

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

Jane Perkins, JD, MPH,^{a,b} Rishi Agrawal, MD, MPH^{c,d}

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.

^aNational Health Law Program, and ^bNetwork for Public Health Law, Carrboro, North Carolina; ^cAnn & Robert H. Lurie Children's Hospital of Chicago, Chicago, Illinois; and ^dLa Rabida Children's Hospital, Chicago, Illinois

Esq Perkins and Dr Agrawal conceptualized and designed the review and drafted the initial manuscript; and all authors approved the final manuscript as written.

DOI: <https://doi.org/10.1542/peds.2017-12841>

Accepted for publication Nov 3, 2017

Address correspondence to Jane Perkins, JD, MPH, National Health Law Program, 200 N Greensboro St, Suite D-13, Carrboro, NC 27510. E-mail: perkins@healthlaw.org

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

Copyright © 2018 by the American Academy of Pediatrics

FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: No external funding.

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

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.¹ 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.² 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.³

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,⁴ 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.⁵

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.^{3,6,7} Although EPSDT is sometimes perceived to be simply a

TABLE 1 Protections for CMC Populations

Population	Applicable Protections	Description
Medicaid	<ul style="list-style-type: none"> • EPSDT mandates 	<ul style="list-style-type: none"> • States must provide “such other necessary health care, diagnostic services, treatment, and other measures...to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services, whether such services are covered under the State plan.”
Income-based Medicaid Disability-based Medicaid	<ul style="list-style-type: none"> • State mandates • Enrollment in mandatory managed care for some children with special needs only through a federal waiver 	
CHIP-funded Medicaid expansions in applicable states Medicaid waivers and state option programs (home- and community-based services waivers, Katie Beckett option) Stand-alone CHIP	<ul style="list-style-type: none"> • Guarantees services Eq to a state “Benchmark” plan, typically more like private insurance • Vision and/or dental care 	<ul style="list-style-type: none"> • CHIP plans vary by state • Benchmark coverage similar to commercial health plans, along with vision and/or dental care <ul style="list-style-type: none"> • Optional services: EPSDT, habilitative care • Plans are not bound by state mandates
Private insurance: employer-based but self-insured	<ul style="list-style-type: none"> • State mandates • Limited 	<ul style="list-style-type: none"> • State mandates may include coverage for autism services, hearing services, and enteral formula <ul style="list-style-type: none"> • Mandates vary considerably by state
Private insurance: employer-based but not self-insured	<ul style="list-style-type: none"> • State mandates 	<ul style="list-style-type: none"> • State mandates may include coverage for autism services, hearing services, and enteral formula <ul style="list-style-type: none"> • Mandates vary considerably by state
Private insurance	<ul style="list-style-type: none"> • EHBs 	<ul style="list-style-type: none"> • Coverage for 10 categories of EHBs, including rehabilitative and/or habilitative care, dental, and vision coverage <ul style="list-style-type: none"> • Coverage based on state benchmark health plans • EHBs cannot discriminate on the basis of diagnosis or disability
Marketplace Small group Individual plans	<ul style="list-style-type: none"> • State mandates 	<ul style="list-style-type: none"> • Public places be accessible
Children of all incomes and insurance plans	<ul style="list-style-type: none"> • ADA • Rehabilitation Act • IDEA 	<ul style="list-style-type: none"> • Children with disabilities cannot be discriminated against • Children should receive services and accommodations in community settings, not institutional settings • Children with disabilities are entitled to a free and appropriate education

TABLE 2 The EPSDT Scope of Benefits

Physician services	Prescription drugs
In-patient hospital	Home health
Outpatient hospital	Physical, speech, and other therapies
Laboratory and/or radiograph	Other licensed practitioners
Clinic services	Private duty nursing
Family planning services	Prosthetic devices
Nurse practitioner services	Eyeglasses
Nurse-midwife services	Hearing aids
Transportation	Respiratory care services
Case management	Rehabilitative services
Personal care services	Preventive services

Adapted from Social Security Act, 42 USC §1396 (2017).

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.³ 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 (eg, 12 visits per month) on adult coverage. The federal Medicaid agency has provided additional examples of

services that can be covered when needed to correct or ameliorate the child's condition, including mobile crisis and intensive outpatient services for children with behavioral health conditions, medication management, decubitus cushions, and augmentative communication devices.⁸

Notably, the Medicaid EPSDT statute requires states "to arrang[e] for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment" that a child needs.³ This means that states may need to take affirmative steps to ensure that providers are available, such as recruiting new providers, entering single service agreements with willing providers, and contracting with out-of-state providers.⁸

Finally, although much of the focus is on its clinical components, EPSDT also faces outward into the community. It includes early intervention services aimed at young children and case management services aimed at assisting children and youth with gaining access to medical, social, educational, and other services. To ensure an effective child health program, EPSDT programs should also make use of other public health, mental health, education, and related programs, such as Head Start, social and vocational rehabilitation programs, and food and nutrition programs (eg, the Special Supplemental Nutrition Program for Women, Infants, and Children program).

Pathways to EPSDT Coverage

Given the robust level of service available through EPSDT, it is important to understand which populations within Medicaid and CHIP are eligible for its protections. Children who qualify for Medicaid on the basis of income or disability must receive EPSDT benefits.

Children whose family incomes, although limited, exceed the Medicaid eligibility levels may be enrolled in their state's CHIP. CHIP is a block grant program for states and, unlike Medicaid, is not a legal entitlement for children who meet income and other eligibility thresholds. In some states, CHIP has been implemented as a Medicaid expansion (raising the Medicaid eligibility threshold to higher levels of family income), and in these programs children are entitled to EPSDT protections. Other states have separate "stand-alone" CHIP programs that have greater service coverage requirements than private insurance, especially with regard to dental and vision services, but are not required to cover the full range of EPSDT services, such as therapies or home nursing care.

CMC of higher income levels may also be able to access Medicaid and EPSDT through a variety of options that vary by state. Optional specialized waiver programs, including home- and community-based services waivers and federal and/or state experimental demonstration waivers are used in many states. States also have the option to extend Medicaid through the Katie Beckett option and the Community First Choice option. These programs all allow children to receive services such as home care to facilitate living at home rather than in an institution. Programs vary in the populations served, services provided, and the ages of participants served. For example, whereas some states provide home- and community-based services waivers for children with a wide range of disabilities, including developmental disabilities, physical disabilities, medical technology, or mental health, others may only provide services for more narrowly selected populations. Moreover, states can place caps on the number of individuals who will be served through these waivers, which has resulted in long waiting lists in some states.

Finally, approximately two-thirds of the states allow families with higher incomes to enroll children in Medicaid if their medical expenses exceed a certain state-set limit. Such "medically needy" programs are not required to provide EPSDT benefits; however, the vast majority do.

EPSDT in the Courts

Medicaid beneficiaries have a right to appeal coverage denials through a "fair hearing," an administrative appeal to the state Medicaid agency. Despite this process, the courts have also played an important role in securing EPSDT benefits for Medicaid-enrolled children and youth, including those with medically complex conditions. Some of these cases have produced system-wide changes and, as such, were implemented over a period of months and years.

For example, some courts are focusing on EPSDT's requirement that states "arrange for" the services needed to correct or ameliorate a child's conditions.³ The Seventh Circuit Court of Appeals recently affirmed this obligation in *O.B. v Norwood*,⁹ a class-action case in which parents charged the Illinois Medicaid agency with violating the Medicaid Act by failing to arrange for private duty nursing as required by the EPSDT laws and also cited a Medicaid provision that requires medical assistance to be "furnished with reasonable promptness."³ Three-year-old O.B., who requires the assistance of a ventilator, illustrates the problems that the families face. Once stabilized and ready for clinical discharge from the hospital, his providers prescribed in-home skilled nursing, and the Medicaid agency approved O.B. for up to 18 hours a day (\$19 718 monthly) of in-home skilled nursing. However, the parents were left on their own to find nurses, and it took them almost a year. During this time, O.B. was living at the hospital, at a cost to Medicaid

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]equiring 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/habilitative 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.¹⁹

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 taking into account 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.⁷

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.^{29,30} 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

1. Kuo DZ, Cohen E, Agrawal R, Berry JG, Casey PH. A national profile of caregiver challenges among more medically complex children with special health care needs. *Arch Pediatr Adolesc Med.* 2011;165(11):1020–1026
2. Perkins J. Ensuring that assessment tools are available to enrollees. 2015. Available at: www.healthlaw.org/about/staff/jane-perkins/all-publications/assessment-tools-enrollees#V96rYiANBc. Accessed October 13, 2016
3. Social Security Act, 42 USC §1320–1396 (2017)
4. Kaiser Family Foundation. Health insurance coverage of children 0-18 (2015 data). Available at: <http://kff.org/other/state-indicator/children-0-18/?currentTimeframe=0&sortModel=%7B%22colld%22:%22Location%22,%22sort%22:%22asc%22%7D>. Accessed October 13, 2016
5. Vestal C; The Pew Charitable Trusts. Improving Medicaid for medically complex kids. 2015. Available at: www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2015/1/08/improving-medicare-for-medically-complex-kids. Accessed October 13, 2016
6. Americans with Disabilities Act, 42 CFR §441.56 (2017)
7. Centers for Medicare & Medicaid Services. *State Medicaid Manual [Part 5]*. Baltimore, MD: Centers for Medicare & Medicaid Services; 1995

8. Centers for Medicare & Medicaid Services. EPSDT - a guide for states: coverage in the Medicaid benefit for children and adolescents. 2014. Available at: https://www.medicaid.gov/medicaid/benefits/downloads/epsdt_coverage_guide.pdf. Accessed November 16, 2016
9. *O.B. v Norwood*, 170 F3d 1186 (7th Cir 2016)
10. *Katie A. ex rel. Ludin v. L.A. Co.*, 481 F3d 1150, 1162 (9th Cir 2007)
11. *Rosie D. v Romney*, 410 F Supp 2d 18 (D Mass 2006)
12. *K.G. ex rel. Garrido v Dudek*, 731 F3d 1152 (11th Cir 2013)
13. *Parents' League for Effective Autism Servs. v Jones-Kelley*, 339 F Appx 542 (6th Cir 2009)
14. *K.C. ex rel. Africa H. v Shipman*, 716 F3d 107, 119 (4th Cir 2013)
15. Kaiser Family Foundation. Employer-sponsored coverage rates for the nonelderly by age (2015 data). Available at: <http://kff.org/other/state-indicator/rate-by-age-2/?currentTimeframe=0&sortModel=%7B%22colld%22:%22Location%22,%22sort%22:%22asc%22%7D>. Accessed October 13, 2016
16. American Speech-Language-Hearing Association. State insurance mandates for autism spectrum disorder. Available at: www.asha.org/Advocacy/state/States-Specific-Autism-Mandates/. Accessed October 13, 2016
17. Affordable Care Act, 42 USC §18022 (2017)
18. Health insurance issuer standards under the Affordable Care Act, including standards related to exchanges. *Fed Regist.* 2014;79(101):30239–30353. To be codified at 45 CFR §156
19. Venteicher W. Father sues Blue Cross for denying nursing care. 2014. Available at: www.chicagotribune.com/lifestyles/health/ct-blue-cross-lawsuit-met-20140902-story.html. Accessed November 24, 2016
20. American with Disabilities Act, 42 USC §12132 (2017)
21. Rehabilitation Act, 29 USC §794 (2017)
22. American with Disabilities Act, Title II, 28 CFR §35.130 (2017)

23. Rehabilitation Act, 28 CFR §41.51 (2017)
24. *Olmstead v L.C.*, 527 US 581 (1999)
25. *A.H.R. v Washington State Health Care Authority*, No. C15-570, 2016 WL 98513 (WD Wash 2016)
26. *Radaszewski v Maram*, No. 01 C 9551, 2008 WL 2097382 at *15 (N.D. Ill. Mar. 26, 2008)
27. Individuals with Disabilities Education Act, 20 USC §1412 (2017)
28. Committee on Child Health Financing. Scope of health care benefits for children from birth through age 26. *Pediatrics*. 2012;129(1):185–189
29. National Center for Medical Legal Partnerships. Partnerships across the US. Available at: <http://medical-legalpartnership.org/partnerships/>. Accessed December 13, 2016
30. National Disability Rights Network. Protection and advocacy (P&A) system and client assistance program (CAP). Available at: www.ndrn.org/about/paacap-network.html. Accessed December 13, 2016