

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 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."*¹

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.² 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.³ 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



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1. 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. <https://doi.org/10.1542/peds.102.1.137>

2. Child and Adolescent Health Measurement Initiative. 2020-2021 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved 1/31/22 from <https://www.childhealthdata.org/browse/survey/results?q=9314&r=1>

3. HRSA Maternal and Child Health Bureau. Title V Federal-State Partnership and state-specific block grants. <https://mchb.hrsa.gov/programs-impact/title-v-maternal-child-health-mch-block-grant>

levels, or both. To some extent, this is a holdover from the historical origins of Title V. It also stems from the fact that Title V is a block grant program, not an entitlement program, and its funding is capped. As a result, there are limits to what services can be delivered through Title V programs and to whom.

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

Medicaid Definition

CYSHCN who receive Medicaid benefits are enrolled through different “eligibility categories,” which do not correspond directly with the MCHB definition of CYSHCN. Currently there are four major pathways to Medicaid eligibility for children. These pathways 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

Any CYSHCN in a very low-income family (below 138% of the federal poverty level) will be eligible for Medicaid based on income criteria, not because they are a child with special needs. This is important because when a child qualifies for Medicaid by 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 to identify CYSHCN⁴ at the point of enrollment into Medicaid and CHIP programs to make sure they receive appropriate services and referrals. This practice, however, is not widespread.

Disability Criteria

Disability is another important pathway to Medicaid eligibility. The eligibility criteria for disability are narrow 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. The strict income limit for SSI means that many children who meet the functional disability criteria are not eligible for Medicaid because their families’ income exceeds the Medicaid eligibility limit. Additionally, most CYSHCN



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1. Income criteria.
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3. Eligibility for institutional levels of care.
4. Out-of-home placement.

4. Bethell, C. D., Blumberg, S. J., Stein, R. E., Strickland, B., Robertson, J., & Newacheck, P. W. (2015). Taking stock of the CSHCN screener: a review of common questions and current reflections. *Academic pediatrics*, 15(2), 165-176. <https://doi.org/10.1016/j.acap.2014.10.003>

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.⁵ 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)⁶ 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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5. Medicaid and CHIP Payment and Access Commission (MACPAC) (2017). People with disabilities. Retrieved from www.macpac.gov/subtopic/people-with-disabilities/

6. 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).

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>

The Catalyst Center (U1TMC31757) is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$500,000, with no financing by nongovernmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government.



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