HOW DO DIFFERENT SYSTEMS THINK ABOUT CHILDREN WITH SPECIAL HEALTH CARE NEEDS?

Before we get into the details of how Medicaid and the Children’s Health Insurance Program (CHIP) work and their importance to children and youth with special health care needs (CYSHCN), let’s take a moment to consider what the term “CYSHCN” may mean to different people. We will begin with the federal Maternal and Child Health Bureau (MCHB) definition, and then compare this definition with 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 CYSHCN, but it’s worth reviewing in the context of the discussion to come. MCHB defines CYSHCN 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.”

This inclusive definition describes a lot of kids: approximately 19% of the U.S. child population, according to the National Survey of Children’s Health. It guides the work of many stakeholders in serving CYSHCN as a population and in improving the system of care for them. The Catalyst Center uses this definition in its work and in this tutorial. However, the MCHB definition is not necessarily the one 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.

For example, the MCHB definition is not necessarily used to determine eligibility for Title V programs or services. Most Title V programs that pay for health care services have more restrictive eligibility criteria, limiting services to children with specific conditions, at certain income levels, or in certain geographic areas. The federal Maternal and Child Health Bureau definition describes CYSHCN 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.”

We use this definition in the 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.


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.

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have disabilities or conditions that are not severe enough to meet the SSI definition. States have a few other options to offer eligibility to children with disabilities, such as having medical expenses that meet a state-specified medically needy income level. In general, however, individuals must meet the SSI definition of disability even if income criteria are different.

**Eligibility for Institutional Levels of Care**

Some CYSHCN from higher-income families may be eligible for Medicaid if their disability is such that they qualify for an institutional level of care. Children who qualify for Medicaid through this pathway may be enrolled in home- and community-based service waiver programs for individuals who have specific health concerns, such as developmental disabilities or traumatic brain injury, or who are medically fragile.

These children may instead be enrolled in Medicaid under the Tax Equity and Fiscal Responsibility Act (TEFRA) state plan option, (sometimes known as a Katie Beckett program) for children who qualify for an institutional level of care. However, the type, availability, and size of home and community-based waiver and TEFRA programs vary widely from one state to another, making it difficult to generalize about Medicaid eligibility for this group of children. For more about TEFRA, please refer to Section 11 of this tutorial.

**Out-of-home Placement**

Finally, children who are placed in foster care or other out-of-home placements are 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 having special health care needs.

For additional details about definitions of CYSHCN and how states operationalize these definitions, please see our resource *The Role of State Medicaid and Title V Program Definitions of Children and Youth with Special Health Care Needs in the Provision of Services and Supports*.

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WHO ARE CHILDREN WITH SPECIAL HEALTH CARE NEEDS?

This document is part of Medicaid and CHIP: A Tutorial on Coverage for Children and Youth with Special Health Care Needs (CYSHCN). The document is available in its entirety at https://ciswh.org/resources/Medicaid-CHIP-tutorial

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