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Editors

Handbook of Autism Spectrum Disorder and the Law

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Chapter 19

Laws Affecting the Health, Security, Autonomy, and Well-Being of People with ASD

Alison Morantz and Lorri Unumb

Introduction

Individuals with Autism Spectrum Disorder (ASD) confront numerous challenges in the educational and employment arenas, which several preeminent federal laws in the United States (such as the Individuals with Disabilities Education Act and the Americans with Disabilities Act of 1990) are designed to address. Yet the welfare of people with ASD and their families is also influenced by myriad other civil laws, regulations, and entitlement programs across the life cycle. Some of these, such as Supplemental Security Income (SSI) and Medicaid, affect people with a wide range of disabilities. Others, such as state insurance mandates that require private insurers to provide in-home Applied Behavior Analysis (ABA) therapy to children diagnosed with autism, are ASD-specific. For some individuals, especially those who require significant support after attaining the age of legal majority, navigating these laws and programs successfully can make the difference between living in highly restrictive settings and leading full and meaningful lives in the community.

This chapter provides a brief overview of these heterogeneous laws and entitlement programs in the United States, highlighting the ways in which they can improve the health, security, autonomy, and well-being of individuals with ASD and their families. We survey six domains: Health Care; Public Benefits, Services and Supports; Custody and Child Support; Economic Security and Financial Planning; Legal Decision-Making Capacity; and Workforce Readiness and the Transition to Adulthood. The list of statutes and benefits discussed is not exhaustive, nor do we

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describe any provisions in great detail or catalogue which ones apply in which jurisdictions. Rather, our goal is to introduce the diverse array of laws and programs that currently exist under state and federal law, and provide a few illustrative examples.

Health Care

Meeting the health care needs of individuals with ASD can pose daunting challenges. Parents of young children who exhibit developmental delays may struggle to obtain an initial ASD screening and evaluation, and to pay for therapies that a clinician recommends following an ASD diagnosis. Adults on the autism spectrum with little income or assets likewise may find it difficult to secure adequate health insurance. In this section, we summarize a variety of laws and programs that affect the capacity of individuals with ASD to meet their medical and behavioral health care needs.

Medicaid

Passed as part of the Social Security Act of 1965 (Centers for Medicare & Medicaid Services [CMS], 2015), Medicaid is a joint federal-state program that provides publicly funded health care to specified categories of children and adults. Medicaid is the largest single provider of health insurance in the United States (Godbolt, 2017), and as such, is an important conduit for medical and behavioral health care services for many individuals with ASD.

Although a detailed description of the numerous pathways to Medicaid eligibility is beyond the scope of this chapter, a few general observations can be made. First, broadly speaking, there are two types of eligibility criteria: means-tested criteria that depend on indicators of economic status such as income and assets; and categorical/demographic criteria that depend on each individual's personal attributes or life circumstances. For many types of Medicaid applicants—such as children, pregnant women, parents, and adults—the family's modified adjusted gross income (MAGI) is the predominant criterion for determining eligibility for a large cluster of means-tested programs (CMS, n.d.-a). The Patient Protection and Affordable Care Act (ACA), passed into law in 2010, significantly relaxed the MAGI-based eligibility criteria and expanded the rate at which the federal government subsidizes program benefits, although the uptake of these provisions has varied by state (Medicaid and CHIP Payment and Access Commission [MACPAC], 2019).

Some individuals with ASD, however, may not be subject to MAGI-based eligibility requirements. For example, the eligibility of those who meet the definition of “disabled” adopted by the Social Security Administration (SSA), are blind, or

are over the age of 65¹ is generally determined using the SSA's other income—and resource-based criteria, discussed below. Additionally, adults with ASD who meet the SSA's definition of disability may, in some states, qualify for Medicaid through other channels as long as they do not exceed certain, less restrictive, income- or asset-based thresholds.² Finally, some state Medicaid programs cover severely disabled children, including those with ASD, even if their families are relatively well off.³

Importantly, even if individuals with ASD are initially deemed ineligible for Medicaid because they exceed the relevant income and/or asset requirements, they sometimes can exploit special legal provisions that reduce their income or assets for purposes of Medicaid eligibility without lowering their standard of living. For example, if a state agency deems an applicant's support needs to be sufficiently profound and extensive that they meet the level of care (LOC) typically provided in an institutional setting,⁴ means-tested criteria sometimes can be relaxed, enabling them to enroll in Medicaid regardless of whether their parents (or spouse) earn significant income or hold significant assets (CMS, n.d.-b). Individuals with ASD who do not meet an institutional LOC may still be able to utilize other provisions discussed later in this chapter—Special Needs Trusts, ABLE Accounts, and “Cafeteria Plans”—to achieve a similar result.⁵

Secondly, Medicaid eligibility criteria vary widely across the United States because states are allowed considerable discretion to opt in (or out) of many programs, and to adjust each program's requirements. For example, although every state deems children of age 18 years or younger with family income up to 133% of the federal poverty level eligible for Medicaid, some states extend eligibility to children whose family incomes exceed this threshold (KFF, 2020). Another source of cross-state variation involves the connection between Supplemental Security Income (SSI), discussed in more detail below, and Medicaid. Although in most states, individuals who receive SSI qualify automatically for Medicaid, a minority of states—collectively known as the 209(b) states—use additional criteria to determine the Medicaid

¹ For these elderly “dual eligible” individuals, Medicare generally pays for covered medical services, as Medicaid is the payer of last resort. Medicaid may cover medical costs that Medicare does not cover or only partially covers (such as nursing home care, personal care, and home and community-based services) (CMS, 2020).

² For example, in California, there are three Medicaid eligibility pathways for individuals with disabilities who would not otherwise qualify for Medicaid benefits: the Aged and Disabled Federal Poverty Level Medi-Cal program; the Aged, Blind, and Disabled Medically-Needy Medi-Cal program; and the 250% Working Disabled Program (Disability Benefits 101, 2020).

³ For example, certain states offer the Katie Beckett or TEFRA option, originally enacted in 1982. This option allows states to provide Medicaid coverage to children with disabilities—who require an institutional level of care—who would otherwise be ineligible due to their parents' income or resources (O'Keeffe et al., 2010).

⁴ Since the Supreme Court's decision in *Olmstead v. L.C.* (1999), there has been an increasing effort to serve these individuals in non-institutional settings through the use of home and community-based services, discussed in detail below.

⁵ For further discussion of these provisions, see *infra* section “Economic Security and Financial Planning”.

eligibility of SSI recipients (CMS, n.d.-c; U.S. Social Security Administration [SSA], 2017).

Finally, Medicaid eligibility criteria often differ between children and adults. For example, some individuals with ASD who do not qualify for SSI (and by extension, Medicaid) as children because their parents' income and assets do not meet the relevant criteria may become eligible after age 18, when parental income is no longer considered.⁶ In addition, a number of Medicaid eligibility pathways are explicitly limited to children,⁷ whereas others are confined to adults.⁸

The scope of benefits available to Medicaid beneficiaries is likewise complex and highly variable. Part of this complexity stems from the fact that the Centers for Medicare and Medicaid Services (CMS) do not require all states to provide the same array of benefits to all recipients. Rather, federal law sets a "floor" of mandatory benefits that every state must provide, and lets each state choose whether to raise this floor by offering additional services. States can raise the federal floor either by amending their Medicaid plans to make additional services available to *all* eligible individuals, or by making targeted Waiver programs available to specific groups of consumers. Importantly, the federal government permits states to ration Waiver services by capping enrollment at pre-specified levels. As a consequence, the provision of Waiver services in some states is characterized by long waiting lists (Foster et al., 2019).

Another contributing factor to the complexity of Medicaid benefits is the fact that the federal floor has shifted over time, and varies considerably by age. For example, the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program, first enacted in 1967 (U.S. Health Resources & Services Administration [HRSA], 2018), sets the benefits floor at a relatively high level for children, requiring states to provide "access to any Medicaid-coverable service in any amount that is medically necessary, regardless of whether the service is covered in the state plan" (MACPAC, n.d.-b). The EPSDT program covers screening and diagnostic services to identify any physical or mental impairments in recipients under age 21, along with the medical treatments and other services necessary to correct or ameliorate them (HRSA, 2018).

Prior to 2014, many states did not treat Applied Behavior Analysis (ABA), the leading behavioral treatment for children with ASD, as medically necessary, and thus only covered it through a Medicaid Waiver if they covered it at all. As a result,

⁶ This age-based distinction does not apply to all Medicaid eligibility pathways. For example, MAGI-based pathways take parental and spousal income into account regardless of age, as long as the claimant is treated as a member of the same household in tax filings (CMS, n.d.-a). Moreover, even though many Medicaid eligibility pathways do not consider parental income when evaluating the eligibility of adult claimants, if a claimant is married, spousal income is typically considered (SSA, 2020a).

⁷ For example, 48 states have implemented the Children's Health Insurance Program (CHIP), at least partly, as an expansion of the Medicaid Program (MACPAC, n.d.-a).

⁸ Many of the 1915(c) Home and Community-Based Services (HCBS) Waiver programs, discussed below, are specifically targeted toward adults with disabilities. For example, the Colorado Supported Living Services Waiver program specifically targets individuals with developmental disabilities who are 18 years of age or older (Colorado Department of Health Care Policy and Financing, 2019).

many children diagnosed with ASD could not access ABA therapy through their Medicaid plans. In July 2014, however, CMS issued a memorandum to all state Medicaid agencies specifying that “medically necessary” care included the screening, diagnosis, and treatment of ASD (Autism Speaks, 2018; Mann, 2014). Following this policy directive, most states began to cover ABA for children diagnosed with ASD through their EPSDT programs (Autism Speaks, 2018).

Generally speaking, the scope of Medicaid benefits is far more limited for adults than it is for children. Although adults are still entitled to a sizable array of mandatory benefits—such as in-patient hospital care, nursing and home health services, and physician services—they may not receive many of the additional (optional) benefits that EPSDT mandates for minors (MACPAC, n.d.-c). Yet here again, the scope of benefits available can vary markedly across state lines. For example, although the guarantee of ABA services through the EPSDT program applies only to children under age 21, in 2019, New Mexico enacted legislation requiring mandatory (i.e., non-Waiver) Medicaid coverage of ABA and other therapeutic care (such as occupational therapy, speech therapy, and physical therapy) to *all* Medicaid recipients with ASD who require these services, regardless of age (H.B. 322, 2019).

Affordable Care Act

As noted above, the Affordable Care Act, passed in 2010, significantly expanded the number of individuals who qualify for Medicaid. Some of the ACA’s other provisions have also, at least indirectly, helped individuals with ASD access health care benefits. For example, the ACA prohibits insurers from denying coverage on the basis of pre-existing conditions whose onset pre-dated the issuance of the insurance policy (U.S. Department of Health & Human Services [HHS], 2017). This prohibition can be vitally important for people with ASD who change insurance plans following a job change or other significant life event. Before the ACA’s passage, people with ASD who sought to change insurance carriers could be denied coverage on the ground that their ASD diagnosis was a pre-existing condition. The ACA expressly prohibited this practice.

Moreover, before the passage of the ACA, children of covered adults generally could only obtain coverage through their parents’ private insurance plans until they turned 19 (or graduated from college if they were full-time students) (Andrews, 2013; Goldman, 2013). Although private insurance policies occasionally covered the disabled children of beneficiaries beyond age 18, such policies often relied upon highly restrictive definitions of disability that excluded some individuals with ASD. The passage of the ACA did not affect this variability in insurance companies’ coverage of policy holders’ disabled adult children. Yet some young adults (aged 18–26) with ASD benefitted from a provision in the ACA allowing *all* individuals (regardless of disability status) to claim benefits through their parents’ insurance policies through age 26 (U.S. Department of Labor, n.d.-a).

A separate provision of the ACA that conceivably could affect the provision of medical services to individuals with ASD, known as the “nondiscrimination provision,” prohibits discrimination on the basis of race, color, national origin, sex, age, or disability in the provision and administration of most health insurance plans (HHS, 2021). Federal regulations passed in 2016 interpreted this clause to prohibit insurers from denying, canceling, limiting, or renewing a health insurance policy; denying or limiting coverage of a claim; or designing benefits in a way that discriminates on the basis of disability. This provision could be used to ensure that health insurance plans do not construe or administer plan provisions in ways that disproportionately burden or disadvantage individuals with ASD. In 2020, however, the U.S. Department of Health and Human Services (HHS) reversed course by removing the 2016 interpretation and making numerous other changes to the provision’s governing regulations, including some that narrow the range of businesses to which the law applies, and potentially reduce the accessibility of health care information to individuals with disabilities (Musumeci et al., 2020a). The regulations were widely opposed by disability rights organizations (Autistic Self Advocacy Network, 2019; Disability Rights California, 2019), but as of this writing, the Biden Administration has not yet proposed new ones pertaining to disability discrimination (HHS, 2021).

State Insurance Mandates for Treatment of ASD

As recently as the turn of the millennium, very few private health insurance plans provided adequate treatment to individuals with ASD. Some insurance companies classified ASD as “uninsurable,” effectively depriving those who carried the diagnosis of many medical services (Indiana Resource Center for Autism, 2016). Even if individuals with ASD were deemed eligible for insurance coverage, the benefits they received were often inadequate or nonexistent. For example, an individual with ASD whose doctor recommended Applied Behavior Analysis (ABA) might find that the family’s insurance policy specifically excluded ABA, or that other plan provisions could be used to effectively deny coverage. If other forms of therapy—such as speech therapy, occupational therapy, and physical therapy—were covered at all, they often conferred little therapeutic benefit because of low caps on the number of sessions covered.

Frustrated by the lack of adequate insurance coverage, families of individuals with ASD and nonprofit organizations began to lobby elected officials, urging them to require health insurance providers to meet the health care needs of individuals with ASD. Since private health insurers are regulated by state law, these campaigns were generally organized at the state level, and by the first decade of the twenty-first century they began to bear fruit. As of this writing, all fifty states mandate that state-regulated health insurance plans cover ASD treatments (Autism Speaks, 2019), albeit with different caps on ABA expenditures (National Conference of State Legislatures, 2018). Importantly, state insurance mandates apply only to conventional health insurance policies, not to health benefit plans offered by large employers that

self-insure (i.e., manage the risks associated with the provision of health care benefits internally, rather than transferring them to a third party). Yet despite being excluded from the scope of these state law reforms, many self-insured employers have opted to provide ABA and other behavioral therapies to individuals with ASD (Autism Law Hub, 2019).

Employment Retirement Income Security Act of 1974 (ERISA)

The Employee Retirement Income Security Act of 1974 (ERISA) is a federal law that sets minimum standards for a variety of employee benefits, including voluntarily established health benefit plans offered by large companies that opt to self-insure (U.S. Department of Labor, n.d.-b). As noted above, large companies that offer self-funded health benefit plans are not covered by state insurance mandates. Although many self-insured companies still choose to offer ASD and ABA coverage, individuals covered by such plans must look to ERISA, not state law, to challenge the scope of coverage or contest claim denials.

ERISA imposes “fiduciary” responsibilities on the individuals involved in controlling the company plan’s assets, management or administration, which means that they must act prudently, diversify the plan’s investments, adhere to the terms of the plan documents, and “run the plan solely in the interest of participants and beneficiaries and for the exclusive purpose of providing benefits and paying plan expenses” (U.S. Department of Labor, n.d.-c). In a highly publicized class action lawsuit, *Wit v. United Behavioral Health* [UBH] (2019), the U.S. District Court for the Northern District of California found that “financial self-interest was a critical consideration [in UBH’s decision] regarding what criteria would be used to make coverage decisions and when Guidelines would be revised,” which constituted a breach of UBH’s fiduciary duty. Among the facts that the court cited in reaching this conclusion was UBH’s decision in 2016 not to amend its guidelines on the provision of ABA services to individuals with ASD—despite the company’s Utilization Management Committee’s recommendation that the coverage be expanded—because of the CEO’s desire to cut costs.

As of this writing, it is unclear how much practical recourse ERISA will provide to individuals with ASD and their families seeking to challenge adverse benefit determinations or claim denials by self-insured health care plans. Yet *Wit v. UBH* suggests, at the very least, that self-insured employers may not allow financial self-interest to taint the process of developing or revising coverage guidelines for the treatment of ASD, especially if those guidelines purportedly adhere to generally accepted behavioral standards of care.

Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA)

In many health insurance plans, the devil is in the details when it comes to accessing benefits. Fine-print exclusions and limitations can make the difference between covered treatments that are robust and readily accessible, and those that are difficult to obtain or so negligible in quantity that they confer little therapeutic benefit. Albeit with some exceptions, the ACA requires health plans to cover ten Essential Health Benefits including, for example, emergency services and mental health treatment (CMS, n.d.-d, n.d.-e; Fernandez et al., 2018; Keith, 2018). Importantly, federal law also prohibits insurers from covering mental health treatments in a more restrictive manner than they cover other forms of treatment. Under the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA), limitations or financial requirements imposed on mental health benefits can be no more restrictive than those imposed on medical and surgical benefits.

Unlike state health insurance mandates, the MHPAEA applies to most group health plans—including both conventional health insurance and self-funded health benefit plans offered by large employers (U.S. Department of Labor, 2010)—as well as Medicaid Managed Care Plans, the Federal Employees Health Benefits Program, State Children’s Health Insurance Programs (S-CHIP), health plans purchased through the Health Insurance Marketplaces, and most individual health plans purchased outside the Health Insurance Marketplaces (National Alliance on Mental Illness, n.d.). Although from a neurodiversity standpoint it is inaccurate (and arguably offensive) to describe ASD as a “mental health disorder,” it is generally treated as such in insurance contexts because it is included in the Diagnostic and Statistical Manual of Mental Disorders (DSM). As a consequence, ASD-related treatments are included in the scope of protection that the MHPAEA provides (Graham, 2017).

In effect, the MHPAEA may help individuals with ASD ensure that their covered therapies are provided at the same level, and subjected to the same limitations, that apply to other forms of treatment. For example, the financial requirements that apply to speech therapy for an individual with ASD—such as deductibles, copayments, coinsurance, and out-of-pocket expenses—cannot be more restrictive than the financial requirements that apply to substantially all of the medical/surgical benefits covered by the policy. The same parity requirement applies to restrictive treatment limitations, such as the frequency or geographic location of treatments; the number of visits; and the duration of coverage. MHPAEA also establishes parity requirements for other limitations relating to:

- Medical management standards limiting or excluding benefits based on medical necessity or medical appropriateness, or based on whether the treatment is experimental or investigative;
- Formulary design for prescription drugs;
- For plans with multiple network tiers (such as preferred providers and participating providers), network tier design;

- Standards for provider admission to participate in a network, including reimbursement rates;
- Plan methods for determining usual, customary, and reasonable charges;
- Refusal to pay for higher-cost therapies until it can be shown that a lower-cost therapy is not effective (also known as fail-first policies or step therapy protocols);
- Exclusions based on failure to complete a course of treatment; and
- Restrictions based on geographic location, facility type, provider specialty, and other criteria that limit the scope or duration of benefits for services provided under the plan or coverage (26 C.F.R. § 54.9812–1(c)(4)(ii)).

Again, it is important to note that federal law does not ban any of these cost-containment practices; it requires only that they be applied in an evenhanded manner to mental health, medical, and surgical benefits alike. Before the passage of the ACA, the mental health parity protections described above were not available to people insured through individual or small group plans; the ACA extended the MHPAEA's protections to the latter groups (Beronio et al., 2013).

Finally, it is worth noting that some states have passed their own mental health parity laws whose provisions may complement, and in some cases augment, the protections of the MHPAEA (Douglas et al., 2018).

Health Insurance Coverage Provided to Active-Duty Military, Veterans, and Their Families

Many individuals in the armed forces and their dependents receive treatment and services through TRICARE, a set of healthcare plans offered by the Department of Defense to active duty and retired military personnel and their families through the Defense Health Agency (DHA) (U.S. Defense Health Agency [DHA], 2019a). Benefits are also available temporarily to veterans transitioning out of the military (DHA, 2019b). Although speech and language therapy is considered a basic TRICARE benefit and as such is available to all beneficiaries, ABA is considered “experimental in nature” and thus outside the scope of basic coverage. The DHA originally offered ABA benefits to discrete groups of TRICARE beneficiaries through a patchwork of programs with varying eligibility requirements, but in 2014, all of these programs were consolidated into the Comprehensive Autism Care Demonstration Project (Autism Care Demo), which covers ABA for all eligible TRICARE beneficiaries with ASD (DHA, 2020a; U.S. Department of Defense [DOD], 2014). Originally scheduled to sunset in 2018, the Autism Care Demo has been renewed until 2023 (DHA, 2020a; DOD, 2014). Yet since the DHA currently *only* covers ABA through the temporary Autism Care Demo, it is unclear whether coverage will be provided after the program sunsets (DHA, 2020b).

Due to a recent policy change, individuals with ASD can also receive ABA benefits through the Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA), a separate health benefit plan available to the family members

of veterans who do not qualify for TRICARE and are either deceased or permanently and totally disabled as the result of service-related conditions (U.S. Department of Veterans Affairs, 2020a, 2020b).

Public Benefits, Services, and Supports

Although laws that improve access to health care can significantly improve quality of life, some individuals with ASD may require non-medical services and supports, including income support, to achieve long-term stability and pursue their life goals. Several federal programs, including Medicaid, can help individuals with ASD cover non-medical costs.

Medicaid Long-Term Services and Supports Delivered in Institutional Settings

In addition to the health care benefits discussed above, Medicaid provides a variety of non-medical services and supports to consumers with disabilities. For example, consumers who require extensive around-the-clock care may receive long-term services and supports (LTSS), including a mix of medical and non-medical services, in institutional environments. The provision of LTSS in institutional settings, such as Skilled Nursing Facilities, is a mandatory component of each state's Medicaid program (Sowers et al., 2016) and accounts for about a third of all Medicaid expenditures (Thach & Wiener, 2018). At such facilities, Medicaid consumers receive extensive support with activities of daily living (such as eating, bathing, and dressing), as well as longer-term tasks such as housekeeping, transportation, and budget management (Thach & Wiener, 2018).

Home and Community-Based Services

In recent decades, a growing proportion of individuals with disabilities, including ASD, have begun to receive Medicaid services and supports, including LTSS, in their own homes or in community-based settings. The federal government provides states with three major conduits for accessing these resources, which are collectively referred to as Home and Community-Based Services (HCBS).

About 13% of Medicaid consumers receiving HCBS do so through federally mandated Home Health State Benefit Plan Policies (Watts et al., 2020), which provide basic HCBS benefits to all Medicaid recipients, such as medical supplies and equipment, nursing care, and home health aide services (Musumeci et al., 2020b).

Another 52.5% of HCBS recipients participate in the Medicaid Waiver programs described in Section I (Watts et al., 2020), which are generally referred to by their respective statutory sections. Recall that the Waiver programs are implemented at each state's discretion, and expand HCBS provision to designated populations. Importantly, states can cap enrollment in Waiver programs, and only individuals who meet an institutional level of care are eligible to participate. The Waiver program that serves the largest number of individuals with ASD, the Section 1915(c) Waiver, allows states to tailor services to meet the needs of a particular target group (CMS, n.d.-b). Notably, states can only require 1915(c) Waiver participants to enroll in capitated managed care plans if they obtain that authority through a separate Medicaid provision.⁹ Thirteen states have chosen to make 1915(c) Waiver programs available to individuals with ASD (CMS, n.d.-f).¹⁰ Another important HCBS Waiver, the Section 1115 Waiver, permits states to target several populations at once and "can be used to authorize both HCBS and mandatory managed care enrollment" without the need to obtain that authority through a separate Medicaid provision (Musumeci et al., 2020b). The Section 1915(c) Waiver served 1.81 million enrollees in FY 2018, compared to 698,500 served through the Section 1115 Waiver, including some diagnosed with ASD (Watts et al., 2020).

The remaining 34.5% of Medicaid HCBS consumers benefit from "State Plan Options" (Watts et al., 2020), also known as "State Plan Amendments," through which states can elect to provide certain services to *all* Medicaid consumers who meet pertinent eligibility requirements (Watts et al., 2020). For example, thirty-four states offer personal care services as an additional benefit in their State Plans. Nearly all of these states cover assistance with household activities, such as meal preparation and housekeeping, and a significant portion also cover additional services, such as transportation (Musumeci et al., 2020b). Another eight states have taken advantage of the ACA's Community First Choice (CFC) State Plan Option. The CFC Plan Option provides states with extra federal funds¹¹ in exchange for offering HCBS benefits to all individuals who would otherwise qualify for an institutional level of care (Musumeci et al., 2020b). Finally, thirteen states offer HCBS to targeted groups of consumers—which in four states includes consumers with intellectual and developmental disabilities (I/DD)—through the 1915(i) State Plan Option (Musumeci et al., 2020b), which permits states to provide HCBS benefits to certain Medicaid consumers who do not require an institutional level of care.¹²

⁹ These other provisions include the Section 1932 State Plan Option, and the respective Waivers contained in Sections 1915(a) and 1915(b) (Musumeci et al., 2020b).

¹⁰ This figure does not include Waiver programs that target the population of individuals with ASD as part of a broader program for those with I/DD.

¹¹ Service expenditures related to the CFC plan option are reimbursed by CMS at a rate that is six percentage points higher than the standard rate they receive for most Medicaid expenditures (CMS, n.d.-g; Mitchell, 2018).

¹² In most states that provide HCBS through Section 1915(i), beneficiaries must already be eligible for Medicaid through a different pathway (Musumeci et al., 2020b). In three states (Ohio, Indiana, and Idaho), however, 1915(i) can be used as an independent pathway to Medicaid eligibility.

Social Security Benefits: SSI and SSDI

For many individuals with ASD living in the community, the cash assistance available through the Social Security Administration (SSA) is critical to secure basic necessities, such as food and housing, that cannot be obtained through the HCBS programs discussed above.

SSA distributes cash benefits through two programs: the Social Security Disability Insurance (SSDI) program and the Supplemental Security Income (SSI) program. Both programs provide monthly cash payments and (in most states) entitle recipients to publicly-funded health insurance;¹³ both also require recipients claiming that they are disabled to meet SSA's definition of disability.¹⁴ To qualify as disabled, a child under age 18 must have a medically determinable physical or mental impairment (including emotional or learning problems) that results in marked, severe, and functional limitations, and is expected to last longer than a year or else result in death (SSA, 2020b). Meanwhile, an adult recipient must have a completely disabling condition that will last longer than a year or result in death (SSA, 2020b). A key difference between the two programs is that SSDI requires recipients themselves (or in certain situations, their parents or spouses) to have amassed long enough work histories to qualify for benefits, whereas the SSI program contains no such requirement. Therefore, SSI is more relevant to individuals with ASD who lack significant work experience and cannot claim SSDI benefits through family members.

In order to qualify for SSI benefits, an individual's assets and "countable" income may not exceed specified thresholds (SSA, 2020a, 2020c). Broadly speaking, countable income includes earned income (wages and net self-employment earnings); unearned income (including Social Security and unemployment benefits, pensions, state disability payments, interest, cash, and dividends); and in-kind income (such as food and shelter obtained for free or purchased at below-market rates). Importantly, however, countable income *does not* include the value of Supplemental Nutrition Assistance Program (SNAP) benefits; need-based food or shelter provided by nonprofit entities; or wages used to pay for items or services that help the individual work (SSA, 2020a). The amount of countable income determines the level of benefits to which an SSI recipient is entitled, and the benefit level declines as income rises.

It is also important to note that in calculating SSI eligibility, the SSA may take into account parental and/or spousal assets and income. This provision is especially important for children under the age of 18 living with their families, since a portion

¹³ As noted above, nine "209(b)" states impose additional eligibility restrictions beyond SSI enrollment for Medicaid eligibility. However, all individuals receiving SSDI qualify for Medicare after a 24-month waiting period (SSA, 2017, n.d.-a).

¹⁴ SSI also has pathways for individuals who are blind, or age 65 or older.

of parental income and resources are included in eligibility determinations.¹⁵ After a child turns 18, parental resources no longer factor into these calculations.¹⁶

Protection & Advocacy Services

As part of the Developmentally Disabled Assistance and Bill of Rights Act of 1975 (DD Act), Congress mandated the creation of state-level Protection and Advocacy Systems (P&As) for the purpose of protecting, and advocating for, the rights of individuals with disabilities (U.S. Administration for Community Living [ACL], 2017a, 2019). Every state and U.S. territory has a P&A authorized to “pursue legal, administrative, and other appropriate remedies or approaches to ensure the protection of, and advocacy for, the rights of such individuals [with disabilities] within the State” (42 U.S.C. § 15043). P&As have been active in ensuring the implementation of the U.S. Supreme Court’s decision in *Olmstead v. L.C.* (1999), which bars the unnecessary segregation of individuals with disabilities and helps ensure that they receive services in the least restrictive environment. P&As typically help individuals engage in self-advocacy, and in some cases also conduct investigations, monitor compliance with laws affecting individuals with I/DD, and provide direct legal representation (ACL, 2017b, 2019).

P&As may also coordinate their activities with other state-level entities authorized by the DD Act, such as State Councils on Developmental Disabilities and University Centers for Excellence in Developmental Disabilities Education, Research, and Services (UCEDDs) (ACL, 2019).

Custody, Visitation, and Child Support

Although published family law cases involving children with ASD are relatively scant, two general patterns seem to apply in most jurisdictions. First, parents’ duty to support a child with ASD does not necessarily terminate when the child reaches adulthood. In the majority of states, the duty of parental support may continue for as long as a child’s disability prevents him/her from earning a living and performing adequate self-care. Consequently, parents may have a duty to provide ongoing support to their adult children with ASD—or in the wake of divorce, non-custodial parents may be required to pay child support to custodial parents—even after children reach the age of legal majority. States differ, however, on whether the level of support is

¹⁵ Certain resources and sources of parental income, such as Temporary Assistance for Needy Families (TANF) and Veterans Affairs pension benefits; foster care payments; and court-ordered child support payments, are not included in these calculations (SSA, 2020d).

¹⁶ If the adult child marries, however, his or her spouse’s income and resources could be considered in SSI eligibility calculations (SSA, 2020a, 2020c).

fixed by child support guidelines, or adjusted to a level that balances the parents' economic circumstances with the needs of the disabled child (National Council of State Legislatures, 2020).

Secondly, in situations where parents seek to acquire or retain custody or visitation rights, published opinions reflect a commitment to several goals: ensuring that the parent or guardian of a child with ASD can address the child's unique needs; providing the child with a consistent routine; and attaining continuity in the provision of services and supports (Dicker & Marion, 2012). Before determining which arrangement is in the child's best interest, courts frequently appoint a *guardian ad litem* (GAL). Although the formal training of GALs may vary and their precise duties vary across jurisdictions, they generally are expected to advocate on the child's behalf for the duration of a legal action. In so doing, GALs may carry out investigatory functions such as reviewing records; interviewing family members; and consulting with clinicians, school personnel, and other individuals with relevant knowledge (Boumil et al., 2011).

The question of whether the parent fully understands the child's disability and can provide appropriate support often looms large in decisions regarding custody and visitation. For example, in *Martocchio v. Savoie* (2008) a father, who had not known that he was a parent for more than two years, petitioned for custody of his child, a four-year-old boy with severe ASD. Not only did the court grant the father sole custody on the ground that he had "immersed himself, almost to a fault, in the study of autism and proper treatment of his son," but the court also ordered the child's mother and maternal grandparents to "endeavor to learn all they can regarding autistic children." The issue of parental capacity has also arisen in child protection cases in which an agency is considering whether to remove a child with ASD from the family home. For example, in *In re Juan R.* (2007), the court affirmed that the Connecticut Department of Children and Families had made sufficient efforts to prevent the removal of an autistic child, opining that the "mother had been unable to significantly benefit" from the services provided from the Department, and could not ensure the health and safety of her son.

Courts also have emphasized the need to maintain consistency in a child's schedule and routine. For example, in *Suleman v. Egenti* (2016) the Maryland Court of Special of Appeals upheld the visitation schedule set by a prior court, noting that an "abrupt return to overnight visitation" by the father "could be disruptive to [the child with ASD] and cause him to regress." Similarly, in *LaGuardia v. LaGuardia* (2005), the Court of Appeals of Tennessee affirmed the visitation schedule determined by the trial court, citing expert testimony that children with ASD require "sameness and consistency."

In addition to maintaining the consistency of schedules and routines, courts have often emphasized the need to maintain continuity in the mix of services provided. For example, in *Ermini v. Vittori* (2013), the U.S. Court of Appeals for the Second Circuit denied a father's petition to relocate his son from New York, where he had been receiving treatment for ASD, to Italy on the ground that such a move posed a "grave risk of harm" to the child by risking "a significant regression in his skills." The court expressed concern that "without such an intensive, structured program, [the child

would] not develop ... cognitive, language, social, emotional and independent living skills.” Moves across state lines can raise similar risks by disrupting relationships with therapists and networks of community support that can take months or years to rebuild; altering the mix of services that school-age children with ASD receive from public schools; and forcing individuals who receive Medicaid Waiver services to forfeit their spot upon their departure and join the Medicaid Waiver waitlist in a new state.

Economic Security and Financial Planning

If individuals with ASD earn significant income from paid employment or hold a sufficient amount of assets in their name, they may be disqualified from some of the means-tested entitlement programs described in prior sections. However, three special legal mechanisms can enable some of these individuals to overcome eligibility barriers without reducing their standard of living: ABLÉ Accounts, Special Needs Trusts, and Cafeteria Plans.

ABLE Accounts

The Achieving a Better Life Experience Act (ABLE Act), passed in 2014, was designed to mitigate the deterrent effects of means-tested eligibility criteria on disabled individuals’ incentives to accumulate savings. In addition to “encourage[ing] and assist[ing] individuals and families in saving private funds for ... health, independence, and quality of life,” the ABLE Act aims to “provide secure funding for disability-related expenses of beneficiaries that will *supplement, but not supplant*, benefits provided through private insurance” and “[the SSI and Medicaid sections] of the Social Security Act” (ABLE Act, 2014).

Under the ABLE Act, people with ASD and/or other disabilities and their families can establish ABLE Accounts, tax-advantaged savings accounts for qualified disability expenses (QDEs). QDEs can include expenses related to education, housing, transportation, employment training, and other costs generally related to the person’s disability (SSA, 2020e). With rare exception, savings accrued in an ABLE Account do not affect eligibility for means-tested public benefits, including SSI and Medicaid. (The two primary exceptions are the fact that ABLE Accounts *are* included in the means tests for SSI distributions for housing expenses, and that SSI benefits are suspended if the amount held in an ABLE Account surpasses \$100,000) (Disability Benefits 101, 2020).

To qualify for the ABLE program, an individual with a disability must be able to prove that his/her disability onset before the age of 26 (ABLE National Resource Center [ABLENRC], n.d.-a). Yet the program places few additional restrictions on qualifying applicants. For example, an ABLE Account can be opened at any stage

of the life cycle, and sometimes can be opened in a state other than the consumer's state of legal residence (ABLENRC, n.d.-b, n.d.-c).

Contributions to an ABLE Account are capped at \$15,000 per year, and starting in 2018, employed account beneficiaries can additionally contribute a portion of their income (Internal Revenue Service [IRS], 2018). The maximum allowable *total* savings in an ABLE Account, however, varies by state. For example, while the limit on allowable savings is \$520,000 in New York as of this writing, the limit is only \$370,000 in Nevada (ABLENRC, n.d.-d, n.d.-e). While federal tax treatment of ABLE Accounts is complex and evolving (American Bar Association, 2017; IRS, 2018, 2019), some aspects of their tax treatment also vary by state (ABLENRC, n.d.-f).

Special Needs Trusts

Like ABLE Accounts, Special Needs Trusts (SNTs) can help individuals with disabilities accumulate assets while preserving their eligibility for public benefit programs such as SSI and Medicaid (Neale, 2017; SSA, 2020f).

There are two main types of SNTs: First Party SNTs and Third Party SNTs. First Party SNTs are funded directly by the assets of the beneficiary, including, for example, money acquired from personal injury settlements or inheritances (Special Needs Alliance [SNA], 2013). Sometimes, multiple beneficiaries can pool their assets in a so-called Pooled Special Needs Trust, which allows them to maintain individual accounts while investing their assets together (California Department of Health Care Services, 2019). In contrast, Third Party SNTs cannot be funded by the beneficiary's assets, and usually contain direct inheritances or life insurance policy proceeds from family members (SNA, 2013).

Although both ABLE Accounts and SNTs are intended to preserve a beneficiary's eligibility for public benefits, there are important differences between the two. With regard to eligibility, only ABLE Accounts require the beneficiary to document that his/her disability onset before age 26. While ABLE Accounts may be created at any age, SNTs must be established before the intended beneficiary turns 65 (SSA, 2018). The two programs also include different sets of restrictions, with corresponding trade-offs. For example, while ABLE Accounts have monthly contribution limits, SNTs do not; SNT contributions are subject to gift tax restrictions, while ABLE Accounts are not (SNA, 2020; Special Needs Answers; 2020). Whereas ABLE Account assets can only be spent on QDEs, as mentioned above, SNT assets can be used for *anything* that directly benefits the beneficiary (SNA, 2020). Finally, ABLE Accounts can be directly managed by the beneficiary him/herself, whereas SNT assets must be controlled by a trustee.

Cafeteria Plans

A Cafeteria Plan is an employee benefit plan that permits a participating company's employees, regardless of their disability status, to select at least one item from a menu of "qualified benefits" in exchange for a reduction in pre-tax earnings (SSA, 2012). Qualified benefits can include, but are not limited to, health plans, life insurance coverage, and childcare expenses (IRS, 2020a, 2020b). Unlike ABLE Accounts and SNTs, Cafeteria Plans cannot help individuals with ASD shelter their savings, but may render them eligible for federal entitlement programs by helping them or their family members reduce their earned income (and, in turn, their modified adjusted gross income). Although employers are not required to offer Cafeteria Plans to their workers, many large companies choose to do so, and some smaller employers offer "Simple Cafeteria Plans" with slightly different eligibility criteria (IRS, 2020b). In short, by helping to reduce the earned income of disabled workers or their family members, Cafeteria Plans can help some individuals with ASD qualify for means-tested public benefit programs.

Legal Decision-Making Capacity

When a person with ASD turns 18, the question sometimes arises of whether he or she is capable of making important life decisions on his/her own behalf. Parents who believe that their child's ASD, which may be combined with other impairments, significantly impairs his/her decision-making capacity sometimes consider special legal arrangements whereby decision-making authority can be transferred to parents or other individuals after the individual reaches the age of legal majority.

Guardianship/Conservatorship

Legal provisions that grant parents, family members, or other individuals the authority to make decisions on behalf of adults with developmental disabilities, including ASD, are generally known as "guardianship" arrangements. Some states, such as California and Massachusetts, instead use the term "conservatorship" to refer to the entirety (or a subset) of these arrangements (California Courts, n.d.; Government of Massachusetts, n.d.). For simplicity's sake, we use the term "guardianship" throughout this section.

Broadly speaking, if a court concludes that an individual is unable to make important life decisions on his or her own behalf, the court may appoint a guardian whose authority encompasses one or both of two domains: guardianship of the person, and guardianship of the estate (Barton et al., 2014). Guardianship of the person includes decisions pertaining to the person's daily activities, health and welfare,

such as “choosing a residence, consenting to medical treatment, and making end-of-life decisions” (Barton et al., 2014: 27). Meanwhile, guardianship of the estate empowers the guardian to assert control over the individual’s assets and personal finances.

Because (essentially by definition) traditional guardianship arrangements strip individuals with disabilities of the authority to make decisions about their daily lives and/or their personal finances, they have become increasingly disfavored. For example, the Uniform Guardianship, Conservatorship And Other Protective Arrangements Act of 2017, a model law designed to harmonize different states’ approaches toward guardianship issues, emphasizes that “guardianship and conservatorship should be options of last resort,” and “recognizes the role of, and encourages the use of, less restrictive alternatives” (National Conference of Commissioners on Uniform State Laws [NCCUSL], 2018: 1–2).

One alternative to full guardianship is a *limited* guardianship, which, as the name implies, limits the scope of the guardian’s authority to specific domains, allowing the individual with a disability to retain decision-making power in others (e.g., Cal. Prob. Code § 1801(d); Mo. Rev. Stat. § 475.080; North Carolina Judicial Branch, n.d.). However, the availability, scope, and procedural aspects of limited guardianships vary by state. In New York, for example, the duties of a limited guardian are left entirely to the judge’s discretion, whereas in California, a limited guardian (called a conservator) is precluded by statute from choosing a residence or making financial decisions on the disabled person’s behalf without express judicial authorization (Barton et al., 2014; Cal. Prob. Code § 2351.5).

Power of Attorney and Supported Decision-Making

Drawing on the United Nations’ Convention on the Rights of Persons with Disabilities, which recognizes the right to legal capacity regardless of disability, and the Americans with Disabilities Act’s mandate to provide services in the least restrictive environment, Supported Decision-Making (SDM) is emerging as an increasingly popular alternative to guardianship (Bach & Kerzner, 2010; Salzman, 2010; Thinking Person’s Guide to Autism, 2017). SDM is a process whereby “people with disabilities use friends, family members, and professionals to help them understand the situations and choices they face, so they make their own decisions” (Francisco & Martinis, 2017: 2). In the SDM framework, the individual with ASD assembles a team of supporters, including friends, family, and various professionals, to assist with important decisions (Francisco & Martinis, 2017). Some states, including Texas and Rhode Island, have statutorily recognized the use of SDM as an alternative to guardianship and created standardized SDM agreement forms that enable supporters to assist in the individual’s decision-making and communication (National Resource Center for Supported Decision-Making, n.d.-a, n.d.-b). In other contexts, the SDM team may utilize informal agreements to establish the SDM relationship and outline the duties of the team (Francisco & Martinis, 2017).

A different legal device that does not require judicial approval, and sometimes can be used in combination with SDM, is the “power of attorney,” a written authorization whereby an adult (called the “grantor”) can grant another person the authority to make decisions on his/her behalf under circumstances specified in the authorization (American Bar Association, n.d.). “Limited” or “special” powers of attorney are limited by their terms to specific domains (such as health care or personal finances); “durable” powers of attorney are designed to endure (unless they are revoked) until the grantor’s death, even if the grantor becomes incapacitated (American Bar Association, n.d.). Some individuals with ASD may use powers of attorney to cede to others the authority to make decisions in specified areas, without the need for court involvement. Yet it is important to note that legally, an individual who grants a power of attorney must do so voluntarily and possess the requisite level of legal capacity. Therefore, a power of attorney bearing the signature of an individual with ASD whom the court deems to be incapacitated, or who did not assent knowingly and voluntarily to the arrangement, may not be enforced if its validity is challenged.

The Social Security Administration’s Representative Payee Program

Some individuals with ASD who receive benefits from the Social Security Administration (SSI and SSDI) may not be well equipped to handle the various financial transactions required to meet their ongoing needs, such as food and housing, or to manage their own budgets. In such situations, it may be helpful to designate another individual or agency, known as a “representative payee,” to receive and manage these funds for the “current needs of the beneficiary and in their best interests” (SSA, n.d.-b). The SSA makes its own determination regarding whether a recipient can manage his or her own benefits, or whether the appointment of a representative payee is warranted (Wynn, 2016). If the benefit recipient expresses preferences regarding which individuals should (or should not) be appointed to serve as representative payees, the SSA generally takes those preferences into account in making its determination (Disability Rights California, 2018). Most individuals for whom representative payees are appointed do not have court-appointed guardians (Belbase & Sanzenbacher, 2017). If guardianship arrangements are in place, guardians are not required to serve as representative payees, but do so in the majority of cases (Special Needs Alliance, 2015).

Workforce Readiness and Transition to Adulthood

Securing paid employment poses significant challenges for many adults with ASD. In 2017, for example, only 29% of surveyed adults with ASD were employed, and

about half of those who did earn wage income did so in segregated “sheltered work-shop[s]” (Roux et al., 2017: 50). In contrast, the nationwide employment rate¹⁷ was about 60% in the same year (Bureau of Labor Statistics [BLS], 2018). Particularly for the estimated 50,000 individuals with ASD who turn 18 each year (Shattuck et al., 2012), accessing programs and resources designed to help individuals with disabilities secure paid employment can be critical to facilitate the transition to adulthood.

Vocational Rehabilitation Agencies

The Rehabilitation Act of 1973 requires state vocational rehabilitation (VR) agencies to provide an array of employment services to people with ASD and other disabilities (34 C.F.R. § 361.48). In accordance with federal law, every U.S. state operates a VR agency that uses a mixture of state and federal funding to provide employment services and resources to people with disabilities (Employer Assistance and Resource Network, n.d.; U.S. Department of Education, 2017). Although the number of people with ASD applying for VR services has increased dramatically in the past decade, an ASD diagnosis alone is not sufficient to qualify for VR services (Roux et al., 2016). The applicant must also demonstrate that his/her impairment “substantially interferes with the ability to get a job” and consequently that he/she “require[s] VR services to prepare for, secure, or regain employment” (Roux et al., 2016: 18).

If an applicant with ASD qualifies for VR services, the VR agency must complete vocational assessment(s) and, ultimately, an Individual Plan for Employment (IPE). The IPE specifies the VR services to which the applicant is entitled, which may include training, counseling, job placement, assistive technology, and supported employment (Autism Speaks, 2013). The average time required for the agency to complete an IPE can vary widely by state. For example, while over 80% of transition-age youth with ASD in California whose VR cases were closed between fiscal years 2014 and 2016 obtained their IPEs within 90 days of their eligibility determination, the comparable figure for Iowa was just 23% (Roux et al., 2020).

Workforce Innovation and Opportunity Act

The Workforce Innovation and Opportunity Act (WIOA), passed in 2014, was intended to address the unique needs of workers with disabilities. Among WIOA’s key reforms were provisions requiring VR agencies to provide additional resources

¹⁷ In calculating the “employment-population ratio” (i.e., the employment rate), the Bureau of Labor Statistics only considers “persons 16 years of age and older residing in the 50 states and the District of Columbia, who are not inmates of institutions (e.g., penal and mental facilities, homes for the aged), and who are not on active duty in the Armed Forces” (BLS, 2018; Federal Reserve Bank of St. Louis, 2020).

to disabled workers in subminimum wage employment (34 C.F.R. § 397.40), and to allocate at least 15% of their federal funding to pre-employment transition services for students transitioning from high school to college or the workforce (U.S. Rehabilitation Services Administration, 2015). The resources funded through WIOA include job exploration counseling, workplace readiness training, instruction in self-advocacy, and other related services (U.S. Department of Education, 2016).

State Laws Designed to Ease Transition to Adulthood

In part because the breadth of federally funded VR services varies widely across states (Roux et al., 2020), some states have passed other laws to help people with ASD and their families better navigate the transition into adulthood. Some of these laws require public schools to take specific steps to prepare students with disabilities for the labor market. In Connecticut, for example, school districts must provide a “Transition Bill of Rights” to parents and guardians of children receiving special education services in middle school and high school, explaining the full range of resources available to students who graduate from (or leave) the public education system (Connecticut State Department of Education, 2016). Some states have also expanded post-secondary education for people with disabilities. In 2013, for example, California appropriated special funds to the community college system to expand the range of educational offerings available to students with disabilities (California Adult Education, n.d.).

Conclusion

Civil rights laws designed to protect the rights of disabled individuals in the workforce and in public education are familiar to many disability rights advocates and stakeholders. Yet numerous other civil statutes, regulations, and entitlement programs, some of which are available to disabled and non-disabled individuals alike, may be just as consequential for individuals with ASD and their families. Many of these diverse laws—such as those that broaden access to affordable health care, provide cash benefits, encourage savings, or fund individualized services and supports—can improve health, stability, and well-being throughout the life span. Others—such as those that pertain to custody and child support, the transition to adulthood, or legal decision-making capacity—only rise to prominence during important life transitions. Overall, our survey of this varied legal landscape suggests that although the rights of individuals with ASD have evolved rapidly in recent decades, there are many areas in which the law is inconsistent or under-developed, leaving plenty of room for continued reform and innovation.

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