Protecting Rights of Children With Medical Complexity in an Era of Spending Reduction

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abstract

Children with medical complexity (CMC) often require multiple services across the continuum of care, such as therapies and home nursing. However, sufficient access to needed services is not assured and varies considerably by payer, many of whom who face pressures to control health spending. In this article, we review the rights of CMC in Medicaid, the Children’s Health Insurance Program, and various forms of private health insurance to receive services that are necessary to promote optimal health, development, and family functioning. Controlling laws such as the Americans with Disabilities Act and the Early and Periodic Screening, Diagnostic, and Treatment provisions of the Medicaid Act are discussed, and precedential court decisions affecting CMC are reviewed. Implications for policy, advocacy, and payment model design are explored in the context of current emphasis on spending reduction.
Children with medical complexity (CMC) require multiple services across the continuum of care. In addition to physician and hospital services, these children often need services such as physical therapy to help develop, maintain, or enhance skills and functioning. CMC may also require coverage for medical equipment, supplies, and long-term supports such as private duty nursing care and personal care services.

Unfortunately, CMC frequently are unable to access these services. Data from the National Survey of Children with Special Health Care Needs suggest that approximately half of families of more complex children with special health care needs experience unmet medical needs, financial problems, and reduced employment related to their children’s conditions. CMC experience higher levels of unmet needs than other children with special health care needs at all income levels.

Several trends in health care financing pose challenges for CMC to access needed services. New risk-based payment models, which create incentives for short-term spending reductions through capitation or shared savings arrangements, may create financial disincentives for physicians to advocate for longer-term therapies and treatments that are critical in maximizing developmental potential in CMC but may not result in immediate reductions in acute care use. In addition, as pressure to reduce spending has increased, payers are increasingly using assessment tools with unclear validity to supersede personal physician judgment in determination of medical necessity of services such as home nursing care. This environment puts access to services at risk for CMC, with the potential for harm. As such, it is critical for providers, health systems, payers, and policy makers to understand the legal rights of CMC to receive needed services.

Our purpose with this article is to review controlling laws and precedential court decisions that address coverage of services for CMC. The enhanced understanding of legal rights and responsibilities can help with the protection and development of reliable coverage and payment policies to ensure the services needed by this vulnerable population.

OVERVIEW OF RIGHTS OF CMC TO SERVICES

The United States has a complex multipayer system, and the rights of CMC to health care services vary according to payer. Table 1 summarizes the protections of various populations of children. Most children in Medicaid and some in the Children’s Health Insurance Program (CHIP) are entitled to a full range of medically necessary services through the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) provisions of the Medicaid Act. Some states have implemented stand-alone CHIPs that may provide the level of coverage available through EPSDT; however, this is optional for states. Notably, some of the government financing options that are currently being considered, including per capita caps and block grants, threaten to replace the comprehensive coverage available through Medicaid and CHIP with restrictions on eligibility, scope of benefits, and provider payments. Medicaid-enrolled children also obtain services through delivery systems that depend on the states where they live. States must obtain waivers from the federal government to extend mandatory managed care enrollment to children enrolled in Supplemental Security Income, home care programs and waivers, Title V programs for Children with Special Health Care Needs, or foster and other out-of-home placements.

CMC with private insurance have fewer coverage requirements. Children in individual, small-group, and marketplace health insurance plans enjoy protections of the essential health benefit (EHB) standard. These children, along with children in large-group private insurance plans, may be subject to state coverage requirements for services, such as mandates for therapies for children with autism. However, children enrolled in self-insured, employer-sponsored insurance plans are exempt from most state requirements.

All children receive protections that are not dependent on income or insurance status. CMC with qualifying disabilities enjoy the protections of the Americans with Disabilities Act (ADA), Rehabilitation Act, and Individuals with Disabilities Education Act (IDEA), which can impact the right to certain services in the home and school environments for some CMC, even if not covered by health insurance.

RIGHTS OF CMC IN MEDICAID AND CHIP: THE ROLE OF EPSDT

Two federal-state partnership programs, Medicaid and CHIP, are particularly important. Nearly 40% of children in the United States qualify for Medicaid and CHIP, and it is estimated that two-thirds of the 3 million children in the United States who have medically complex conditions are covered by Medicaid.

The Medicaid Act requires states to cover EPSDT services for most Medicaid-eligible children and youth under age 21. EPSDT begins with outreach and informing, and states must aggressively inform families about the existence of EPSDT services and how to obtain them. States must also offer appointment scheduling and transportation assistance to help children get to screening and treatment. Although EPSDT is sometimes perceived to be simply a

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screening program, states are obliged to cover a broad range of diagnostic and treatment services when medically necessary. Importantly, EPSDT establishes a broad scope of benefits for covered children, including all Medicaid optional services, regardless of whether they are covered for adults. Table 2 presents a list of those services.

Federal law also requires services within the scope of benefits to be covered by state Medicaid programs when they are necessary to “correct or ameliorate” a child’s condition. Thus, to be covered, the service need not cure a condition; rather, coverage is mandated when needed to maintain or improve the child’s condition or prevent it from worsening. Moreover, restrictions that states place on services for adults do not apply to children if the service is needed to correct or ameliorate the child’s problem. For example, private duty nursing services must be covered if needed to ameliorate a child’s condition even if those services are not covered for adults. Multiple physical therapy visits must be covered if needed by the child even if the state places a quantitative limit (e.g., 12 visits per month) on adult coverage. The federal Medicaid agency has provided additional examples of...
Pathways to EPSDT Coverage

Given the robust level of service required to address the needs of children with complex medical conditions, states are required to ensure that EPSDT services are provided in a timely manner. This includes providing services on an inpatient and outpatient basis, as well as ensuring access to home health services. The EPSDT statute requires states to ensure that eligible children receive all necessary and appropriate services, including medical, social, educational, and psychological services.

Finally, although most of these cases have not resulted in court action, it is important to note that the courts have played an important role in securing EPSDT benefits. For example, O.B. v Norwood, a class-action case in the Seventh Circuit Court of Appeals recently affirmed this obligation in a fair hearing, "an administrative procedure through which parents or other individuals may seek to appeal denials of Medicaid benefits. The courts have also played an important role in ensuring that children with complex medical conditions receive the necessary services to manage their conditions.

Children whose families are eligible for Medicaid if their medical expenses exceed a certain state-set limit. Such children are not medically needy, as defined, and are not enrolled in Medicaid as a result. The various changes and as such were implemented over a period of months.

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of roughly $78,000 monthly. The Court of Appeals found the situation unacceptable: “[T]he plaintiffs… are asking for the nurses, and there is no indication that [the state agency] will (unless compelled by the courts) lift a finger to find nurses to provide home nursing” for the children.9 The court concluded that the state agency was likely violating the Medicaid Act’s EPSDT and reasonable promptness provisions and affirmed a preliminary injunction that requires the state to take “immediate and affirmative steps to arrange directly or through referral to appropriate agencies, organization, or individuals,” for the in-home shift nursing services that the Medicaid-eligible children need.

A California case, Katie A. ex rel. Ludin v. L.A. County,10 produced a settlement whereby the state agreed to cover in-home support services needed by children in the foster care system, including intensive behavioral services and therapeutic foster care. Before the settlement, the Ninth Circuit Court of Appeals had noted that “[r]epiring the State actually to provide EPSDT services that have been found to be medically necessary is consistent with the language of the Medicaid Act that requires that each state arrange for corrective treatment…” Similarly, in Rosie D. v. Romney,11 a federal court ordered the Massachusetts Medicaid program to cover home and community-based support services needed by children with serious emotional disturbances, including crisis intervention, in-home behavioral supports and therapy services, mentoring, and parent and/or caregiver support.

Other EPSDT cases have focused on ensuring coverage of particular treatment services that reflect prevailing evidence-based standards of care. For instance, 2 federal circuit courts of appeals, the 11th and the Sixth, have confirmed that state Medicaid programs must cover Applied Behavioral Analysis therapy services for young children with autism spectrum disorders.12,13 But whereas these cases are focused on the evidence base establishing the effectiveness of Applied Behavioral Analysis, a state- or health plan-imposed requirement that premises treatment of an individual child on the need for an evidence basis can raise conflicts with the federal EPSDT coverage requirements. Many treatments and clinical therapies, although effective for an individual child, will not have an evidence base. Congress has enacted provisions to protect Medicaid- and CHIP-eligible children from the improper use of evidence-based quality measures to limit services to an individual child.3

As Medicaid beneficiaries are increasingly moved from fee-for-service to managed care, accountable care organizations, and other risk-based payment structures, it is important to note that Medicaid beneficiaries entitled to EPSDT retain the rights to receive all medically necessary services. Courts have been called on to confirm that EPSDT’s broad coverage and treatment requirements continue in full force and effect. Whether management is delegated to a third party, the state Medicaid agency remains responsible for ensuring that EPSDT is provided as the law intends. As the Fourth Circuit Court of Appeals has concluded, “One head chef in the Medicaid kitchen is enough,” and that is the state Medicaid agency, not the managed care organization.14

**Rights of Children with Private Insurance**

Private insurance may also be available to children, and approximately half of the children in the United States receive coverage through employer-sponsored insurance plans of their parents and/or caretakers.15 The rights of children with private insurance vary depending on whether the insurance policy is employer-sponsored, employer-sponsored and self-funded, or purchased on the marketplaces.

Certain services, such as services for children with autism spectrum disorders or hearing aids, may be covered under state-mandated benefit laws that require coverage from insurers operating in the state, but these vary considerably by state.16 Even so, self-funded employer-sponsored health plans, typically offered by most larger companies, are exempt from these state coverage mandates.

Some children with private health insurance receive further protections under the Affordable Care Act’s EHB requirements. Under EHB requirements, most health plans in the individual and small group markets and state marketplace plans must cover certain benefits, such as pediatric oral and vision care and rehabilitative (including habilitative) services and devices;17,18 States, however, are allowed to determine their own benchmark coverage for “rehabilitative/habilitation services and devices,” leaving open the question of what exactly is and is not covered from state to state. Children in these plans do have a right not to be discriminated against on the basis of disability; however, case law in this area is limited at this time.

The Affordable Care Act also introduced new rights for all individuals with private insurance who have been denied a service or item. Families are now able to appeal not only to the insurance company directly but may also request an external review, typically performed by a physician with no relationship to the insurer. External reviews shift the decision of medical necessity back to physicians who are more likely to understand standard practices of care. These appeals can be vitally important, particularly for expensive
medical equipment and services like nursing care. One area of occasional litigation has been the improper denial of private duty nursing services as custodial care.24

Under any of these private insurance options, the scope of long-term services and supports that is available to CMC is typically limited, and premium and cost-sharing obligations are more demanding than in Medicaid and CHIP. As a result of these various features, many CMC who have access to private insurance are underinsured. Many lack access to private duty nursing, coverage for durable medical equipment and/or supplies, medical foods, and developmentally optimal quantities of therapy services. Some may qualify for secondary Medicaid coverage to fill gaps in private insurance coverage, but others simply are unable to have their needs met.

**PROTECTION AGAINST DISCRIMINATION BASED ON HEALTH NEEDS AND DISABILITY**

CMC, regardless of income or insurance status, may be able to access services through statutes that make discrimination against individuals with disabilities illegal, particularly the ADA and the Rehabilitation Act. Children with disabilities are also entitled to a free and appropriate education through the IDEA.

Title II of the ADA prohibits public entities from discriminating against individuals with disabilities.20 Similarly, section 504 of the Rehabilitation Act prohibits recipients of federal funds from discriminating on the basis of disability.21 Federal regulations clarify that Title II of the ADA and the Rehabilitation Act require public entities to administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.22,23

In 1999, the US Supreme Court addressed and interpreted the integration mandate in the landmark *Olmstead*24 decision, affirming that integration into community life is a central aspect of the legislation prohibiting discrimination against persons with disabilities. This provision means that children have a right to live at home instead of in institutions if the child can handle and benefit from a community setting, wants to be in the community setting, and if community-based services can be reasonably accommodated to account for the resources of the state and the needs of others with comparable disabilities.

Parents and caretakers have relied on the antidiscrimination statutes and the integration mandate to obtain care and services for CMC and young adults, in some cases filing complaints that team EPSDT claims with causes of action to enforce provisions of the ADA and/or Rehabilitation Act. For example, *A.H.R. v Washington State Health Care Authority*25 involved infants and toddlers who needed private duty nursing because of their medically complex conditions. Although the state Medicaid agency had determined that each of the children needed 16 hours per day of nursing, neither the families nor the state or its contracting managed care entities had located sufficient staffing to fill nursing shifts. As a result, some children were being forced into institutional settings and others were at serious risk of group home or nursing facility placement. On these facts, the court found that the children were likely to succeed on their EPSDT and ADA claims and ordered the Medicaid agency employees to “take all actions within their power necessary for Plaintiffs to receive 16 hours per day of private duty nursing, as previously authorized by Defendants.” Courts have also assessed the EPSDT-ADA interplay when children with disabilities age out of EPSDT coverage and the Medicaid program does not cover the same scope of home and community-based services for adults, thus placing the individual at serious risk of institutionalization to obtain the needed services. In *Radaszewski v Maram*,26 the court cited the ADA in requiring the state to continue to provide the in-home services that a young adult needed when he turned 21 years old.

Finally, the IDEA requires that every child with a disability have available a free appropriate public education that includes special education and related services.27 This law allows all CMC with qualifying disabilities to access services such as physical therapy, occupational therapy, personal care, behavioral health services, and services for children with speech, hearing, and language disorders.2

**IMPLICATIONS**

The American Academy of Pediatrics recommends that children from birth to age 26 receive a broad range of health benefits, including rehabilitative and/or habilitative services and long-term services and supports typically required by CMC.28 Unfortunately, CMC face barriers to procurement of such services. In some cases, state Medicaid programs may place inappropriate restrictions on access to federally mandated services. In other cases, such as with privately insured children, insurance protections may be inadequate to ensure that CMC receive the services they need, and families must rely on laws such as the ADA to ensure that home- and community-based services are available without excessive waiting.

The role of the medical provider in advocating for needed services...
for families is essential. Locally available care coordination, family navigation, and training programs may help providers and families when services are not obtained. Providers can help families secure services by attesting to the medical necessity of services with state Medicaid programs, lending support to appeals of service denials, and referring families to legal aid organizations, disability rights organizations, or medical-legal partnerships for legal assistance. Medical-legal partnerships in particular can allow clinical providers to collaborate with local legal professionals to secure services for CMC. National organizations like the National Health Law Program can provide technical and litigation assistance to providers and advocates in different locations (www.healthlaw.org).

Payers and health systems may use knowledge of the rights of CMC to negotiate risk-based payment structures that do not create incentives for limiting the range of long-term services that CMC need, and thus are consistent with the central principle in child health of maximizing developmental outcome.

Given the challenges CMC face in accessing services, advocacy may take several forms. First, policy to ensure that children with private insurance receive the recommended scope of benefits should be considered. Second, it is essential to maintain and grow pathways to EPSDT coverage for middle-income CMC, as data suggest that income above poverty does not eliminate unmet need in this population. For those who do receive EPSDT, its mandates for the amount, scope, and duration of benefits should be enforced regardless of state of residence or managed care participation.

**ABBREVIATIONS**

ADA: Americans with Disabilities Act  
CHIP: Children’s Health Insurance Program  
CMC: children with medical complexity  
EHB: essential health benefit  
EPSDT: Early and Periodic Screening, Diagnostic, and Treatment  
IDEA: Individuals with Disabilities Education Act

**REFERENCES**

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17. Affordable Care Act, 42 USC §18022 (2017)  
23. Rehabilitation Act, 28 CFR §41.51 (2017)
27. Individuals with Disabilities Education Act, 20 USC §1412 (2017)