

POPULATION SPECIFIC FACT SHEET

What to Know When Assisting a Consumer who has a Child or Youth with Special Health Care Needs (CYSCHN)

This fact sheet is intended to help Navigators identify what issues are unique to children and youth with special health care needs so that they can assist their families as they make decisions related to their healthcare coverage.

Q1. What do I need to know about children and youth with special health care needs (CYSCHN)?

A. “Special Health Care Needs” is a broad umbrella term that covers a broad range of children and youth with chronic health conditions and disabilities. The federal Maternal and Child Health Bureau defines CYSCHN as: “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.”¹ According to the 2009/2010 National Survey of Children with Special Health Care Needs (NS-CSHCN), more than one in five families (23%) has at least one child with special health care needs.² That translates into approximately 14.6 million children ages 0-17 years in the US, or nearly 20%, who meet this definition. Of those 20%, more than 65% have more than one current chronic health condition.³ Conditions include autism, cerebral palsy, developmental delay, intellectual disabilities, depression, learning disabilities, and epilepsy. Over 90% of CSHCN have functional difficulties that impact their daily lives—with more than 45% having four or more of these difficulties, including breathing, communicating, chronic pain, learning, moving around, behavior, or challenges in making and keeping friends.⁴ Their families typically experience greater stress, struggling to meet the needs of their child in a maze of multiple and complex systems of care. According to the 2011-2012 National Survey of Children’s Health, many families of CSHCN find that insurance is not adequate (29%), care coordination is ineffective (43.6%), and referrals are difficult (24.5%).⁵ Thirty-three percent of CYSCHN do not experience family-centered health care.⁶ For more information, see: http://www.familyvoices.org/admin/miscdocs/files/One-in-Five_05-01-2014.pdf

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 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN): <http://childhealthdata.org/browse/survey/results?q=2625&r=1>

³ 2011-2012 National Survey of Children’s Health (NSCH): <http://childhealthdata.org/browse/survey/results?q=2473&r=1>

⁴ 2009-2010 NS-CSHCN: <http://childhealthdata.org/browse/survey/results?q=1809>

⁵ Child and Adolescent Health Measurement Initiative (2013). “Who Are Children with Special Health Care Needs (CSHCN).” Data Resource Center, supported by Cooperative Agreement 1-U59-MC06980-01 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Available at www.childhealthdata.org. Revised 4/15/13. http://childhealthdata.org/docs/drc/whoarecshcn_09-10-21-13-final.pdf?Status=Master

⁶ 2011-2012 NSCH: <http://childhealthdata.org/browse/survey/results?q=2510&r=1&q=461>

Q2. What type of health care providers do children and youth with special health care needs need to access?

A. By definition, CYSHCN need more than the usual amount of health care. In addition to the well-visit care, which is as important for these children as it is for all children, they are likely to need specialists (including mental health specialists), therapies (speech, occupational, physical), nutritional supplements, home nursing, vision/dental, and durable medical equipment such as wheelchairs and braces. Most importantly, CYSHCN must have access to pediatric specialists and pediatric subspecialists and often need care from children's hospitals. CYSHCN must have access to out of network providers at no additional cost if no network provider is accessible or available in a timely manner. For older youth, there must be a plan to transition to adult health care providers.

Q3. What are some of the prescription needs that children and youth with special health care needs may have?

A. Prescription medication requirements would be based on the individual needs of the child. Because the definition of CYSHCN is broad, and because within each specific condition or disability there is a range of severity, a wide range of medication is needed. These children could need anti-seizure medications, asthma/allergy medications, psychiatric prescriptions, and neuromuscular, cardiac or gastrointestinal medications. For more information on medications, please see Fact Sheet #5 at <http://www.nationaldisabilitynavigator.org/ndnrc-materials/fact-sheets/fact-sheet-5/> Note that this Fact Sheet is specifically written about medications for people with disabilities, but much of the information is relevant to the broader population of CYSHCN.

Q4. What type of therapies (physical, occupational, speech, etc.) and/or devices (durable, disposable, etc.) would children and youth with special health care needs potentially require?

A. Many CYSHCN benefit from physical, occupational, and speech therapy as well as behavioral health interventions. Some children may also need mobility devices such as walkers, wheelchairs, and leg braces.) Fewer children may need disposable supplies such as incontinence supplies. Others may benefit from nutritional supplements prescribed by a physician such as caloric supplements and food thickeners, or may be on medical diets. Some children may need augmentative communication devices. Home modification and assistive technology could include lifts, ramps, accessible bathrooms, etc. For more information on rehabilitation/habilitation, see Fact Sheet #4 at <http://www.nationaldisabilitynavigator.org/ndnrc-materials/fact-sheets/fact-sheet-4/>. For additional information on medical supplies, please see Fact Sheet #10 at <http://www.nationaldisabilitynavigator.org/ndnrc-materials/fact-sheets/fact-sheet-10/>.

Q5. What other services and supports, which are not generally medically arranged therapies and devices, are typically required for children and youth with special health

care needs? Are these arranged and financed in some private health insurance plans or in some Medicaid programs?

A. Medicaid has more generous benefits for children due to the EPSDT (Early, Periodic, Screening, Diagnostic, and Treatment) provision than traditional health insurance plans. CYSHCN may be eligible for Medicaid and Supplemental Security Income based on family income. CYSHCN (and children in general) may be eligible for SCHIP (State Children’s Health Insurance Plan). Please note that when a child turns age 18, parental income is no longer considered and the individual is considered a “family of one.” In addition, some children may be eligible for the disabled dependent provision and continue under a parent’s plan regardless of age as long as that parent is employed. Children who require dialysis or kidney transplant would be eligible for Medicare as well. It is possible that a child could be covered under Medicaid, Medicare, and a private plan simultaneously, requiring coordination of benefits. Also note that a child could be listed as a DAC (disabled adult child) dually eligible for Medicaid/Medicare if their parent retires, becomes disabled, or dies. Lastly, some state Title V programs will reimburse families for expenses related to “catastrophic” illness. Note that there may be value in having a separate insurance coverage for their child/ren if the parents are buying on the marketplace. Another source of some health services is the public school system if related services such as speech, occupational, and physical therapy are needed in accordance with the provision of FAPE (free, appropriate public education) under federal law. Federal education law might also help CYSHCN get some health services through the public school system, and CYSHCN ages 0-3 get services through the Early Intervention program.

Q6. Are there any other unique medical needs that families of children and youth with special health care needs should consider when evaluating a health plan?

A. Besides access to pediatric specialists, families must ensure that all providers are in network to reduce costs. This means that primary care physicians, pediatric specialists and sub-specialists, hospitals, pharmacies, therapists, and durable medical equipment suppliers must all be listed in the plan’s network. As noted above, CYSHCN must have access to out of network providers at no cost if the provider is not accessible or available in the plan’s network.

Q7. Are there any type of accommodations I should consider when I’m planning to meet with a family of a child with special health care needs?

A. It is important to take the time to understand the unique needs of each family with CYSHCN. The needs of their children are unique, and families understand those needs—and the barriers they face—in trying to meet those needs. It is important that the provider’s office is physically accessible to children with disabilities, including wheelchair accessible entrances, restrooms and exam rooms. Some children will also require accessible examination tables and weight scales or communication assistance. Another-tangible way of promoting awareness of CYSHCN is by using “people first” language (e.g., not saying “wheelchair-bound child,” but “child uses a wheelchair”).

Families are their own experts when it comes to living with CYSHCN—but will rely on your expertise in helping to find the best insurance to meet those needs. Knowing where to refer families for additional support and resources, or when the help they need is beyond your scope and experience is important. An excellent resource for such help is the **Family-to-Family Health Information Center (F2F HIC)** available in each state and the District of Columbia. These family-staffed organizations provide support, information, resources, and training around health issues and can assist families in navigating health coverage options. For more information, and to locate the F2F HIC in the family's state, go to: http://www.fv-ncfpp.org/f2fhic/about_f2fhic/.

Q8. Are there any resources you would recommend to obtain additional information about CYSHCN?

A. Each state has its own set of health care financing resources that families need to be aware of. These may include: Katie Beckett waiver, catastrophic illness in children relief fund, autism insurance mandate, Title V CSHCN program, etc. Any of these may intersect with or impact the health insurance in the market place.

As mentioned above, an important resource for families is the Family-to-Family Health Information Center (F2F HIC), available in each state and the District of Columbia. F2F HICs are family-staffed organizations that assist families of CYSHCN and the professionals who serve them. F2F HICs provide support, information, resources, and training around health issues, and can assist families in navigating health coverage options. For more information, and to locate the F2F HIC in the family's state, go to: http://www.fv-ncfpp.org/f2fhic/about_f2fhic/

Family Voices is a national family-led organization promoting quality health care for children and youth with special health care needs. See www.familyvoices.org for more information. In addition, the National Center for Family/Professional Partnerships (NCFPP), a major project of Family Voices, provides additional information and resources for supporting families with CYSHCN and the professionals who serve them. See www.fv-ncfpp.org for more information, especially <http://www.fv-ncfpp.org/cyshcn1/cyshcn/> to learn more about CYSHCN and the impact on their families.

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