MEETING THE NEEDS OF LOW-INCOME CHILDREN WITH SPECIAL HEALTHCARE NEEDS

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First Focus
Children with special healthcare needs (CSHCN) are defined by the U.S. Department of Health and Human Services (HHS) as children who “have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and also require health and related services of a type or amount beyond that required by children generally.”¹ These children have multiple conditions, including autism spectrum disorder, Down syndrome, complex medical needs, rare diseases, cerebral palsy, and many other medical, developmental, and emotional conditions. Children with special healthcare needs may also have conditions that can potentially be less life limiting, such as asthma or attention deficit disorder.

This paper provides a very brief overview of CSHCN, the challenges they and their families face, types of health insurance coverage they have in the United States, the importance of Medicaid and Children’s Health Insurance Program (CHIP) to such children, and finally, the need for a far more coordinated and streamlined system of care for the current array of programs and requirements, which are exceedingly difficult and confounding for families to navigate, and thus limit their access to necessary care for CSHCN.

CSHCN are especially vulnerable, and this vulnerability is amplified by poverty. They have comprehensive needs and typically receive services from multiple systems of care—health, mental health, education, and social services, to name just a few. Thus, their families must coordinate and navigate multiple providers and subspecialty providers of healthcare, as well as other systems, particularly as children get older.

As policy improvements are considered for CSHCN, the need for care coordination and care integration is primary and cannot be separated from an emphasis upon accountability and improvements in healthcare delivery and costs, particularly since passage of the Patient Protection and Affordable Care Act (ACA) in 2010. Nor can care coordination and integration be separated from corresponding alternative payment models (APMs), not traditionally found under fee-for-service insurance models, that may cover the cost of care coordination and management with families. These include Medicaid managed care models, which have been adopted by a majority of states and vary significantly across states. Multiple APMs are being utilized and evaluated across the country, and a full description is beyond the scope of this paper, but it is critical to note that poverty, as a factor in health, “has an adverse impact on a family’s ability to coordinate care across systems.”²
Moreover, when developing policy improvements for children with special healthcare needs, the line between low- and middle- (and sometimes higher-) income families is often not very distinct. Children in families that qualify for Medicaid or CHIP often have more robust benefits, and typically lower cost-sharing, than private plans provide. Many middle-income families who do not qualify for Medicaid/CHIP face bankruptcy, losing their homes, and other serious financial hardships due to private underinsurance (uncovered expenses for general healthcare, mental health, prescriptions, therapies, equipment, etc.) for their children, effectively reducing them to the income status of lower-income families. The stress of poverty, or poverty resulting from medical expenses, can be overwhelming for families caring for their children with special healthcare needs.

Creating a streamlined and coordinated system of care for children and their families is a goal currently being researched and piloted but requiring much more work and prioritization to effectively operationalize. The intersection of federal and state programs and services, and the variability between states, is enormous. This goal goes beyond current challenges of services, eligibility, and costs, and addresses multiple ways in which the overall system of care can be made more streamlined and user-friendly. Currently, eligibility for various state and federal services is disjointed at best.

As noted by Edward M. Schor, senior vice president for programs and partnerships at the Lucile Packard Foundation for Children’s Health, attention needs to focus on the current shortcomings of our healthcare system, particularly their impact on vulnerable populations such as children, especially children with complex medical needs. Addressing this need, the Lucile Packard Foundation sponsored a March 2018 supplement of the journal Pediatrics, titled Building Systems That Work for Children with Complex Health Care Needs. While children with complex medical needs are a subset of CSHCN, the recommendations and findings in these articles from policymakers, parents, researchers, and healthcare providers provide meaningful input into the critical and ongoing development of genuine systems of care to facilitate better, more accessible and coordinated, and higher-quality health and ancillary care for children with special healthcare needs.
Definitions and eligibility requirements abound around children with special needs. As only one example, children with disabilities are a subset within the scope of CSHCN, but specific disabilities provide eligibility for specific federal and state benefits, including the federal Supplemental Security Income (SSI) benefit. Although eligibility for SSI automatically qualifies a child for Medicaid in some states, that is not universally true. Some states have a separate eligibility process for Medicaid.

The definition of eligibility for SSI benefits is more limited than the HHS definition of CSHCN. To qualify for SSI, a child must have a medically diagnosed physical or mental disorder that

- results in marked or severe functional limitations; and
- can be expected to result in death, or
- has lasted and can be expected to last a continuous period of not less than 12 months.

Under this definition, children under 18 can qualify as early as birth; for example, certain children with low birth weight (under 2 lb., 10 oz.) may qualify.

Medicaid and CHIP, but Medicaid in particular, are critical to a large percentage (nearly half, see below) of CSHCN. All states, the District of Columbia, and five U.S. territories operate Medicaid, CHIP, or Medicaid-expanded CHIP programs. Each of these has its own application and eligibility levels (32 states and the District of Columbia have expanded Medicaid pursuant to the ACA) for these healthcare programs.

The CHIP Reauthorization Act of 2009 (CHIPRA) and the ACA’s increased funding for streamlining technology provided incentives for states to streamline enrollment for Medicaid and CHIP with other means-tested programs such as the Supplemental Nutrition Assistance Program (SNAP) and the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). This “Express Lane Eligibility” provision of CHIPRA was extended for 10 years when the Bipartisan Budget Act of 2018 was signed on February 8, 2018.
Another key funding source for children with special healthcare needs is Title V Maternal and Child Health Block Grants. While other programs serve children with special healthcare needs, this is the only one with specific responsibility for this group of children. As compared with Medicaid and CHIP, federal funding for Title V programs is relatively low, but it is matched by state and local funding and is a significant investment. Currently, however, more coordination with Medicaid and CHIP is needed.

**WHO ARE CHILDREN WITH SPECIAL HEALTHCARE NEEDS?**

The most recent data show that approximately 14.2 million children, or nearly 20 percent of all children in the United States, have disabilities or special healthcare needs. Nearly half (48 percent) of these 14.2 million children qualify for Medicaid or CHIP. Figure 1 depicts the health insurance status of U.S. children with special healthcare needs.8
Of this 48 percent of children with special healthcare needs who qualify for Medicaid or CHIP, the majority, approximately 80 percent, qualify on the basis of their family’s income, while the remainder become eligible on the basis of their disability.\textsuperscript{9}

Given the high expenditures incurred by families of children with special needs, most states opt to provide Medicaid coverage based on a child’s disability, disregarding parental income.

One state plan option is the Katie Beckett waiver, also known as TEFRA because it was passed in the Tax Equity and Financial Responsibility Act of 1982. This state option allows states to disregard parental income for children with disabilities under the age of 19 who meet certain functional eligibility requirements as set by states, allowing children to access Medicaid and remain at home with their families.\textsuperscript{10} Because it is part of the state’s Medicaid plan, there are no waiting lists for this option.

Some states have variations on the Katie Beckett waiver or utilize home- and community-based services Medicaid waivers so that children with disabilities can remain at home. States may also provide assistance to families who adopt children with special healthcare needs. These programs provide options but are subject to caps on the number of people funded, as well as waiting lists and other limitations.

The Family Opportunity Act (FOA), passed in 2006, provides another option, allowing states to offer families the option to “buy in” to Medicaid, subject to certain minimal premium requirements. As of 2015, five states utilize the FOA option.\textsuperscript{11}

\section*{WHY IS MEDICAID SO CRITICAL FOR CHILDREN WITH SPECIAL HEALTHCARE NEEDS?}

While low-income children with special healthcare needs are especially at risk, those who qualify for Medicaid have access to what is considered the best pediatric standard of care in the United States: EPSDT, or early and periodic screening, diagnosis, and treatment. The EPSDT benefit is currently guaranteed to children who qualify for Medicaid (although some states are seeking waivers to exclude 19- and 20-year olds from EPSDT) and covers comprehensive and preventive healthcare services, including appropriate preventive, dental, mental health, developmental, and specialty services. Medicaid defines EPSDT in the following way:
• **Early**: Assessing and identifying problems early
• **Periodic**: Checking children’s health at periodic, age-appropriate intervals
• **Screening**: Providing physical, mental, developmental, dental, hearing, vision, and other screening tests to detect potential problems
• **Diagnostic**: Performing diagnostic tests to follow up when a risk is identified
• **Treatment**: Controlling, correcting, or reducing health problems found

Provided that families are aware of their eligibility for state Medicaid programs and can access Medicaid providers, EPSDT coverage is of the highest quality for children with special healthcare needs.

In light of the complexities and variations described above regarding eligibility, requirements, definitions, and so on in the array of federal and state programs available to children with special healthcare needs, as well as funding and provider payment challenges in Medicaid, the ability to access and navigate care is absolutely critical to children receiving that care.

In 2014, the Association of Maternal and Child Health Programs released a white paper, *Developing Structure and Process Standards for Systems of Care Serving Children and Youth with Special Health Care Needs*. The paper included a literature review, key stakeholder interviews, state case studies, and a proposed set of system standards developed and reviewed by a national working group comprising experts from around the country in healthcare for children with special healthcare needs.

The National Conference of State Legislatures has also focused on the need for improving systems of care for children with special healthcare needs. In a 2017 report, the conference provided recommendations, noting the difficulties faced by families, including these:

• More than 21 percent of families of children with special healthcare needs reported financial problems due to their child’s health conditions.
• Approximately 35 percent of minority children with special healthcare needs were reported to have one or more periods without insurance during the previous year.
• Twenty-five percent of children with special healthcare needs lived in families in which a family member cut back on or stopped working altogether to care for a
child with health needs.\textsuperscript{14}

In view of the challenges facing Medicaid and the overwhelming need for integrated and coordinated systems of care for children with special healthcare needs and their families, the following are recommendations for action and improvements.

**PROTECTIVE PROPOSALS**

First and foremost, any cuts to the Medicaid program, including block grants or the imposition of per capita caps, will fall disproportionately on children with special healthcare needs. Multiple legislative attempts to block grant and restructure Medicaid, which would have resulted in the effective dismantling of Medicaid services for these vulnerable children, were defeated in 2017. The president’s 2019 budget resurrects these legislative proposals, and they are being discussed in Congress. Advocates and families must continue to strongly oppose all such efforts.

Attacks on the Medicaid program have proceeded at the administrative level, with states seeking Medicaid waivers that will result in decreased access to care for vulnerable Medicaid beneficiaries. Medicaid waivers, particularly those sought under Section 1115 demonstration project waivers, are intended to encourage innovations in access and payments, not denials of care and a distortion of the principles upon which Medicaid is founded. Advocates and families must continue to oppose all such efforts.

**PROACTIVE PROPOSALS**

Simplify Medicaid/CHIP enrollment and eligibility policies:

- As noted above, many states have utilized Express Lane Eligibility options to streamline and simplify enrollment in Medicaid and CHIP vis-à-vis qualification for other means-tested programs such as SNAP and WIC. States should be incentivized to expand and strengthen these efforts, increasing access to care and saving costs that are incurred when regular and preventive healthcare is not available.
- At least 20 states utilize “presumptive eligibility” for Medicaid and CHIP children, authorizing certain qualified providers to “presume” eligibility and allow care to proceed without waiting for the full application process. All states should utilize
presumptive eligibility.

- Thirty-five states provide “continuous eligibility,” meaning Medicaid and CHIP families have 12 months of continuous eligibility, regardless of family income changes, allowing care to proceed with no interruptions. All states should utilize continuous eligibility.
- Children with special healthcare needs who have been diagnosed with lifelong conditions—for example, cerebral palsy, certain rare diseases, complex medical conditions, developmental disorders—should have “permanent eligibility” in accordance with age requirements for Medicaid and CHIP. They should not be subject to yearly renewals of eligibility when their conditions are not changing. This approach will maintain continuity of care and save states unnecessary bureaucratic costs.

**Improve Medicaid EPSDT**

- Incentivize partnerships and collaboration between Title V Maternal and Child Health grantees and state Medicaid agencies.
- Provide information and education about the availability of EPSDT services in Medicaid through other early childhood programs such as the Maternal, Infant, and Early Childhood Home Visiting Program and WIC.

**Encourage innovation in Medicaid provider payments:**

- Include bonuses for EPSDT visits for CSHCN.
- Increase incentives and reimbursements for care integration and care coordination for CSHCN.
- Increase reimbursement rates for well-child visits for children with special healthcare needs as an acknowledgment of the time and complexities involved.

**Continue significant work at the federal and state levels for developing and improving systems of care, emphasizing care coordination for CSHCN, including parents and community-based organizations, such as the approach currently supported by the Lucile Packard Foundation for Children’s Health:**

- Create a national vehicle for dissemination of promising practices and technical assistance for states that have developed or would like to develop more coordinated systems of care for CSHCN.
• Utilize a national working group of experts and families to identify effective care coordination, medical and/or health homes, and other developing improvements and innovations for CSHCN across public health and other public assistance programs.
ENDNOTES


6. Ibid.


9. Ibid.


