



Section 1

# WHO ARE CHILDREN WITH SPECIAL HEALTH CARE NEEDS?

## How Do Different Systems Think About Children With Special Health Care Needs?

Before we get into the details of how the Medicaid and Children’s Health Insurance Program (CHIP) programs work and their importance to children with special health care needs (CSHCN), let’s take a moment to consider what different people may think when they hear the term “CSHCN.” We will begin with the federal Maternal and Child Health Bureau (MCHB) definition, and then compare this definition to the way Title V and Medicaid programs think about children with disabilities, chronic illnesses, and other special health care needs.

### MCHB Definition

Most users of this tutorial are familiar with the federal MCHB definition of CSHCN, but it’s worth reviewing in the context of the discussion to come. It describes CSHCN 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.*”<sup>3</sup> This inclusive definition describes a lot of kids: approximately 15% of the U.S. child population, according to the National Survey of Children with Special Health Care Needs 2009/10. It guides the work of many stakeholders in serving CSHCN as a population and improving the system of care for them. The Catalyst Center uses this definition in its work and in this tutorial, but it is not necessarily the definition that either individual state Title V or Medicaid programs use when thinking about the children for whom they have responsibility. It is important to recognize and understand these differences.

The MCHB definition is not necessarily used to determine eligibility for Title V programs or services.<sup>4</sup> Most Title V programs that pay for health care services have more restrictive eligibility criteria, limiting services to children with specific conditions and/or at certain income levels. Some of this is a holdover from the historical origins of Title V, and much of this is due to the

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<sup>3</sup>McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P.W., . . . Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics*, 102(1 Pt. 1), 137-140, pg. 138.

<sup>4</sup>Title V is used in this tutorial to describe the part of the Social Security Act that administers the Maternal and Child Health Block Grant, including policies and services that promote family-centered, community-based, coordinated care for children with special health care needs and facilitate the development of community-based systems of services for such children and their families.

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fact that Title V is not an entitlement program and its funding is capped. As a result, there are limits to what services it can deliver and to whom. When not paying directly for services, however, Title V programs are expected to develop broad systems of care for CSHCN.

## Medicaid Definition

CSHCN who receive Medicaid benefits are enrolled into different “eligibility categories,” which do not correspond directly with the MCHB definition of CSHCN either. Currently there are four major pathways to Medicaid eligibility for children. They are based on (1) income criteria; (2) disability criteria (functional limitations); (3) eligibility for institutional levels of care; or (4) out-of-home placement.

### Income Criteria

Using the MCHB definition, any CSHCN in a very low-income family (below 100% of the federal poverty level) will be eligible for Medicaid based on income criteria, not because they are a child with special needs. Because the child is eligible due to low income, information about the child’s functional status may not be obtained during the enrollment process. A couple of states have incorporated a screening questionnaire for CSHCN<sup>5</sup> into their Medicaid and CHIP enrollment forms, and thus can identify CSHCN at the point of enrollment. However, this practice is not widespread.

### Disability Criteria

Disability is another important pathway to Medicaid eligibility, but the disability eligibility criteria are narrow as compared with the MCHB definition. For example, low-income children with significant disabilities who receive Supplemental Security Income (SSI) are eligible for Medicaid in most states. But the strict income limit for SSI means that many children who do meet the functional disability criteria are not eligible for Medicaid because their families are over-income, and the majority of CSHCN have disabilities or conditions that are not severe enough to meet the SSI definition.

### Eligibility for Institutional Levels of Care

Some CSHCN from higher income families may be eligible for Medicaid if their disability is such that they qualify for an institutional level of care. These children may be enrolled in home and community-based service waiver programs for individuals with specific diagnoses such as developmental disabilities, traumatic brain injury, or those who are medically fragile. They may also be enrolled in TEFRA<sup>6</sup> programs, formerly known as Katie Beckett

<sup>5</sup>The Child and Adolescent Health Measurement Initiative (CAHMI). (n.d.). *Children with Special Health Care Needs – Overview*. Retrieved Jan. 10, 2012 from <http://www.cahmi.org/pages/Sections.aspx?section=10>

<sup>6</sup>In 1982, Congress created a new Medicaid state plan option for children who require an institutional level of care under Section 134 of the Tax Equity and Fiscal Responsibility Act (TEFRA).

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waivers, for children who qualify for an institutional level of care. However, the type, availability, and size of TEFRA programs and home and community-based waiver programs vary widely from one state to another, making it difficult to generalize about Medicaid eligibility for this group of children.

## Out-of-home Placement

Finally, children who are placed in foster care or other out-of-home placements are also eligible for Medicaid. Many of these children have documented special health care needs, and it can be argued that all of them are at risk for special health care needs.

It may be useful to bear the differences in definition in mind as you proceed through the tutorial and work with the Medicaid program in your state. Both Title V and Medicaid provide vital services to CSHCN, but they may be thinking about different groups of children at different times.

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This document is part of *Public Insurance Programs and Children with Special Health Care Needs: A Tutorial on the Basics of Medicaid and the Children's Health Insurance Program (CHIP)*, available in its entirety at <http://hdwg.org/catalyst/medicaid-tutorial>

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