduced health care costs

Case (con’t)

Jayden’s mom thanks you for explaining the medical home concept and is happy that your practice will be his medical home. Currently his medical issues are stable, with no acute complaints. His mom reports that Jayden has been having difficulty in his new school. She tells you that he had previously been in a private school and had been getting extra help. Now he is in public school and she wants to know how she can get the school to provide extra help for Jayden.

Question 4. What can you tell her about disability laws and educational rights for children with disabilities?
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You recognize that becoming informed about disability laws is an important public health role of pediatricians and represents an action step in the SEPA public health approach.

The Individuals with Disabilities Education Act (IDEA), which was updated and revised in 2004 requires schools to provide students with disabilities “free and appropriate public education…in the least restrictive environment.” As much as possible, students must be placed in classes with typical children. (http://idea.ed.gov/)

- IDEA provides for Early Intervention programs (Part C), preschool education (Part B), as well as primary and secondary education.
- A family may request that the school evaluate their child for special education services or other developmental services and develop an Individualized Education Plan (IEP) [or Individualized Family Service Plan (IFSP) for Early Intervention.] Parents must provide consent for the evaluation.
- The school has 30 school days to complete the evaluation and 45 school days to have a meeting with the IEP team and the family to discuss the evaluation and resulting IEP.
- Parents have the right to participate in the IEP meetings, and to bring an advocate or the child’s primary care provider.
- Families have the right to review a written copy of the IEP prior to the meeting, and have 30 days to reject or accept the IEP.
- The IEP must be reviewed at least every year, and the IEP evaluation must be repeated at least every 3 years.
- Additionally, IEPs must begin to address transition of services into adulthood starting at age 14 years, with a identification of specific interventions and services by age 16 years.
- For children in EI from birth to 3 years, their IFSP must be reviewed at least every 6 months, and between 90 days and 6 months before transition to preschool-based EI services.

Children who do not qualify for special education services under IDEA may be eligible for services under Section 504 of the Rehabilitation Act of 1973. This act ensures that children who have a mental or physical disability which impairs activities of daily life, such as education, receive accommodations in order to fully participate in general educational activities.
Accommodations under this law may include:

- Assistive technologies
- Special seating arrangements
- Additional time to complete assignments

Often children with ADHD who are not eligible for special education services under IDEA will qualify for services under Section 504.

Public education services are provided to children with disabilities until age 22 years.

Young adults with disabilities may continue to be eligible for services for obtaining jobs, special accommodations at work, and additional financial assistance through other programs, including:

- The Rehabilitation Act of 1973
- The American with Disabilities Act (ADA)
- Supplemental Security Income (SSI)

Case (con’t)

Jayden’s mom will request an IEP for Jayden at his new school tomorrow. She realizes that Jayden is growing up and says she probably should have taken him to an adult doctor instead of a pediatrician, but she is worried that Jayden would not be as well taken care of.

Question 5. What is the transition of care from pediatric to adult-oriented care? How does it differ from transfer of care?
**Question 5.** What is the transition of care from pediatric to adult-oriented care? How does it differ from transfer of care?

Transition of care is a planned and orderly process of change from child oriented to adult models of care.

Transfer is the step whereby a patient moves care from one provider to another. It is one step in the transition process.

**Question 6.** What are some of the barriers to transitioning CSHCN from pediatric to adult health care?
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Surveys of youth with SHCN, their families, and pediatric providers identified several barriers to transitioning CSHCN to adult health care:

- Significant cognitive impairment
- Difficulty finding adult providers who are familiar with their child’s special health care need
- Lack of confidence in adult providers – by both families and pediatric providers
- Lack of continuous and comprehensive health insurance coverage

Question 7. What are the AAP recommendations regarding transition and transfer of care?
Question 7. What are the AAP recommendations regarding transition and transfer of care?

The AAP, in conjunction with the American Academy of Family Practitioners and the American College of Physicians (governing body for internal medicine) developed an algorithm and jointly agreed upon recommendations for transition and transfer of care. Due to lack of evidence regarding best practices, these guidelines are based on expert opinion.

The highlights from these guidelines are as follows:

- The guidelines emphasize the importance of each practice having a set and well-publicized age at which patients can no longer be seen.
  - The general recommendation is that patients should transfer some time between the ages of 18 and 21.

- Whatever age is chosen, the policy should be listed in the waiting area, and a formal written version of the transfer age and the practice’s general transition planning process should be given to parents.

- Transition should begin at age 12 with a discussion of the practice policy and general transition plan.
  - This discussion should ideally occur at a health maintenance or chronic condition management visit.
  - The discussion should also include reassurance to the patient and family that the medical home will support the family through the transition process and after transfer if the accepting provider needs help or information.
  - The initial discussion should be documented.

- A transition plan should be developed with the family and patient at age 14 or 15.

- The transition plan should be updated at least annually from the time of its development until the patient is transferred to adult-oriented care.

- The guidelines recommend use of a checklist to both empower patients and families to take ownership of the transition process and to help practices identify areas of strength and weakness in transition plan development.
  - Example: Transition Health Care Checklist on the PA state Medical Home portal

- Additional responsibilities for the pediatric provider in the transition process also include the following:
  - Providing a complete, but succinct medical summary of the patient’s history, including relevant psychosocial history that an accepting provider would need to know.
  - Complete a medication reconciliation prior to transfer.
  - Provide contact information to the accepting provider so that the accepting provider can ask questions if needed.
Question 8. What extra considerations should be made for children with special needs in their transition?
Question 8. What extra considerations should be made for children with special needs in their transition?

- The transition guidelines discuss the following considerations for CSHCN and their families as they proceed through transition.
  - **Insurance coverage** – ensuring continuous coverage for CSHCN is of paramount importance. The provisions of the Affordable Care Act (ACA) make this easier, but patients and families should consider this well in advance of transfer.
  - **Self-advocacy** – CSHCN should receive education in self-advocacy and decision-making as they proceed through adolescence to adulthood to ensure they can participate in healthcare decisions to the full extent that their capacity will allow.
  - **Legal issues** – families need to consider in advance who will be making healthcare decisions when a patient reaches 18 and for patients who will not have full capacity at the age of 18, guardianship planning should be considered.
  - **Caregiver’s issues** – Caregivers may be struggling with the loss of control as patients assume more responsibility for their care. They may also be experiencing stress and fear as transfer approaches. The medical home team should support caregivers through these stressors.
Take home points

- The Medical home concept emphasizes comprehensive, continuous, coordinated care for children and families.

- By law (IDEA), once a family requests that the school evaluate their child for special education services, the school has 30 school days to complete the evaluation.

- Transition is a planned and orderly process of preparation towards adult-oriented care, of which transfer to an adult-oriented provider is but one step.

- Transition should begin at age 12 and be planned out starting from age 14 to ensure adequate preparation prior to the time of transfer.

- CSHCN will require extra consideration in their transition planning.
References


