

Making the Law More ABLE: Reforming Medicaid for Disability

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Passed on the eve of Medicaid's fiftieth anniversary, the Achieving a Better Live Experience (ABLE) Act was a hard-fought victory for individuals with significant disabilities and their families. The law, which creates a new form of tax-preferred savings account, represents an invaluable work-around for highly restrictive Medicaid eligibility requirements. Medicaid eligibility is crucially important for individuals with intellectual, developmental, and other significant disabilities because it provides nearly exclusive access to government-coordinated habilitative care, such as in-home assistance, job supports, and adaptive equipment. These services are necessary to maintain a base-level quality of life, facilitate independent living, and preserve the dignity of individuals with disabilities. Despite their importance, they are difficult to purchase and coordinate in the private market, and due to income and asset holding restrictions on eligibility, only the very poor can access them through Medicaid, even after passage of the Affordable Care Act. This Article argues that despite their facial neutrality, income and asset holding restrictions, commonly referred to as means testing, result in undue hardship when they are applied to the provision of government-coordinated habilitative care for individuals with significant disabilities. Congress's attempts to mitigate this hardship, including the recently passed ABLE Act, are important steps forward, but they also can impose economic, dignitary, and emotional harms on individuals with disabilities.

Based on the distinctive needs of individuals with significant disabilities, this Article takes the counterintuitive position that these individuals should be afforded access to government-coordinated habilitative care through Medicaid without regard to income or wealth. Under current market conditions, non-means-tested access to habilitative care is a normatively superior solution because it

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preserves the autonomy and dignity of individuals with disabilities and may be simultaneously cost-neutral and utility-increasing. Granting unrestricted access to government-coordinated habilitative care to individuals with significant disabilities would eliminate perverse employment and financial planning incentives created by Congress's past attempts to broaden access. Finally, it would create parity among parents who plan for the future of children with disabilities and those whose children are typically-abled, as well as parity for retirement savings among workers with significant disabilities and those without. As a result, Congress should revisit and revise means-tested access to disability-related services through Medicaid.

TABLE OF CONTENTS

I.	INTRODUCTION	1257
II.	A LAY PERSON'S BACKGROUNDER.....	1264
	A. <i>Antidiscrimination Law As an Incomplete Solution</i>	1264
	B. <i>Setting Goals for Reform</i>	1268
III.	THE IMPORTANCE OF HABILITATIVE CARE AND RESTRICTIONS ON ACCESS.....	1271
	A. <i>The Enactment of Waivers: A Shift from Custodialism to Integrationism</i>	1272
	B. <i>Waiver Services</i>	1274
	C. <i>Restrictions on Eligibility</i>	1275
	D. <i>Waiver Eligibility Is Generally Pegged to Medicaid Eligibility, and Medicaid Is Only Available to the Very Poor</i>	1277
	1. <i>Medicaid Eligibility Under Section 1634 of the Social Security Act</i>	1279
	2. <i>Medicaid Eligibility Under the 209(b) Option</i>	1281
	3. <i>Medicaid Eligibility Through Buy-In</i>	1282
	4. <i>Medicaid Eligibility Under the Affordable Care Act</i>	1284
IV.	TRUST PLANNING AND THE DELIBERATE IMPOVERISHMENT OF INDIVIDUALS WITH QUALIFYING DISABILITIES	1286
	A. <i>A Brief Explanation of Protection Trusts</i>	1287
	1. <i>Medicaid Payback Trusts</i>	1287
	2. <i>Pooled Trusts</i>	1289
	3. <i>Common Law Discretionary Trusts</i>	1289
	B. <i>Protection Trusts Are Not Enough</i>	1290
V.	THE ABLE ACT: A STEP FORWARD	1293
	A. <i>A Brief Description of the ABLE Act</i>	1293
	1. <i>The ABLE Act: A Long Awaited (Partial) Solution</i>	1295

2.	<i>Normative Weaknesses of the ABLE Act</i>	1299
a.	<i>Contribution Limits Measured by College Tuition Make No Sense In this Context</i>	1300
b.	<i>Placing the ABLE Account in the Internal Revenue Code Restricts Access but May Produce Structural Gains</i>	1304
c.	<i>Dignitary Concerns</i>	1307
VI.	REMOVAL OF MEANS TESTING FOR WAIVER SERVICES IS NORMATIVELY SUPERIOR TO ABLE ACCOUNTS OR ASSET PROTECTION TRUSTS	1308
A.	<i>Normative Considerations Favor Removal of Means Testing</i>	1308
1.	<i>Increased Autonomy</i>	1308
2.	<i>Less Reliance on Norms of the Able-Bodied</i>	1309
3.	<i>Potential for Cost Savings</i>	1310
4.	<i>Parity Among Families</i>	1312
B.	<i>Possible Objections to the Removal of Means Testing for Waiver Services</i>	1313
VII.	CONCLUSION.....	1317

I. INTRODUCTION

Thomas, a healthy and beautiful baby boy, was born in 2015 into an upper-middle class family. Within months of his birth, and with the assistance of a highly specialized attorney, his parents drafted a trust that, in the event of their deaths, would prevent him from ever using family resources to pay for food, shelter, or other necessary expenses. Next, the parents contacted their insurers, their employers, and their investment advisors to make sure that, in the event of their deaths, Baby Thomas would receive no life insurance proceeds and no payments from their retirement accounts. These, too, were given to the trust. Thomas's parents did everything in their power to make sure that when he reached adulthood, Thomas would be penniless and forced to rely on government assistance for his entire adult life. They even included language in the trust providing that any expense covered by a government program could not be covered by the trust. In other words, because Thomas would qualify for government-assisted housing, the trust could not help him with rent. Because the government would provide food assistance, the trust could not help Thomas with groceries. The trustee was expressly forbidden from making support payments to Thomas, and the trust document gave absolute discretion to the trustee, who could choose to make no payments at all. Stranger still, Thomas's legal impoverishment and his future reliance on public assistance are encouraged by federal law.

Why would Thomas's parents be so perverse, and why would federal law sanction their behavior? The answer is that he was born with Down Syndrome. Because of his disability, it is likely that Thomas will need assistance, usually referred to as "habilitative" care, to live and work in a community setting.¹ Habilitative care typically includes aids to daily living such as personal care, homemaking, transportation, and adult day care.² It also covers case management by a social worker and, for individuals who have a regular caretaker, respite care to provide the caretaker with a break.³ Habilitative care is crucial, particularly to individuals with intellectual and developmental disabilities. One study indicated that over 60% of these individuals need help with bathing, eating meals, and taking medications.⁴ Over 70% of them need help with finances and home maintenance, and over 80% of them need help using transportation.⁵ Although family members currently provide much of the habilitative care needed by individuals with disabilities, they cannot be omnipresent.⁶ Siblings have careers and families; parents age and die. Furthermore, habilitative services can be difficult to purchase and coordinate in the private market.⁷ For many, government-coordinated care is absolutely essential to maintain quality of life.

¹ See *Life After High School*, NAT'L DOWN SYNDROME SOC'Y (NDSS) [hereinafter NDSS], <http://www.ndss.org/Resources/Transition-and-Beyond/Life-After-High-School/> [<http://perma.cc/Z6L8-KDWT>] (describing supports needed to transition adults with Down Syndrome from high school into adult living).

² *Id.*

³ *Id.*

⁴ THE ARC, *STILL IN THE SHADOWS WITH THEIR FUTURE UNCERTAIN: A REPORT ON FAMILY AND INDIVIDUAL NEEDS FOR DISABILITY SUPPORTS (FINDS) 6* (June 2011), <http://www.thearc.org/document.doc?id=3672> [<http://perma.cc/7MML-BS5B>].

⁵ *Id.*

⁶ *Id.* ("Parents, siblings and family members struggle mightily so that their family member with I/DD can continue to live at home, or independently, and have a typical life. The majority of families report that they provide personal care . . ."); Sheryl Larson et al., *Characteristics of and Service Use by Persons with MR/DD Living in Their Own Homes or with Family Members: NHIS-D Analysis*, MR/DD DATA BRIEF (Research and Training Center on Community Living & Institute on Community Living (UAP), Minneapolis, Minn.), Apr. 2001, at 11, <http://rtc.umn.edu/docs/dddb3-1.pdf> [<http://perma.cc/TX8A-XVLG>] (finding that while only 20% of adults in the general population live with relatives, among those with intellectual or developmental disabilities 60% do).

⁷ See THE ARC, *supra* note 4, at 7–8 (finding that more than 75% of families report that they cannot find reliable care providers, and 80% report that they do not have enough money to pay for care that their family member with a disability needs); THE KAISER COMM'N ON MEDICAID & THE UNINSURED, *MEDICAID: A PRIMER* 10 (Mar. 2013) [hereinafter *MEDICAID PRIMER*], <https://kaiserfamilyfoundation.files.wordpress.com/2010/06/7334-05.pdf> [<https://perma.cc/D9UB-YZHC>] (reporting that individuals with disabilities often are unable to obtain adequate private coverage, and Medicaid allows them to obtain services needed to live and work in the community); see also Yael Zakai Cannon, *There's No Place Like Home: Realizing the Vision of Community-Based Mental Health Treatment for Children*, 61 DEPAUL L. REV. 1049, 1063 (attributing the limited access to

This Article is the first to address the newly enacted Achieving a Better Life Experience Act (the ABLE Act).⁸ The ABLE Act partially addresses outdated legal restrictions on access to government-provided habilitative care.⁹ Although it is a clear victory and a major improvement in financial planning for the disability community, its solution is incomplete. As we mark the fiftieth anniversary of Medicaid,¹⁰ the twenty-fifth anniversary of the Americans with Disabilities Act (ADA),¹¹ and the fifteenth anniversary of the Supreme Court's decision in *Olmstead v. L.C.*,¹² there still exists no comprehensive means of safeguarding the quality of life of individuals like Thomas. Under the ADA, employers are not required to make accommodations for personal needs of daily living, such as hygiene, nutrition, and transportation, without which employment and community living are impossible.¹³ Instead, this responsibility falls to the states, which must provide care to individuals with developmental disabilities "in the most integrated setting appropriate."¹⁴ The Supreme Court's decision in *Olmstead* requires states to provide support for community living when "the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities."¹⁵ Indeed, a series of sweeping consent decrees has brought to light the power of *Olmstead* by requiring states to provide an unprecedented level of job and personal support to individuals with serious disabilities who are living in community with their typically-abled peers.¹⁶

mental health care for children to the "frequent failure of private insurance" and lack of adequate government-provided resources).

⁸ Stephen Beck, Jr., Achieving a Better Life Experience Act of 2014, Pub. L. No. 113-295, 128 Stat. 4056 (codified at I.R.C. §§ 529A, 3511, 7705 (West Supp. 2015)) [hereinafter ABLE Act of 2014].

⁹ The purpose of the new law is to "assist individuals and families in saving private funds for the purpose of supporting individuals with disabilities [and t]o provide secure funding for disability-related expenses . . . that will supplement, but not supplant, benefits provided" through Medicaid and other government programs. ABLE Act of 2014, § 101, 128 Stat. at 4056.

¹⁰ Social Security Amendments of 1965, Pub. L. No. 89-97, § 121(a), 79 Stat. 286, 343-52 (codified as amended at 42 U.S.C. §§ 1396, 1396a-b, 1396c-d (2012)).

¹¹ Americans with Disabilities Act of 1990 (ADA), Pub. L. No. 101-336, 104 Stat. 327 (codified as amended at 42 U.S.C. §§ 12101-12213 (2012)).

¹² *Olmstead v. L.C.*, 527 U.S. 581 (1999).

¹³ See Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1, 25-26 & nn.95-101 (2004).

¹⁴ 28 C.F.R. § 35.130(d) (2015); see also 42 U.S.C. §§ 12131-12165 (codification of ADA Title II).

¹⁵ See *Olmstead*, 527 U.S. at 607.

¹⁶ U.S. Dep't of Justice, Civil Rights Div., *DOJ Olmstead Enforcement by Circuit Court*, ADA.GOV, [hereinafter *Olmstead Enforcement*], <http://www.ada.gov/>

Olmstead's new breadth is not enough. States provide some or all of the *Olmstead* mandates through Medicaid, and Medicaid is not universally available to individuals with serious disabilities. Instead, its reach is limited to those who live with very limited means. Income and asset limitations that bar access to Medicaid are impactful because states rely on Medicaid to provide *Olmstead*- and ADA-related services such as personal care and special job assistance, even when those services are not medical in nature.¹⁷ As a result, even the most sweeping consent decree or court decision under *Olmstead* may fail to provide greater access to disability-related services to individuals who are not Medicaid-eligible.

Because it dictates access not only to medical care but also to necessary disability-related social services, Medicaid eligibility is crucially important to people with developmental disabilities, and through it, the government coordinates and pays for many services that are either not supported by private markets or that are cost-prohibitive.¹⁸ Means testing, which is the limitation of Medicaid eligibility to individuals at low levels of income and asset holdings, creates a bar to access for individuals with disabilities. As a result, typically only those individuals who qualify for other forms of public assistance, such as public housing and food stamps, can receive such services through Medicaid.¹⁹ Those who have savings, who receive an inheritance from a family member, or who earn a living wage are ineligible, even though habilitative services may be critical to continued employment and life satisfaction.²⁰ For these people, securing access to Medicaid's disability-related services requires careful financial planning and limitations on employment. In light of these facts, the motivation of Thomas's parents becomes clear. In order to ensure his future access to habilitative services, Thomas's parents must turn him into a welfare claimant. Their seemingly bizarre choice preserves his access to disability-related social services that will enable him to avoid institutionalization when his parents can no longer care for him.²¹

olmstead/olmstead_enforcement.htm [<http://perma.cc/2Z7T-8SHX>] (describing court cases and consent decrees under *Olmstead*).

¹⁷ See Bagenstos, *supra* note 13, at 26 (noting that society's response to disability historically has been "heavily medicalized" and that personal assistance and adaptive technology "are typically regarded as 'medical' services for which the health insurance system is responsible").

¹⁸ *Id.* at 27–28 ("[P]rivate insurance—on which most nondisabled people rely for their health needs—fails to cover the services people with disabilities most need for independence and health.").

¹⁹ See *infra* Part III.D.

²⁰ See Bagenstos, *supra* note 13, at 27 ("[P]ublic insurance is saddled with requirements that lock people with disabilities out of the workforce.").

²¹ Under 42 U.S.C. § 1396p(d)(4)(A) (2012), assets in a federally sanctioned special needs trust are not counted as Thomas's assets for purposes of determining supplemental security income (SSI) or Medicaid eligibility.

As Thomas's example demonstrates, Medicaid eligibility rules create perverse incentives when applied to disability-related services that are cost-prohibitive or not readily available through private markets. Individuals with disabilities are incentivized to choose low-wage, volunteer, and part-time positions in order to preserve access to habilitative services. Furthermore, families like Thomas's must preemptively choose government dependency for their children, even when families would prefer to help with necessities like rent, groceries, utilities, or private medical insurance.

In an attempt to address perverse incentives created by Medicaid eligibility rules, Congress passed the ABLE Act in late December of 2014.²² This Article is the first to address the new legislation. Like the *Olmstead* consent decrees, the ABLE Act is both a vitally important lifeline and an insufficient one. It will allow individuals with significant disabilities and their families to save money for necessities without affecting Medicaid eligibility. But legislative compromises have limited its effectiveness. Contributions to savings are capped at a low amount that bears no relation to the magnitude of disability-related expenses, and easy fixes that could have both preserved the fisc and protected individuals with disabilities went unused.²³ Legal impoverishment, then, will remain a requirement for Medicaid eligibility for many people, and it will continue to be accomplished through the use of a federally sanctioned special needs trust like the one created for Thomas. These financial planning instruments may simultaneously force adult beneficiaries with disabilities to rely on public benefits such as housing, food assistance, and other entitlements while limiting their employment opportunities, denying them autonomy of decision-making, and interfering with natural family support relationships.

Access to Medicaid for individuals with significant disabilities must be broadened. Prior attempts to remedy the problem have relied on the resources and participation of private actors such as family members. These attempted fixes are important because they preserve access. But at the same time, they impose dignitary and financial costs on individuals with disabilities, their families, the federal budget, and society as a whole. They also impose distributional costs because not all individuals with disabilities have access to private assistance. There is no compelling normative justification for the imposition of these costs, and the law should be amended to reduce or eliminate them. A public, rather than a private solution must be found. Amendment must be done with a conscious regard for commonly accepted goals, including freedom from paternalism, maximization of the autonomy of individuals with disabilities and their family members, and integration of

²² See ABLE Act of 2014, Pub. L. No. 113-295, 128 Stat. 4056 (codified at I.R.C. §§ 529A. 3511. 7705 (West Supp. 2015)).

²³ I.R.C. § 529A(b) (limiting yearly contributions to the amount in effect under I.R.C. § 2503(b) (\$14,000 in 2015), and aggregate contributions to the limitation in effect for the relevant state's § 529 college savings accounts).

individuals with disabilities into the community to the extent possible and desired.²⁴

This Article takes a counterintuitive position. Individuals with significant disabilities should be entitled to disability-related services and habilitative care through Medicaid regardless of their level of income or wealth. This solution is public rather than private; it does not rely on private actors for its implementation. Broadening access to Medicaid in this way has the potential to both increase tax revenue and reduce costs for state and federal government. By removing poverty as a barrier to access, government can offer disability-related services to a broader segment of the population, enabling more individuals to enter the workforce. In addition, removing poverty as a barrier to access will eliminate perverse financial planning incentives that currently result in the artificial impoverishment of individuals with disabilities who then rely on non-disability-related government programs such as food and housing assistance.

In recognition of the political difficulty and potential distributional concerns raised by the creation of a new entitlement, the Article offers a second solution: the removal of means testing as a bar to government-coordinated habilitative care coupled with an income and asset insensitive Medicaid buy-in model for individuals at high levels of income or asset holding. If the unique fact of disability is found insufficient to justify the provision of habilitative care at no cost to the recipient, individuals with disabilities who have access to large pools of resources could be asked to pay either for inclusion in Medicaid and/or for government coordination of their services. To entirely deny these individuals access to government-coordinated, disability-related services, as the current law often does, makes little sense from either a normative or pragmatic perspective if these services are difficult to find or cost-prohibitive on the private market.²⁵ Furthermore, broadening the constituency for government-coordinated, disability-related services is likely to bring political pressure to bear that might result in better, higher quality, or more varied services in the future.

Part II of this Article provides a brief overview of federal attempts to foster the integration of individuals with serious disabilities into the community. It also explains why these attempts have been insufficient to address the distinctive needs of those individuals. To date, the federal government has

²⁴ See Bagenstos, *supra* note 13, at 7–8 (noting consensus among “diverse disability rights activists” on the subjects of paternalism and integration).

²⁵ One objection may be that if Medicaid resources are scarce, entry of wealthier individuals into the program will result in a shortage that will be detrimental to all enrollees. This argument ignores the possibility that a new revenue stream would allow Medicaid to expand its network of service providers. In addition, to the extent that Medicaid is currently viewed as a program for the poor, there may be less political will to improve or expand its disability-related services. Entry of individuals of higher socioeconomic position into the system may raise its political visibility and result in better or more services.

focused primarily on preventing overt discrimination on the basis of disability. There is, however, a growing recognition on the part of scholars and advocates that individuals with intellectual or other serious disabilities often need not only antidiscrimination measures but also specialized social support tailored to their distinctive needs.²⁶ Part II concludes by drawing upon this insight to set normative goals for the revision of Medicaid eligibility guidelines that determine access to government-coordinated habilitative care.

Part III describes the importance of a particular form of social support—Medicaid-funded waiver services for the provision of government-coordinated habilitative care—and describes laws that both mandate and restrict access to those services. Waiver services, which allow individuals with intellectual disabilities to live in the community rather than in an institution, are difficult to purchase privately.²⁷ Their provision is not, however, universally mandated by the ADA. Rather, their availability is governed by state law and may be severely restricted on the basis of a recipient's income and asset holdings.²⁸ As a result, individuals with disabilities and their families are presented with perverse incentives for minimization of work and saving as a means of preserving access to disability-related services.

Part IV describes special needs trust planning, through which the federal government and some states have provided a means to work around state income and asset holding restrictions on Medicaid eligibility. This Part argues that special needs trust planning, while important, is normatively inferior to other solutions because it disproportionately burdens less wealthy or less legally sophisticated families and imposes dignitary and emotional harms on the trust beneficiary and the beneficiary's family. In addition, because it relies on private actors for its implementation, special needs trust planning is not available to all individuals with disabilities.

Part V describes the ABLE Act, a recent addition to the Internal Revenue Code. The ABLE Act provides a second means of preservation of Medicaid

²⁶ See, e.g., Bagenstos, *supra* note 13, at 4 (“[T]he future of disability law lies as much in social welfare law as in antidiscrimination law.”); Ruth Colker, *Anti-Subordination Above All: A Disability Perspective*, 82 NOTRE DAME L. REV. 1415, 1421–22 (2007) (arguing that modern disability law should “leav[e] room for modern approaches to the delivery of separate services and maintenance of some disability-only institutions”); Francine J. Lipman, *Enabling Work for People with Disabilities: A Post-Integrationist Revision of Underutilized Tax Incentives*, 53 AM. U. L. REV. 393, 409 (2003) (calling for more aggressive redistribution to individuals with disabilities); Theodore P. Seto & Sande L. Buhai, *Tax and Disability: Ability to Pay and the Taxation of Difference*, 154 U. PA. L. REV. 1053, 1062 (2006) (noting that census data indicate that roughly half of all public benefits claimants have a disability); Mark C. Weber, *Disability and the Law of Welfare: A Post-Integrationist Examination*, 2000 U. ILL. L. REV. 889, 942–56 (proposing amendments to welfare law affecting individuals with disabilities).

²⁷ See THE ARC, *supra* note 4, at 7–8 (more than 75% of families report that they cannot find reliable care providers, and 80% report that they do not have enough money to pay for care that their family member with a disability needs).

²⁸ See *infra* Part III.C–D.

eligibility for individuals with intellectual or other serious disabilities by creating a tax-preferred savings account, the contents of which are not counted against Medicaid eligibility. This Part argues that although passage of the ABLE Act was a watershed moment for individuals with intellectual disabilities in the workforce, it remains a second-best solution. Once again, it relies on private actors for its implementation, but not all individuals with disabilities have access to private assistance or funds. As a result, like many tax expenditures, the ABLE Act favors legally sophisticated families who have disposable income. It may provide little or no additional Medicaid access to others.

Part VI concludes that removal of income and asset restrictions on the provision of government-coordinated habilitative care is a superior, if counter-intuitive, solution. It is a public solution that does not rely on private actors or funds for its implementation. It would satisfy normative goals on multiple fronts by preserving the autonomy of individuals with intellectual or other serious disabilities, by eliminating perverse incentives that encourage reduced employment and counterproductive trust planning, and by removing barriers that exclude families with lesser access to disposable income or legal advice. In addition, higher levels of workforce participation and saving by individuals with disabilities and their families would lessen the dependency of those individuals on non-disability-related government programs, freeing assets in those programs for other uses.

II. A LAY PERSON'S BACKGROUNDER

A. Antidiscrimination Law As an Incomplete Solution

Calls for disability law reform have evolved from custodialism to post-integrationism over several decades.²⁹ Prior to the 1970s, the prevailing norm for care of individuals with disabilities was custodialism, in which individuals with significant disabilities were cared for in institutional settings.³⁰ The late 1960s, with the rise of the civil rights movement, marked a turning point in legal thinking about disability, with advocates calling for full inclusion of individuals with disabilities into work and community life.³¹ Called "integrationism" by its founders, Jacobus tenBroek and Floyd Matson, this movement was "part of a progression from the idea that others need to care for and protect persons with disabilities—custodialism—toward the idea that persons with disabilities should assert their own rights to equal treatment."³²

²⁹ See Weber, *supra* note 26, at 890–91 (observing that since the mid-twentieth century, "dramatic changes have occurred in the field of disability equality").

³⁰ See Seto & Buhai, *supra* note 26, at 1055–56 (providing an overview of the development of the post-integrationist model of disability law).

³¹ *Id.*; see also Weber, *supra* note 26, at 889 (describing progression in legal thinking).

³² Weber, *supra* note 26, at 890.

The late twentieth century saw notable victories of integrationism over custodialism in federal law, culminating in Congress's 1990 enactment of the ADA.³³ As the Supreme Court noted in *Olmstead*, the preamble to the ADA observes that "historically, society has tended to isolate and segregate individuals with disabilities," and that "discrimination against individuals with disabilities persists in such critical areas as . . . institutionalization."³⁴ Accordingly, Title I of the ADA prohibits discrimination in employment.³⁵ Title II prohibits discrimination in public services provided by government,³⁶ and Title III prohibits discrimination in public accommodations provided by private actors.³⁷

The Supreme Court's decision in *Olmstead* was also a victory for integration, albeit a measured one.³⁸ The case involved two women who were confined to the psychiatric unit of an Atlanta hospital but who could have been given appropriate care in a community setting.³⁹ The women claimed that Georgia's failure to provide such care violated Title II of the ADA.⁴⁰ In its ruling for the plaintiffs, the Supreme Court wrote that institutionalization "severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."⁴¹ In construing the ADA's mandate that individuals with disabilities not "be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity,"⁴² the Court looked to a regulation of the Attorney General requiring public entities, such as the Atlanta hospital, to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."⁴³ The Court concluded that states must provide treatment in

³³ The most celebrated of these, the ADA, prohibits discrimination on the basis of disability "in private employment, state and local governmental services, public accommodations, public transportation, communications, and other activities." *Id.* at 890–91. Precursors to the ADA included the Rehabilitation Act of 1973, which "forbade discrimination against persons with disabilities in federally assisted activities," and the Education for All Handicapped Children Act of 1975, which "required that all children with disabilities receive a free, appropriate public education." *Id.* at 890.

³⁴ *Olmstead v. L.C.*, 527 U.S. 581, 588 (1999) (alteration in original) (quoting 42 U.S.C. § 12101(a)(2)–(3)).

³⁵ Americans with Disabilities Act of 1990 (ADA), Pub. L. No. 101-336, §§ 101–108, 104 Stat. 327, 303–37 (codified as amended 42 U.S.C. §§ 12111–12117 (2012)).

³⁶ *Id.* §§ 201–246, 104 Stat. at 337–53 (codified as amended at 42 U.S.C. §§ 12131–12165 (2012)).

³⁷ *Id.* §§ 301–310, 104 Stat. at 353–65 (codified as amended at 42 U.S.C. §§ 12181–12189 (2012)).

³⁸ See generally *Olmstead*, 527 U.S. 581.

³⁹ *Id.* at 581 (syllabus).

⁴⁰ *Id.*

⁴¹ *Id.* at 601.

⁴² 42 U.S.C. § 12132.

⁴³ *Olmstead*, 527 U.S. at 592 (quoting 28 C.F.R. § 35.130(d) (1998)).

the community rather than in an institution when state medical professionals determine that a community placement is appropriate; the individual with a disability does not oppose community placement; and “the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.”⁴⁴ In other words, the requirements of the ADA are met if a state has “a comprehensive, effectively working plan” to place individuals with disabilities “in less restrictive settings,” and a wait list that moves “at a reasonable pace not controlled by the State’s endeavors to keep its institutions fully populated.”⁴⁵ Two things are notable about the Court’s decision. First, integration was clearly the driving force behind the Court’s decision, and second, the Court struck a very pragmatic balance between the interests of states and those of individuals with disabilities.

In recent years, litigated disputes between the federal government and the states have highlighted the potential reach of *Olmstead* and have increased access to community integration for individuals with disabilities who receive government-coordinated habilitative care.⁴⁶ For example, a recent consent decree with Rhode Island requires the state to provide work opportunities for individuals with serious disabilities who are currently participating in sheltered workshops or who are graduating from high school.⁴⁷ The state must provide support for forty hours during the work week, with the expectation that individuals will work, on average, in a supported employment job at competitive wages for at least twenty hours per week.⁴⁸ For the remainder of the time, the state will assist individuals in community living “by aiding the development of social capital, including broad personal and professional networks, and individuals’ active participation and membership in integrated settings.”⁴⁹ In addition, services “must include an adequate mix of leisure, employment-related, and daily life activities that are comparable to those activities” of typically-abled peers.⁵⁰ An interim agreement with Texas requires the state to extend additional community living options to Medicaid-eligible individuals currently in congregate care, including “supported and competitive employment, community volunteer activities, community learning and recreational opportunities, and other integrated day activities.”⁵¹ The government reached a similar settlement with Virginia that applies only to

⁴⁴ *Id.* at 607.

⁴⁵ *Id.* at 605–06 (opinion of Ginsburg, J.).

⁴⁶ See *Olmstead Enforcement*, *supra* note 16 (providing summaries of and links to litigated disputes).

⁴⁷ Consent Decree at 11–13, *United States v. Rhode Island*, No. 1:14-CV-00175-L-PAS (D. R.I. Apr. 8, 2014).

⁴⁸ *Id.*

⁴⁹ *Id.* at 12.

⁵⁰ *Id.*

⁵¹ Interim Settlement Agreement at 9, *Steward v. Perry*, No. 5:10-CV-01025-OG (W.D. Tex. Aug. 26, 2013).

those individuals who qualify for state assistance or who are currently residing in an institution.⁵² An agreement with Georgia requires the state to cease admitting individuals with disabilities to state-operated institutions entirely and to instead provide home and community based habilitative care, including supports for the families of individuals with disabilities.⁵³ These broad agreements undoubtedly facilitate the integration of individuals with disabilities into the community in states where they apply.

While they are great victories, the *Olmstead* consent decrees are not enough. They do not adequately protect individuals with disabilities who do not qualify for government assistance on financial grounds. Title II of the ADA prohibits discrimination in access to public services by requiring that “no qualified individual with a disability shall, *by reason of such disability*, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”⁵⁴ The ADA says nothing about the exclusion of individuals from government programs on the basis of income, despite the fact that individuals with disabilities who wish to live in the community may need access to government programs that are not adequately replicated in the private market.⁵⁵ To benefit from the breadth of the ADA under the *Olmstead* decrees, most individuals with disabilities still must qualify for Medicaid.⁵⁶

Medicaid eligibility remains a critical and high hurdle to the receipt of government-coordinated habilitative care. As the twenty-fifth anniversary of the ADA and the fifteenth anniversary of *Olmstead* approach, it has become clear that the simple prohibition on discrimination embodied in the ADA is not sufficient to safeguard the quality of life of individuals with disabilities, and particularly individuals with intellectual disabilities.⁵⁷ Integration must be accompanied by social support that is available to all individuals with significant disabilities and not just those whose level of impoverishment qualifies them for Medicaid.

⁵² Settlement Agreement at 3, *United States v. Virginia*, No. 3:12-CV-00059-JAG (E.D. Va. Aug. 23, 2012) (defining target population for receipt of services described in the settlement).

⁵³ Settlement Agreement at 5, *United States v. Georgia*, No. 1:10-CV-249-CAP (N.D. Ga. Oct. 19, 2010).

⁵⁴ ADA, 42 U.S.C. § 12132 (2012) (emphasis added).

⁵⁵ See *supra* note 7 and accompanying text.

⁵⁶ For a discussion of the impact of *Olmstead* on entitlement to home-based community services for individuals who meet means testing requirements, see generally Mark C. Weber, *Home and Community-Based Services, Olmstead, and Positive Rights: A Preliminary Discussion*, 39 WAKE FOREST L. REV. 269 (2004).

⁵⁷ See Colker, *supra* note 26, at 1422–23 (“Support for integration has not always accompanied support for genuine equality as measured by the principle of anti-subordination.”).

B. *Setting Goals for Reform*

Current scholarship on disability theory recognizes not only the need for prohibitions on discrimination but also the need for positive intervention to remove structural barriers that prevent individuals with disabilities from accessing and participating in the workforce and community.⁵⁸ For example, although an employer may not exclude an otherwise qualified employee on the basis of disability, nothing in the ADA requires the employer to help the employee choose appropriate clothing or travel to work.⁵⁹ The needs for these things—a separate workplace location and a particular style of dress, such as a wrinkle-free shirt—are social constructs based on typically-abled employees, and they create barriers to employment that are not mitigated by a simple ban on discrimination.⁶⁰ As Ted Seto and Sande Buhai have described it, these impediments to full participation “have not been decreed by immutable natural laws They represent conscious choices that had the effect of including some groups, such as the dominant segments of society, and excluding others who were ‘different’ or disabled.”⁶¹ Currently, the costs of removing these barriers to full participation in work and other community activities fall primarily not on those who have created them, but rather on individuals with disabilities.⁶² These individuals, however, may not be well-positioned to defray such costs and are therefore disadvantaged in both the workplace and the community.⁶³

Mitigation of structural barriers can be accomplished in part through laws that either remove them or provide a means of surmounting them. The social safety net is of critical importance in this regard.⁶⁴ “In short,” Samuel Bagenstos has argued, “the future of disability law lies as much in social welfare law as in antidiscrimination law.”⁶⁵ Similarly, Francine Lipman has written, “If people with disabilities are to realize the promise of emancipation, society must . . . implement more aggressive measures that redistribute power and material resources in their favor.”⁶⁶ Medicaid eligibility, and in particular the way in which it affects the eligibility pool for government-coordinated habilitative services, is an obvious target for reform.

⁵⁸ See Lipman, *supra* note 26, at 411 (“Specialized treatment is necessary to provide people with disabilities as a group sufficient power to end their disadvantaged status.”).

⁵⁹ See Bagenstos, *supra* note 13, at 25–26 (describing structural barriers to employment).

⁶⁰ *Id.*

⁶¹ Seto & Buhai, *supra* note 26, at 1072 (quoting Harlan Hahn, *Accommodations and the ADA: Unreasonable Bias or Biased Reasoning?*, 21 BERKELEY J. EMPL. & LAB. L. 166, 174 (2000)).

⁶² Lipman, *supra* note 26, at 409.

⁶³ *Id.* at 410 (observing that individuals with disabilities “have neither the resources nor the opportunities to achieve superiority”).

⁶⁴ See *id.* (calling for redistribution to individuals with disabilities).

⁶⁵ Bagenstos, *supra* note 13, at 4.

⁶⁶ Lipman, *supra* note 26, at 410.

Autonomy and integrated living, to the extent that they are feasible and desired by particular individuals with disabilities, have historically been and should remain important goals of reform.⁶⁷ Both are forwarded by access to habilitative services such as in-home assistance, transportation assistance, and adaptive equipment. Without these goals, and without such services, the law may regress toward custodialism. More than 187,000 individuals with intellectual or developmental disabilities lived in state institutions in 1967.⁶⁸ That number had fallen below 34,000 in 2009, and today, most individuals with intellectual or developmental disabilities live with their families.⁶⁹ Without a continued focus on fostering autonomy and independent living for these individuals, families will be unable to meet the challenges posed by caretaking.⁷⁰ These families have very little market recourse, and without government assistance, integrated living arrangements may become unduly difficult.⁷¹

Because of the distinctive needs of individuals with disabilities, antidiscrimination measures have proven inadequate to address barriers to integration.⁷² A second goal for reform should be to revise Medicaid eligibility rules in a way that avoids reliance on norms that have developed over time with reference to people who are typically-abled. “[S]pecial treatment for people with disabilities remains necessary in society and in the economy.”⁷³ As a result, scholars and advocates for reform must “imagine a world that acknowledges the fact of disability but avoids relying on norms and standards drawn with reference to the nondisabled individual.”⁷⁴ These norms include adult self-sufficiency, the expectation of regular employment, literacy, and numeracy among others.⁷⁵ Stated more specifically, current Medicaid

⁶⁷ Bagenstos, *supra* note 13, at 7–8 (noting “broad agreement among diverse disability rights activists” on goals of autonomy and full integration).

⁶⁸ THE ARC, *supra* note 4, at 3.

⁶⁹ *Id.*

⁷⁰ *See id.* at 6 (nearly half of all caregivers report that they have more caregiving responsibilities than they can handle, and in twenty percent of families, one member has quit a job to stay home and provide support).

⁷¹ For instance, in the FINDS survey, more than eighty percent of families reported problems with finding noninstitutional community services, trained reliable home care providers, or respite services. *Id.* at 7.

⁷² *See* Bagenstos, *supra* note 13, at 4–5 (“Although this point may not be obvious from a scan of legal scholarship, activists ‘on the ground’ have increasingly understood the importance of the social welfare system to achieving the goals of the disability rights movement.” (footnote omitted)); Weber, *supra* note 26, at 891 (“The economic role of people with disabilities continues to depend less on the law of employment discrimination than on the law of welfare . . .”).

⁷³ Weber, *supra* note 26, at 891.

⁷⁴ *Id.* at 891–92.

⁷⁵ For instance, Mark Weber has argued that designing reasonable accommodations with reference to typically-abled people may further the integration of individuals with disabilities but may not fully address concerns about dignity and equality. Mark C. Weber, *Disability Rights, Welfare Law*, 32 CARDOZO L. REV. 2483, 2503–08 (2011).

eligibility rules assume that an adult who earns a sufficient amount of income or who possesses a sufficient amount of assets does not need habilitative assistance. In addition, the rules assume that a Medicaid claimant is able to understand the import of income and asset guidelines and to comply with them. This assumption may be unfounded in the case of individuals with intellectual and developmental disabilities, and yet failure to comply with the rules can result in the loss of habilitative care. Finally, by penalizing through loss of benefits individuals with disabilities who receive financial assistance from family and friends, the law embodies a stark false dichotomy between dependent and independent living. The issue of means testing was not addressed by the Affordable Care Act, meaning that change remains necessary.⁷⁶ Any reform to the Medicaid eligibility rules affecting the provision of habilitative care should be cognizant of such assumptions. Making access to Medicaid waiver services dependent upon the income and asset holdings of the individual recipient does little to forward that vision. Rather, it imposes upon the individual and his or her family a social construct that direct beneficiaries of the social safety net must be economically poor.

As a third goal, reform should abandon facial neutrality of the law in favor of equality of opportunity to maximize individual utility.⁷⁷ (For the sake of simplicity, I will refer to this as “opportunity” or “quality of life,” although as I discuss in Part V, the distinctive needs of individuals with significant disabilities and the lack of homogeneity among their typically-abled counterparts make true comparison impossible for purposes of assessing horizontal equity. My comparison here is simply for the sake of rough justice.) Although strict income and/or asset limitations currently apply to all Medicaid claimants (i.e., the law is somewhat neutral on its face), the interaction of physical, intellectual, and developmental impediments with structural barriers to inclusion produces an adverse impact on individuals with significant disabilities.⁷⁸ For all other claimants, the eligibility rules act as a gatekeeper to Medicaid programs that cover traditional healthcare, but for individuals with significant disabilities, they regulate access to both traditional healthcare and government-coordinated habilitative care. Without habilitative care, individuals with significant disabilities cannot have opportunities for the maximization of personal utility that are functionally equivalent to those of

⁷⁶ For a discussion of the Affordable Care Act’s effect on access to disability-related social services, see *infra* Part III.D.4.

⁷⁷ Here, I am not referring to opportunities for employment, but rather to opportunities for an individual to maximize his or her utility. Maximization of personal utility might, for some individuals, come from employment, but for others, it might come from taking a class, enjoying time outside, or simply having company. Because the spectrum of disabilities covered by government-coordinated habilitative care is wide, a one-size-fits-all definition of opportunity (such as employment) would not be appropriate.

⁷⁸ I am not claiming that individuals with severe disabilities are the *only* subgroup of Medicaid claimants that are adversely impacted. Because they are the focus of my inquiry, though, I will confine my discussion to the impact of eligibility rules on those individuals.

their typically-abled counterparts.⁷⁹ To produce some semblance of neutrality with regard to opportunity, the law must account for the different ex ante positions of individuals with disabilities and those without. Medicaid income and asset limitations not only prevent individuals with significant disabilities from claiming traditional healthcare, but they also bar the delivery of services uniquely tailored to distinctive natural impediments as well as socially constructed barriers to full participation in the community. Failure to meet the income and asset requirements, then, affects more than just medical outcomes for individuals with significant disabilities. It also affects social and economic wellbeing; education and employment opportunities; political influence; and the satisfaction of other preferences tied to community living. Because Medicaid eligibility requirements produce this disparate result solely with reference to significant disability, they are discriminatory in their effect and should be amended to account not for the relative economic position of claimants ex ante but for the effect of eligibility on their opportunities and quality of life ex post.⁸⁰

III. THE IMPORTANCE OF HABILITATIVE CARE AND RESTRICTIONS ON ACCESS

Social support, particularly habilitative care, is essential to the integration of individuals with developmental disabilities into the community.⁸¹ As Professor Bagenstos has noted, “[M]any individuals with disabilities face significant barriers to employment that operate well before they are ever in a position to be discriminated against”⁸² This is because they may have difficulty with everyday activities. As a result, “[m]any people with disabilities need personal-assistance services—attendants who assist with personal hygiene and other activities of daily living—to help them get out of bed and get to work.”⁸³ In addition, these individuals may require assistive technology and transportation alternatives to fully participate in community life.⁸⁴

Statistics bear out the asserted need for habilitative care. A 2001 study estimated that over 65% of individuals with intellectual or developmental disabilities need assistance with activities of daily living, including bathing,

⁷⁹Larson et al., *supra* note 6, at 6 (finding that over 65% of individuals with intellectual or developmental disabilities need assistance with activities of daily living).

⁸⁰I recognize that under some theories of justice, this argument may lead to the conclusion that groups other than individuals with severe disabilities should receive government-coordinated habilitative care. This, however, is not the subject of my inquiry, so I will not address it in this paper. I also do not attempt to argue that the Medicaid eligibility rules are unconstitutional as a result of disparate impact.

⁸¹See NDSS, *supra* note 1.

⁸²Bagenstos, *supra* note 13, at 25.

⁸³*Id.*

⁸⁴*Id.* at 26.

dressing, eating, using a toilet, and getting in and out of bed.⁸⁵ In a 2010 national survey, more than 40% of family caregivers reported that individuals with intellectual or developmental disabilities had unmet needs “getting outside of the home for errands or to see a doctor . . . , managing finances . . . , transportation . . . , and household management.”⁸⁶ More than 80% of family caregivers also reported providing transportation, cooking, doing laundry, or cleaning the house for their family member with a disability.⁸⁷ Over 70% reported providing support with financial affairs, social arrangements, monitoring outside services, home maintenance, or recreational activities.⁸⁸ Sixty-nine percent provided help with administration of medications, and sixty-one percent aided in personal care and toilette.⁸⁹ *Eighty-four percent of these families reported difficulty in finding reliable home care providers;*⁹⁰ *80% did not have enough money to pay for care;*⁹¹ *and only 8% received private insurance funds to cover the cost of providing such care.*⁹² Failure of the private market for habilitative care is clear, and government assistance is justified in this context.

States typically provide coordinated habilitative care through a program colloquially referred to as a Medicaid or HCBS “waiver.”⁹³ This section will provide a brief history of waiver programs, and it will describe, in pragmatic terms, the importance of waiver programs to individuals with intellectual disabilities. Finally, because access to waiver programs requires Medicaid eligibility, this section will describe Medicaid eligibility requirements that may apply to individuals with intellectual disabilities in various states.

A. The Enactment of Waivers: A Shift from Custodialism to Integrationism

A 1981 amendment to section 1915(c) of the Social Security Act—the Home and Community-Based Services (HCBS) waiver program—permits the federal government to waive certain Medicaid eligibility requirements,

⁸⁵ Larson et al., *supra* note 6, at 6.

⁸⁶ LYNDY ANDERSON ET AL., UNIV. OF MINN., RESEARCH & TRAINING CTR. ON CMTY. LIVING, 2010 FAMILY AND INDIVIDUAL NEEDS FOR DISABILITY SUPPORTS (FINDS) NATIONAL SURVEY, TECHNICAL REPORT PART 1, at 9–10 (May 2011), <http://www.thearc.org/document.doc?id=3673> [<http://perma.cc/Q2MN-8K6F>] [hereinafter 2010 FINDS SURVEY].

⁸⁷ *Id.* at 10.

⁸⁸ *Id.*

⁸⁹ *Id.*

⁹⁰ *Id.* at iv.

⁹¹ *Id.* at 24.

⁹² 2010 FINDS SURVEY, *supra* note 86, at 12.

⁹³ This a shortened way of referring to the Home and Community-Based Services (HCBS) Waiver program, which was enacted in section 1915(c) of the Social Security Act to provide community-based alternatives to institutionalization for individuals who are elderly, handicapped, or have intellectual disabilities. See 42 U.S.C. § 1396n(c) (2012).

allowing states to offer community-based care as an alternative to institutionalization for individuals who are elderly or who have qualifying disabilities.⁹⁴ Prior to the federal government's creation of the waiver program, many individuals with intellectual or other qualifying disabilities received habilitative care solely within the confines of an institution.⁹⁵

Several factors led to Congressional recognition that community-based care was an important addition to social safety net.⁹⁶ First, waivers were seen as "a first step towards recognizing that many individuals at risk of institutionalization can be supported in their homes and communities, thereby preserving their independence and bonds to family and friends, at a cost not higher than institutional care."⁹⁷ This was important because those individuals "frequently reported an unsatisfactory quality of life."⁹⁸ Second, institutionalization was too common.⁹⁹ A number of studies showed that "at least one-third of persons residing in nursing facilities that were Medicaid funded would have been capable of living at home or in community residential settings if additional supportive services were available."¹⁰⁰ Finally, institutionalization was too costly.¹⁰¹ At the time, "[a] disproportionate percentage of Medicaid resources were being used for institutional long-term care."¹⁰² Furthermore, the cost was not likely to decline.¹⁰³ A contemporaneous study predicted that Medicaid nursing home expenditures

⁹⁴ See *id.*; see also Mary Jane Duckett & Mary R. Guy, *Home and Community-Based Services Waivers*, HEALTH CARE FINANCING REV., Fall 2000, at 123, 123, <http://www.cms.gov/Research-Statistics-Data-and-Systems/Research/HealthCareFinancingReview/downloads/00fallpg123.pdf> [<http://perma.cc/6ETN-LRGX>]; Allen J. LeBlanc et al., *Medicaid 1915(c) Home and Community-Based Services Waivers Across the States*, HEALTH CARE FINANCING REV., Winter 2000, at 159, 159–60, <http://www.cms.gov/Research-Statistics-Data-and-Systems/Research/HealthCareFinancingReview/downloads/00winterpg159.pdf> [<http://perma.cc/QNV6-HTCJ>].

⁹⁵ See Colker, *supra* note 26, at 1427–28 (describing the rise in prevalence of residential institutions serving individuals with disabilities during the 1950s through 1970s).

⁹⁶ It is worth noting that waiver services are also available not only to individuals with intellectual disabilities, but also to some individuals who are elderly or who have a certain physical disabilities. 42 C.F.R. § 441.301(b)(6) (2015) provides that states may provide a waiver to the aged or disabled, individuals with intellectual or developmental disabilities, and individuals with mental illness.

⁹⁷ See Duckett & Guy, *supra* note 94, at 123.

⁹⁸ *Id.*

⁹⁹ *Id.*

¹⁰⁰ *Id.*; see also A.E. Benjamin, *An Historical Perspective on Home Care Policy*, 71 MILBANK Q. 129, 145 (1993) (describing conclusion of the Congressional Budget Office that up to between twenty to forty percent of individuals in institutions could be cared for less intensively).

¹⁰¹ Duckett & Guy, *supra* note 94, at 123.

¹⁰² *Id.*

¹⁰³ Benjamin, *supra* note 100, at 145.

would triple over the coming decade,¹⁰⁴ but in 1981, Congress and the Reagan administration slashed the federal budget.¹⁰⁵ Waivers were statutorily required to “provide a cost-neutral alternative to institutional care, requiring the States to keep waiver costs at or below those of comparable institution-based service.”¹⁰⁶ Finally, the matter carried some urgency as courts across the country were issuing orders to “deinstitutionalize persons with developmental disabilities.”¹⁰⁷ Congress’s recognition of the need for some autonomy and community access, coupled with courts’ move toward forced deinstitutionalization culminated in the creation of waiver programs across the country and signaled a move away from a custodial model of care for individuals with developmental disabilities.

B. Waiver Services

Waiver programs allow states to provide a wide range of habilitative services through Medicaid.¹⁰⁸ These services typically include aids to daily living such as personal care, homemaking, companionship, transportation, and adult day care.¹⁰⁹ They also include case management by a social worker, and for individuals who have a regular caretaker, respite care which provides the regular caretaker with a break.¹¹⁰ The Social Security Act explicitly provides for those enumerated services, but other services can be provided by a state if the federal government approves the service.¹¹¹ Because of this, “[s]tates have a great deal of flexibility in designing their own unique HCBS waiver program(s).”¹¹² The original waivers focused on the individuals who were elderly or who had a qualifying disability (typically an intellectual disability) but the program has evolved to include waiver services that assist individuals with “physical disabilities, acquired immunodeficiency syndrome (AIDS), acquired brain injuries and other forms of severe disability, including, to a limited extent, chronic mental illness.”¹¹³

¹⁰⁴ *Id.*

¹⁰⁵ John William Ellwood, *Congress Cuts the Budget: The Omnibus Reconciliation Act of 1981*, PUB. BUDGETING & FIN., Spring 1982, at 50, 50, <http://onlinelibrary.wiley.com/doi/10.1111/1540-5850.00549/pdf> [<http://perma.cc/E57W-38VW>].

¹⁰⁶ See LeBlanc et al., *supra* note 94, at 160.

¹⁰⁷ Duckett & Guy, *supra* note 94, at 123.

¹⁰⁸ 42 C.F.R. § 440.180(b) (2015) (listing specific services, including the following: (1) case management, (2) homemaker, (3) home health aide, (4) personal care, (5) adult day health care, (6) habilitation, and (7) respite care).

¹⁰⁹ *Id.*

¹¹⁰ *Id.*

¹¹¹ See Duckett & Guy, *supra* note 94, at 124.

¹¹² See *id.*

¹¹³ LeBlanc et al., *supra* note 94, at 159–60.

Various states provide a range of waiver services to individuals with qualifying disabilities.¹¹⁴ For instance, in Illinois, the Persons with Disabilities Waiver provides services including a personal assistant, home health aide, homemaker, adult day care, and specialized medical equipment.¹¹⁵ Similarly, the Adults with Developmental Disabilities Waiver provides services including home accessibility modifications, personal support, vehicle modification, skilled nursing, and occupational, speech and physical therapy.¹¹⁶ Another state, Ohio, provides services as varied as adult daycare, home delivered meals, and even pest control.¹¹⁷ All of these are examples of services that recognize the individual needs of people with qualifying disabilities while allowing them to live more independently in the larger community.

C. Restrictions on Eligibility

Waivers, while generally necessary for supported community living, are not universally available to individuals with disabilities. Instead, eligibility is restricted on the basis of medical and financial need.¹¹⁸ Because waivers were created as an alternative to institutionalization, federal regulations initially required states to offer them only to individuals who were eligible to be institutionalized.¹¹⁹ That restriction was loosened in 1997, and states may now choose to extend services to some individuals who would not qualify for institutional care.¹²⁰ In addition, federal law places financial restrictions on the receipt of waiver services.¹²¹ “States have the option of setting financial eligibility criteria for the 1915(c) waivers at the same level as those for institutional placement, up to 300 percent of [the \$2,000] Supplemental

¹¹⁴ All fifty states provide waiver services to some degree. For additional information on states’ allocation of resources to waiver programs, see *Medicaid Section 1915(c) Home and Community-Based Services Waivers Participants, by Type of Waiver*, KAISER FAM. FOUND., <http://kff.org/health-reform/state-indicator/participants-by-hcbs-waiver-type/> [<http://perma.cc/8JVE-YWW5>].

¹¹⁵ *Persons with Disabilities*, ILL. DEP’T HEALTHCARE & FAM. SERVS., <http://www.illinois.gov/hfs/MedicalClients/HCBS/Pages/disabilities.aspx> [<http://perma.cc/MG4X-N9CK>].

¹¹⁶ *Adults with Developmental Disabilities*, ILL. DEP’T HEALTHCARE & FAM. SERVS., <http://www.illinois.gov/hfs/MedicalClients/HCBS/Pages/DD.aspx> [<http://perma.cc/CK9C-NBFW>].

¹¹⁷ For a fuller description of Ohio’s waiver services, see *infra* note 128 and accompanying text.

¹¹⁸ For a description of eligibility restrictions, see LeBlanc et al., *supra* note 94, at 160.

¹¹⁹ 42 C.F.R. § 441.302(c)(1) (2015) (requiring that an evaluation show a reasonable chance that the individual would require institutional care within a month if waiver services are not provided).

¹²⁰ 42 U.S.C. § 1396n(i) (2012).

¹²¹ *Id.* § 1396a(a)(10)(A)(ii).

Security Income (SSI) [asset holdings limitation].¹²² Alternatively, states may have more stringent financial requirements for eligibility.¹²³ Finally, each state must place a limit on the number of people who can receive the benefits of the waiver program.¹²⁴ As a result, it may be difficult for an individual to qualify for waiver services despite the importance of those services for inclusion in the community.

State restrictions on waiver eligibility generally track the federal statute with minor variations. For instance, New York focuses somewhat on autonomy. To be eligible for a waiver on the basis of developmental disability, an individual must be eligible for Medicaid; have a diagnosed developmental disability; be eligible for institutional care; have exercised agency in making the decision between receipt of waiver services or placement in an institutional facility; and maintain an appropriate living arrangement.¹²⁵ Illinois adds language on cost-effectiveness. There, an individual must be a United States citizen or legal alien; be a resident of Illinois; be financially eligible for Medicaid; and require the necessary level of care for the requested waiver.¹²⁶ In addition, it must cost less to provide waiver services than it would cost to provide appropriate institutional care.¹²⁷ Another variant, Ohio, focuses on categorization by providing different eligibility standards for an entire smorgasbord of waivers.¹²⁸

¹²² LeBlanc et al., *supra* note 94, at 160. The asset limitation for SSI is \$6,000 for an individual in 2014, 300% of \$2,000. See *OASDI and SSI Program Rates & Limits, 2014*, SOC. SEC. ADMIN. (Oct. 2013), https://www.ssa.gov/policy/docs/quickfacts/prog_highlights/RatesLimits2014.html [<http://perma.cc/S2FZ-GRYU>] [hereinafter *SSI Limits*].

¹²³ *SSI Limits, supra* note 122 (showing that the statute creates a ceiling by specifying maximum income eligibility).

¹²⁴ 42 U.S.C. § 1396n(i)(1)(C).

¹²⁵ N.Y. COMP. CODES R. & REGS. tit. 14, § 635-10.3 (2008).

¹²⁶ *Home and Community Based Services Waiver Program*, ILL. DEP'T HEALTHCARE & FAM. SERVS., <http://www.illinois.gov/hfs/medicalclients/HCBS/Pages/default.aspx> [<http://perma.cc/4XLU-2B5B>] [hereinafter *IL HCBS*]. Recipients may be eligible through the traditional route or through Medicaid buy-in, which allows individuals whose income exceeds the prescribed amount to purchase Medicaid access. This encourages Medicaid recipients to return to work while allowing them to maintain their Medicaid eligibility through the program. To be eligible for Medicaid under the buy-in program, known as Health Benefits for Workers with Disabilities (HBWD), an individual must (1) be ineligible for Medicaid for those with disabilities, (2) be a resident of Illinois, (3) be a U.S. Citizen or an eligible noncitizen, (4) be between the ages of 16 and 65, (5) meet the SSA definition of disability, (6) have a disability, (7) be employed, (8) have countable assets of \$25,000 or less, and (9) have income less than 350% of the federal poverty line for the family size. See *HBWD Eligibility*, HEALTH BENEFITS FOR WORKERS WITH DISABILITIES (HBWD), <http://www.hbwdillinois.com/eligibility.html> [<http://perma.cc/P6C8-L6EX>].

¹²⁷ *IL HCBS, supra* note 126.

¹²⁸ To be eligible for waiver services in Ohio, an individual must be (1) eligible for Ohio Medicaid (through traditional Medicaid or the Medicaid buy-in), (2) in need of HCB Waiver services, and (3) enrolled in at least one HCB Waiver program. Each of the waivers in Ohio has its own set of eligibility criteria, but none are less restrictive than the general eligibility criteria listed above. They include, but are not limited to, the following: First, the

In all of the examples above, access to waiver services is limited on the basis of medical need (if one assumes that habilitative care is medical), but more importantly for individuals with qualifying disabilities, on the basis of financial need with waiver eligibility generally pegged to Medicaid eligibility. As discussed below, the definition of financial need adopted by the various states is unduly restrictive in many cases.¹²⁹ In other words, a real-world definition of financial need, if one were to craft it, likely would be much broader than the legal definitions adopted by the federal government and the various states. As a result, it may be difficult for individuals to obtain waiver services even when financial need is real and habilitative need is great.

D. Waiver Eligibility Is Generally Pegged to Medicaid Eligibility, and Medicaid Is Only Available to the Very Poor

To be eligible for waiver services, an individual with intellectual or other qualifying disabilities generally must qualify for Medicaid assistance. Established in 1965, “[t]he Medical Assistance program, commonly known as ‘Medicaid,’ ‘is a cooperative federal–state venture designed to afford medical assistance to persons whose income and resources are insufficient to meet the

Ohio Home Care Waiver (OHCW) Program provides nursing, personal care and skilled therapy services in addition to other more specific services. OHIO ADMIN. CODE § 5160-46-04 (2015). To be eligible for OHCW, an individual must be financially eligible for HCBS in Ohio, be fifty-nine years or younger and require an intermediate or skilled level of care. *The Ohio Home Care Waiver Program*, OHIO DEP’T MEDICAID, <http://medicaid.ohio.gov/FOROHIOANS/Programs/OhioHomeCareWaiver.aspx> [<http://perma.cc/AF6H-T5RX>]. Second, the Assisted Living Waiver Program pays the costs of living in an assisted living waiver program, freeing up income for the waiver beneficiary. *Assisted Living Waiver Program*, OHIO DEP’T MEDICAID, <http://medicaid.ohio.gov/FOROHIOANS/Programs/AssistedLiving.aspx> [<http://perma.cc/QLK6-AK9C>]. To be eligible for the Assisted Living Waiver, individuals must be eligible for Medicaid, 21 years old or older, and in need of at least intermediary care. *Id.* Third, the PASSPORT Waiver Program provides a similar package of services as the Choices program, but is more widely available. *PASSPORT Program*, OHIO DEP’T AGING, <http://www.aging.ohio.gov/services/passport/> [<http://perma.cc/SB7K-FR5S>]. To be eligible for PASSPORT, an individual must be eligible for Medicaid, sixty years old or older, and in need of at least intermediary care. *Id.* In addition, some costs that the state pays for can be subject to estate recovery by Ohio. *Id.* Finally, the Individual Options Waiver Program and the Level One Waiver Program offer a similar list of services that are available, with the Level One program providing more options for services overall. To be eligible for either of those waiver programs, an individual must be eligible for Medicaid and need an ICF-IID (Level One), see *Level One Waiver Program*, OHIO DEP’T MEDICAID, <http://medicaid.ohio.gov/FOROHIOANS/Programs/LevelOne.aspx> [<http://perma.cc/5ZDR-KZ7V>], or ICF-MR (Individual Options) level of care, see *Individual Options Waiver Program*, OHIO DEP’T MEDICAID, <http://medicaid.ohio.gov/FOROHIOANS/Programs/IndividualOptions.aspx> [<http://perma.cc/D7PJ-SUQX>].

¹²⁹ See *infra* Part III.D.

financial demands of necessary care and services.”¹³⁰ States administer the federal program and receive reimbursements for administration costs and “partial reimbursement for the costs of providing medical services.”¹³¹

Each state sets its own Medicaid eligibility rules within guidelines provided by the federal government. States have three options for eligibility determinations applicable to individuals with disabilities.¹³² (A fourth method of eligibility determination, the use of modified adjusted gross income under the Affordable Care Act, applies to waiver services only at the election of the states and so far is of little help to individuals with disabilities who are seeking waiver services.)¹³³ First, under section 1634 of the Social Security Act, a state may provide Medicaid to anyone who is determined to be eligible for supplemental security income (known as “SSI,” or more commonly, “welfare”) by the Social Security Administration.¹³⁴ Second, a state also may choose to grant Medicaid to all SSI recipients who complete a separate state application.¹³⁵ Third, under section 209(b) of the Social Security Act, a state may choose criteria that are more restrictive than SSI criteria, as long as they are not more stringent than the criteria used by the state in 1972.¹³⁶ This is commonly referred to as the 209(b) option.

¹³⁰ *Ramey v. Reinertson*, 268 F.3d 955, 957 (10th Cir. 2001) (quoting *N.M. Dep’t of Human Servs. v. Dep’t of Health & Human Servs. Health Care Fin. Admin.*, 4 F.3d 882, 883 (10th Cir. 1993)).

¹³¹ *Id.*

¹³² See 42 C.F.R. § 435.601 (2015) (describing financial eligibility methodologies that states may use).

¹³³ See *id.* § 435.603(a), (j) (2015) (requiring states to calculate financial eligibility on the basis of modified adjusted gross income except in enumerated cases, of which disability is one); see also Dep’t of Health and Human Servs., Ctr. for Medicaid & CHIP Servs., *MAGI: Medicaid and CHIP’s New Eligibility Standards* 1 (Sept. 30, 2013), <http://www.medicaid.gov/medicaid-chip-program-information/program-information/downloads/modified-adjusted-gross-income-and-medicaid-chip.pdf> [<http://perma.cc/9Z5C-K39H>] (“The new rules apply to most people who are eligible for Medicaid and CHIP, but not the elderly or people who qualify based on a disability.”); MARYBETH MUSUMECI, THE KAISER COMM’N ON MEDICAID & THE UNINSURED, *ISSUE BRIEF: THE AFFORDABLE CARE ACT’S IMPACT ON MEDICAID ELIGIBILITY, ENROLLMENT, AND BENEFITS FOR PEOPLE WITH DISABILITIES* 4 (Apr. 2014), <http://kaiserfamilyfoundation.files.wordpress.com/2014/04/8390-02-the-affordable-care-acts-impact-on-medicaid-eligibility.pdf> [<http://perma.cc/N7PS-YU63>].

¹³⁴ See 42 C.F.R. § 435.601 (describing financial eligibility methodologies that states may apply).

¹³⁵ *Id.* States electing this option include Alaska, Idaho, Kansas, Nebraska, Nevada, Oregon, Utah and the Commonwealth of the Northern Mariana Islands. See SOC. SEC. ADMIN., PROGRAM OPERATIONS MANUAL SYSTEM (POMS), at SI 01715.010 (May 2014) [hereinafter POMS], <https://policy.ssa.gov/poms.nsf/lnx/0501715010> [<http://perma.cc/UJ5E-YZ7D>]; see, e.g., State of Alaska, Dep’t of Health & Soc. Servs., Div. of Pub. Assistance, *Application for Services* (revised Feb. 2012), <http://dpaweb.hss.state.ak.us/e-forms/pdf/gen50b.pdf> [<http://perma.cc/P2QY-Z6ST>].

¹³⁶ 42 C.F.R. § 435.811(d); *Ind. Dep’t of Pub. Welfare v. Payne*, 592 N.E.2d 714, 722 (Ind. Ct. App. 1992) (finding that Indiana’s Medicaid eligibility requirements in 1972

1. Medicaid Eligibility Under Section 1634 of the Social Security Act

To qualify for Medicaid, a person must satisfy stringent restrictions on income, asset holding, and severity of disability.¹³⁷ In many states, an individual with a disability is eligible for Medicaid if that individual also is eligible for supplemental security income (SSI) under federal rules.¹³⁸ An individual is eligible for SSI if that individual meets several requirements including but not limited to the following: the individual is aged, blind, or disabled; has a limited income;¹³⁹ and has limited resources.¹⁴⁰ Other requirements include certain restrictions on citizenship, time spent abroad, and fulfillment of certain administrative requirements.¹⁴¹

For SSI purposes, “disability” is the “inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.”¹⁴² This definition of disability “is much more exacting”¹⁴³ than the definition provided by the ADA, which merely requires “a physical or mental impairment that substantially limits one or more major life activities.”¹⁴⁴ Because the scope of the SSI definition has been discussed elsewhere, let us assume (perhaps unrealistically) that most individuals with intellectual or other qualifying disabilities meet the definition and that income and asset limitations are the primary impediments to Medicaid eligibility.¹⁴⁵

The income limitations applicable to SSI eligibility are strict. The maximum federal benefit available to an otherwise qualifying individual who pays for her own living expense is \$733 per month in 2015.¹⁴⁶ A qualifying

allowed a resource spend down and the state’s current rule could not be more restrictive than its 1972 resource rule).

¹³⁷ See generally Part III.D. (describing eligibility requirements).

¹³⁸ Only ten states do not use the SSI rules as a basis for determining eligibility. They are Connecticut, Hawaii, Illinois, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma, and Virginia. See POMS, *supra* note 135, at SI 01715.010.

¹³⁹ SOC. SEC. ADMIN, UNDERSTANDING SUPPLEMENTAL SECURITY INCOME 10–12 (2015) [hereinafter UNDERSTANDING SSI], <https://www.socialsecurity.gov/ssi/text-understanding-ssi.htm> [<https://perma.cc/Q69D-L7GD>] (explaining that limited income includes money earned at work, free food and shelter, and any other money received such as SSI, worker’s comp., and unemployment benefits).

¹⁴⁰ *Id.* at 9 (explaining that limited resources are \$2,000 for an individual, and \$3,000 for a couple with certain exclusions).

¹⁴¹ *Id.* at 12.

¹⁴² 42 U.S.C. § 423(d)(1)(A) (2012).

¹⁴³ Weber, *supra* note 26, at 896.

¹⁴⁴ ADA, 42 U.S.C. § 12102(1)(A).

¹⁴⁵ Bagenstos, *supra* note 13, at 33; Lucie Schmidt, *The Supplemental Security Income Program and Welfare Reform* 3 (Fed. Reserve Bank of Bos., Public Policy Discussion Paper No. 12-3, 2012), <http://ssrn.com/abstract=2285082> [<http://perma.cc/F6TR-EVJ8>].

¹⁴⁶ See UNDERSTANDING SSI, *supra* note 139, at 9.

couple may receive up to \$1,082 in the same circumstance.¹⁴⁷ These amounts are reduced dollar-for-dollar by “countable income.”¹⁴⁸ The term “countable” is defined in the negative.¹⁴⁹ Income that is not countable includes, among other things, the first \$20 received each month, the first \$65 of earned income each month, half of earned income received over \$65, and the value of other forms of public assistance, such as home energy assistance or Supplemental Nutrition Assistance Program (SNAP) payments.¹⁵⁰ In other words, an individual who receives more than the aggregate of these amounts plus the allowed amount will receive no SSI payment at all and will not be eligible for Medicaid under this standard.¹⁵¹

The asset limitations applicable to SSI eligibility are also difficult to satisfy. To qualify for SSI, an individual must not have more than \$2,000 in resources, and a couple must not have more than \$3,000 in resources.¹⁵² Countable resources include cash, assets in bank accounts, stocks and bonds, real and personal property, life insurance policies, vehicles, and anything that could be sold for cash.¹⁵³ Resources owned by an adult’s spouse or a child’s parent are also included.¹⁵⁴ Not all resources are countable, however. Resources that are exempt include a personal home, household goods and personal effects, burial spaces, and one motor vehicle.¹⁵⁵ In addition, under the Plan to Achieve Self Support (PASS) program, the Social Security Administration will allow individuals with disabilities to save money in furtherance of an employment related goal, such as the purchase of a computer, without counting the savings against SSI eligibility.¹⁵⁶ Generally speaking, though, the asset limitations are low.

¹⁴⁷ *Id.*

¹⁴⁸ *Id.* at 21–22.

¹⁴⁹ *See id.* at 20–21 (listing income items that are not countable).

¹⁵⁰ *Id.* at 21.

¹⁵¹ *See id.* at 20–23.

¹⁵² SOC. SEC. ADMIN., *supra* note 139, at 9.

¹⁵³ *Id.* at 17.

¹⁵⁴ *Id.*

¹⁵⁵ *Id.*

¹⁵⁶ “PASS lets persons with disabling conditions set aside money for purchases, installment payments and down payments for things like a vehicle, wheelchair, or a computer if needed to reach their work goal.” *Plan to Achieve Self-Support (PASS)*, SOC. SEC. ADMIN., <https://www.socialsecurity.gov/disabilityresearch/wi/pass.htm> [<http://perma.cc/ZGK2-U2D4>]. Money set aside through the PASS program will not count towards SSI eligibility, and if an individual is already SSI eligible then enrolling in the PASS program will increase the benefits received through SSI. *Spotlight on Plan to Achieve Self-Support*, SOC. SEC. ADMIN., <http://www.socialsecurity.gov/ssi/spotlights/spot-plans-self-support.htm> [<http://perma.cc/5LK3-YBLR>]. To enroll in the PASS program, an individual must (1) state a specific work goal, (2) in writing, (3) with a detailed list of necessary expenses to achieve the work goal, and (4) a reasonable time frame for the work goal to be achieved. *Elements of a Plan to Achieve Self-Support*, SOC. SEC. ADMIN., <http://www.socialsecurity.gov/disabilityresearch/wi/passelements.htm> [<http://perma.cc/5NS4-XUA6>].

Despite PASS and similar programs, the income and asset limitations placed on SSI recipients militate against financial security. Individuals with intellectual or other qualifying disabilities who depend on Medicaid for access to waiver services are necessarily impoverished under this standard. Applicable income limitations may complicate work arrangements, and asset limitations leave these Medicaid recipients exposed to financial shock. For instance, imagine having only \$2,000 to replace the engine in a car or move to a new apartment. Making the availability of waiver services dependent on this level of impoverishment makes little sense, particularly when these services may be necessary for independent living and yet difficult to coordinate and purchase.

2. Medicaid Eligibility Under the 209(b) Option

A second avenue to Medicaid eligibility, known as the 209(b) option, allows states to adopt Medicaid eligibility criteria which are more restrictive than the SSI rules, so long as the criteria chosen are not more restrictive than those employed by the state in 1972 for medical assistance under the state–federal welfare program replaced by SSI.¹⁵⁷ In order to maintain their forty-year old income and asset limitations, though, states must offer a spend-down option.¹⁵⁸ Meant to aid the “medically poor,” a spend-down option requires a state to provide Medicaid coverage if an individual’s out-of-pocket medical expenses are greater than the amount by which the individual’s income exceeds the eligibility amount.¹⁵⁹ For example, if a state requires income of less than \$800 per month, and an individual’s income is \$1,000 each month, the individual may still qualify for Medicaid if the excess \$200 is used for qualifying medical expenses.

Virginia is one example of a 209(b) state. To receive Medicaid coverage, an individual with a disability must have income of less than eighty percent of the federal poverty line¹⁶⁰ and must not have “countable resources in excess of \$2,000 for one person or \$3,000 for a couple.”¹⁶¹ This income requirement for Medicaid eligibility, which is \$9,336 in 2014, is even lower than that employed in SSI determinations.¹⁶² As a consequence, it restricts access to

¹⁵⁷ 42 C.F.R. § 435.811(d)(2) (2015). According to the Social Security Administration, there are ten 209(b) states: Connecticut, Hawaii, Illinois, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma, and Virginia. See POMS, *supra* note 135, at SI 01715.010.

¹⁵⁸ 42 C.F.R. § 435.135(c).

¹⁵⁹ *Id.*

¹⁶⁰ 12 VA. ADMIN. CODE § 30-40-220(D) (2010).

¹⁶¹ Va. Dept. of Soc. Servs., *Medicaid Fact Sheet #15: Aged, Blind or Disabled Individuals with Income Less than or Equal to eighty percent of the Federal Poverty Level* (Jan. 2012), http://www.dss.virginia.gov/files/division/bp/medical_assistance/intro_page/covered_groups/adults_aged_65/D032-03-0631-13-eng.pdf [<http://perma.cc/HWM4-XARD>]; see also 12 VA. ADMIN. CODE § 30-40-230(B) (2010).

¹⁶² Annual Update of the HHS Poverty Guidelines, 79 Fed. Reg. 3593 (Jan. 22, 2014).

waiver services even more severely than the SSI eligibility requirements would. A medical spend-down provision applies to individuals whose income exceeds the limit but whose medical expenses soak up the excess income.¹⁶³ Again, because of the very low threshold on income and asset holdings, individuals in 209(b) states must choose between access to waiver services or financial security and independence from non-disability-related government programs.

3. Medicaid Eligibility Through Buy-In

In an effort to ameliorate the harsh effect of Medicaid eligibility requirements on the work-related decisions of individuals with disabilities, the federal government permits states to create Medicaid buy-in programs for such individuals who are employed.¹⁶⁴ Under a Medicaid buy-in program, individuals with disabilities can pay for access to Medicaid in the same way that they might pay for private insurance (although private insurers' coverage of habilitative care is usually limited or nonexistent).¹⁶⁵ Buy-in programs have been adopted by at least thirty-seven states to date,¹⁶⁶ and they represent an important step forward in preserving autonomy and dignity for individuals with qualifying disabilities. Individuals who qualify for the buy-in may choose to work without losing access to waiver services.

Buy-in programs are not available to everyone, and the premiums may be costly. The Balanced Budget Act “[a]llows a state to offer Medicaid coverage to any employed person with a disability who has a net family income below 250% of the Federal poverty level for a family of the size involved.”¹⁶⁷ In addition, the Ticket to Work and Work Incentives Improvement Act allows a state to cover individuals through Medicaid through two separate groups: the basic coverage and medical improvement groups.¹⁶⁸ The basic coverage group allows states to offer Medicaid “to working individuals . . . who, except for

¹⁶³ VA. DEPT. OF SOC. SERVS., VOL. XIII, MEDICAID ELIGIBILITY MANUAL § M1320.100(a) (May 2015), https://www.dss.virginia.gov/files/division/bp/medical_assistance/manual_transmittals/manual/m13r.pdf [<http://perma.cc/QM53-VY5X>].

¹⁶⁴ BOB WILLIAMS ET AL., KAISER FAMILY FOUND., KEEPING MEDICARE AND MEDICAID WHEN YOU WORK: MEDICAID BUY-IN PROGRAMS 17 (Feb. 2005), <https://kaiserfamilyfoundation.files.wordpress.com/2013/01/keeping-medicare-and-medicaid-when-you-work-2005-report.pdf> [<https://perma.cc/2QTE-83XK>].

¹⁶⁵ *Id.*

¹⁶⁶ LAW, HEALTH POLICY & DISABILITY CTR., A RESOURCE GUIDE TO STATE MEDICAID INFRASTRUCTURE GRANT (MIG) INITIATIVES: MEDICAID BUY-IN PROGRAMS § D.1 (Dec. 2006), <http://disability.law.uiowa.edu/lhpdcrtrc/mig/#sectD1> [<http://perma.cc/8M5Z-5MUP>] (Table of State Medicaid Buy-In Program Implementation and Enrollments).

¹⁶⁷ WILLIAMS ET AL., *supra* note 164, at 17. For additional explanation, see the Balanced Budget Act of 1997, Pub. L. No. 105-33, § 4733, 111 Stat. 251, 522, adding subclause (XIII) to 42 U.S.C. § 1396a(a)(10)(A)(ii).

¹⁶⁸ For additional explanation, see generally WILLIAMS ET AL., *supra* note 164, at 17.

their income and resource levels, are eligible to receive SSI.”¹⁶⁹ Under basic coverage, states can establish their own income and resource standards.¹⁷⁰ For instance, the State of Illinois allows individuals to buy-in so long as their countable assets do not exceed \$25,000 and their income does not exceed 350% of the federal poverty line.¹⁷¹ For a single individual in 2014, that amount was \$3,404 per month.¹⁷² Premiums for the buy-in may be as low as \$6 per month or as high as \$500 per month depending on the purchaser’s income.¹⁷³ In addition to basic coverage, states may provide a medical improvement buy-in “to employed individuals with a medically improved disability who lose Medicaid eligibility under the group described above [basic coverage] because they no longer meet the SSI definition of disability.”¹⁷⁴ This option is important because the SSI definition of disability hinges on an individual’s ability to work.¹⁷⁵ By definition, someone who is able to “engage in any substantial gainful activity” does not have a disability for purposes of SSI, making the medical improvement buy-in an important backstop to the basic coverage buy-in.¹⁷⁶

Medicaid buy-in programs are valuable to individuals who must protect access to waiver services, but they have two serious flaws: they are available only to individuals who are employed, and asset limitations continue to apply.¹⁷⁷ The requirement that an individual be employed before using a buy-in makes little sense if Congress’s purpose in creating the buy-in was to counteract the harsh effect of Medicaid eligibility requirements on individuals with intellectual or other significant disabilities. These individuals may have income from sources other than employment, such as gifts from family and

¹⁶⁹ *Id.*; see also 42 U.S.C. § 1396a(a)(10)(A)(ii)(XV) (2012).

¹⁷⁰ WILLIAMS ET AL., *supra* note 164, at 17. For an example of basic coverage, see OHIO ADMIN. CODE § 5160:1-5-03 (Westlaw through Oct. 2, 2015), describing Ohio’s Medicaid Buy-In for Workers with Disabilities (MBIWD). In Ohio, only income is counted for eligibility purposes and an individual’s countable income must be below 250% of the federal poverty line. *Id.* § 5160:1-5-03(D)(1). Illinois permits countable assets of up to \$25,000 and income up to 350% of the federal poverty level. See *HBWD Eligibility*, *supra* note 126.

¹⁷¹ *HBWD Eligibility*, *supra* note 126.

¹⁷² *Id.*

¹⁷³ See *HBWD Premium Chart*, HEALTH BENEFITS FOR WORKERS WITH DISABILITIES (HBWD), <http://www.hbwdillinois.com/assets/hfsweb004.pdf> [<http://perma.cc/DL3L-R796>].

¹⁷⁴ WILLIAMS ET AL., *supra* note 164, at 17.

¹⁷⁵ 42 U.S.C. § 423(d)(1)(A) (2012).

¹⁷⁶ *Id.*

¹⁷⁷ See *Medicaid Employment Initiatives*, MEDICAID.GOV, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Grant-Programs/Employment-Initiatives.html> [<http://perma.cc/BD2Q-F4X9>]. For a description of asset limitations, see LAW, HEALTH POLICY & DISABILITY CTR., A RESOURCE GUIDE TO STATE MEDICAID INFRASTRUCTURE GRANT (MIG) INITIATIVES: MEDICAID BUY-IN PROGRAMS § D.2 tbl.2 (Dec. 2006), <http://disability.law.uiowa.edu/lhpdc/rtrc/mig/#sectD2> [<http://perma.cc/Z7FU-8VLT>] (Tables of State Medicaid Buy-In Program Design Features). In 2006, the applicable asset restriction could be as low as \$999.99 or as high as \$75,000. *Id.*

friends, or perhaps even investment income. There simply is no empirical evidence to suggest that individuals with disabilities who are employed are in greater need of waiver services than those who are not, and requiring employment as a condition of buy-in wrongly suggests a higher level of deservedness inherent in those who are able-bodied enough for work. In some cases, strongly incentivizing work for an individual with a significant disability may even be economically wasteful and not in keeping with a civil rights approach to disability law.¹⁷⁸ Denying buy-in access to individuals with disabilities who cannot work may preclude them from participation solely on the basis of their disability, which is the source of their exclusion from community life in the first instance. In effect, the work requirement says, “we will not help you with inclusion because you have been already excluded.”

Even if we accept employment as a criterion for buy-in eligibility, the buy-in requirement creates inequality on the basis of disability as between workers who are otherwise similarly situated with the exception of disability. This is because the medical needs of typically-abled workers are more likely to be fully covered by private insurance, whereas habilitative services typically are not.¹⁷⁹ A worker who requires habilitative services already stands at a disadvantage relative to her able-bodied colleagues, and forcing her to expend resources for the Medicaid buy-in further exacerbates that inequality. Finally, imposition of asset holding requirements on access to buy-in programs prevents individuals with disabilities from saving adequate resources to protect against financial shock, and it leaves them exposed to loss of waiver services through receipt of a disqualifying gift or bequest.¹⁸⁰ So while Medicaid buy-in programs are an improvement over more limited access to waiver services, they suffer from some of the same normative problems as the eligibility guidelines themselves.

4. Medicaid Eligibility Under the Affordable Care Act

Implementation of the Affordable Care Act¹⁸¹ has encouraged some states to increase access to Medicaid, but the expansion does not automatically apply

¹⁷⁸ See Weber, *supra* note 75, at 2507–08.

¹⁷⁹ See Bagenstos, *supra* note 13, at 27 (noting that private insurance “fails to cover the services people with disabilities most need for independence and health”).

¹⁸⁰ See *Saving for an Uncertain Future: How the ABLE Act Can Help People with Disabilities and Their Families: Hearing Before the Subcomm. on Taxation & IRS Oversight of the S. Comm. on Fin.*, 113th Cong. 33 (2014) [hereinafter *ABLE Hearing*] (prepared statement of Sara C. Wolff, Self-Advocate & Board Member, National Down Syndrome Society (NDSS)) (“Like most individuals with disabilities, people with Down Syndrome and other conditions are out living their parents. Families, like mine, need to rest assured that they can equally care for their children and adults with disabilities, just like they can for their other children and family members.”).

¹⁸¹ Thirty states and the District of Columbia implemented the Affordable Care Act expansion at the beginning of 2015: Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Hawaii, Illinois, Indiana, Iowa, Kentucky, Maryland,

to waiver services for individuals with disabilities. States that adopted the expansion have opened Medicaid to all adults whose modified adjusted gross income is up to 138% of the federal poverty line.¹⁸² In 2015, that amount was \$16,242 for a single individual.¹⁸³ Adults with disabilities whose incomes fall below this threshold amount qualify for Medicaid coverage under the expansion.¹⁸⁴ Furthermore, no asset limitation applies.¹⁸⁵ As a result, a larger number of adults with disabilities may be covered for routine medical care under the expansion.

Eligibility under the expansion, however, does not automatically provide the same suite of benefits as eligibility resulting from disability.¹⁸⁶ Unless a state elects otherwise and receives permission from the Department of Health and Human Services (HHS), the state must provide a particular suite of benefits, known as the alternative benefit plan, to individuals that qualify through the expansion.¹⁸⁷ Because states must craft the alternative benefit plan with reference to designated commercial insurance plans, waiver services typically will not be covered by the Medicaid expansion.¹⁸⁸ In states that do not seek HHS approval for an election to deviate from the alternative benefit plan, individuals with intellectual or other qualifying disabilities who seek government-coordinated habilitative care still must satisfy the requirements applicable to eligibility through disability.¹⁸⁹

States may request permission from HHS to offer waiver services to adults who become eligible for Medicaid through the expansion.¹⁹⁰ In doing so, the state must choose whether to add some or all of its waiver programs to the

Massachusetts, Michigan, Minnesota, Montana, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Dakota, Ohio, Oregon, Pennsylvania, Rhode Island, Vermont, Washington, and West Virginia. *See Status of State Action on the Medicaid Expansion Decision*, KAISER FAM. FOUND., <http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/> [<http://perma.cc/PPQ5-A8FQ>].

¹⁸² 42 U.S.C. § 1396a(a)(10)(A)(i)(VIII) (2012). The eligibility standard is effectively 138% of the federal poverty line (FPL) even though the ACA expands coverage to 133% of the FPL because there is a 5% income disregard under the FPL for people applying for Medicaid based solely on income eligibility. *See* MUSUMECI, *supra* note 133, at 7.

¹⁸³ 80 Fed. Reg. 3236–37 (Jan. 22, 2015); MARYBETH MUSUMECI & ROBIN RUDOWITZ, THE KAISER COMM’N ON MEDICAID & THE UNINSURED, ISSUE BRIEF: THE ACA AND MEDICAID EXPANSION WAIVERS 1 (Nov. 2015), <http://files.kff.org/attachment/issue-brief-the-aca-and-medicaid-expansion-waivers> [<http://perma.cc/77PH-TEWX>].

¹⁸⁴ *See* MUSUMECI, *supra* note 133, at 6.

¹⁸⁵ 42 U.S.C. § 1396a(e)(14)(C).

¹⁸⁶ *Id.* § 1396a(e)(14)(D)(i).

¹⁸⁷ MUSUMECI, *supra* note 133, at 8. (citing 42 C.F.R. § 440.347(c)); *see also* Medicaid and Children’s Health Insurance Programs, 78 Fed. Reg. 42,160, 42,200–01 (July 15, 2013).

¹⁸⁸ MUSUMECI, *supra* note 133, at 8.

¹⁸⁹ *Id.* at 9.

¹⁹⁰ *Id.* (citing Medicaid and Children’s Health Insurance Programs, 78 Fed. Reg. at 42,238).

expansion coverage.¹⁹¹ If the state fully conforms the new alternative coverage to its original state plan and vice versa, individuals with disabilities may qualify for waiver services under the Medicaid expansion.¹⁹² If the traditional state plan and the alternative benefit plan vary, however, an individual's access to particular services will continue to be governed by that individual's form of eligibility, and some or all waiver services will be available only to individuals that meet the state's existing eligibility criteria for coverage of disability.¹⁹³ As of November 2015, of the thirty-one states adopting Medicaid expansion, only six sought to deviate from the statutorily described program, and of these, none sought to include HCBS waiver eligibility in their Medicaid expansion package.¹⁹⁴

In summary, waiver services may be essential to an individual with a qualifying disability who wants to live and work in a community, but waivers are subject to strict income and asset limitations. Although there is some variance among states, federal law limits the availability of Medicaid-funded services to only those individuals who live in poverty. This approach might be unobjectionable if coordinated services were readily available and easily affordable in the private marketplace, but where this assumption fails, Medicaid eligibility rules applicable to waiver services fail to live up to normative goals of promoting autonomy, assisting with integration in the community to the extent possible and desired, and refraining from the imposition of norms developed with reference to the typically-abled.

IV. TRUST PLANNING AND THE DELIBERATE IMPOVERISHMENT OF INDIVIDUALS WITH QUALIFYING DISABILITIES

The strict income and asset limitations embodied in states' Medicaid eligibility guidelines may lead families to protect a loved one's eligibility through use of a special needs trust (also sometimes referred to as a Medicaid protection trust). Recall the example of Thomas. In the absence of trust planning, he will inherit some or all of his parents' assets upon their death. Unless his parents are virtually penniless, this inheritance will result in Thomas's disqualification from Medicaid, causing him to lose access to habilitative services that he will need to maintain a satisfactory quality of life. However, the assets inside of a properly structured protection trust are not counted as assets of the beneficiary for purposes of Medicaid.¹⁹⁵ Three forms of trust are commonly used, two of which are sanctioned by federal statute: the

¹⁹¹ *Id.* (citing 42 C.F.R. § 440.330(d)).

¹⁹² *Id.*

¹⁹³ *Id.*

¹⁹⁴ See MUSUMECI & RUDOWITZ, *supra* note 183, at 1.

¹⁹⁵ See Taryn D. Walker, Comment, *Congress or the Social Security Administration: Who Defines a Special Needs Trust?*, 48 WAKE FOREST L. REV. 1055, 1056 (2013) (stating that funds in a special needs trust are not counted as income or assets of the trust beneficiary).

Medicaid payback trust and the pooled trust.¹⁹⁶ With each of these trusts, families preserve assets for use of a beneficiary with a disability while also preserving the beneficiary's ability to claim government benefits.¹⁹⁷

Despite its initial appeal, the Medicaid protection trust is not costless. Assets protected in trust may not be used to purchase goods or services that are available through government programs.¹⁹⁸ As a result, a trust may hold limitless assets, none of which could be distributed to the beneficiary for basic costs of living, such as housing, without jeopardizing the beneficiary's access to Medicaid.¹⁹⁹ So an individual with a qualifying disability might use trust funds to vacation in Tahoe every winter but would still be required to qualify for government food assistance in order to receive waiver services. The following paragraphs will describe three commonly used protection trusts and will describe why (in terms more technical than "Tahoe") they are insufficient to address normative problems and perverse incentives created by means testing Medicaid's provision of habilitative services.

A. A Brief Explanation of Protection Trusts

1. Medicaid Payback Trusts

Medicaid payback trusts were created by Congress in 1993 as a means of protecting individuals with disabilities from government cutbacks in Medicaid spending.²⁰⁰ Two kinds are available.²⁰¹ The first is created for the benefit of a person with a disability who is under the age of sixty-five and from which "the State will receive all amounts remaining in the trust upon the death of such individual up to an amount equal to the total medical assistance paid on behalf

¹⁹⁶ 42 U.S.C. § 1396p(d)(4) (2012) (describing common law supplemental needs trusts); Joseph A. Rosenberg, *Supplemental Needs Trusts for People with Disabilities: The Development of a Private Trust in the Public Interest*, 10 B.U. PUB. INT. L.J. 91, 109 (2000) (describing Medicaid payback and pooled trusts).

¹⁹⁷ 3 CCH Health Law Editors, *MEDICARE AND MEDICAID GUIDE* ¶ 14,311 (2003) (explaining that special needs and pooled trusts are not counted as resources of the Medicaid applicant).

¹⁹⁸ See Rosenberg, *supra* note 196, at 120–21 (surveying cases and observing that a trust will not be counted as an available resource for purposes of Medicaid eligibility if it "clearly expresses the creator's intent to supplement and not to replace government benefits"). For a state statutory example, see OHIO ADMIN. CODE § 5123:1-5-01(C) (Supp. 2015), in which the State of Ohio prohibits the use of trust assets for "basic necessities" including "essential food, clothing, shelter, education, and medical care."

¹⁹⁹ See Rosenberg, *supra* note 196, at 120–21.

²⁰⁰ See Jacqueline d. Farinella, *Come on in, the Water's Fine: Opening up the Special Needs Pooled Trust to the Eligible Elderly Population*, 14 ELDER L.J. 127, 137–38 (2006) (describing creation of the payback trust as a political compromise meant to satisfy the conservative push for Medicaid contraction while still serving constituents in the disability community).

²⁰¹ 42 U.S.C. § 1396p(d)(4)(A)–(B).

of the individual [by Medicaid].”²⁰² This form of trust may only be established by a parent, grandparent, legal guardian of the beneficiary, or a court, using assets of the beneficiary.²⁰³ A second form of payback trust does not suffer from the same limitation on settlors, but it may receive only pension, Social Security, or other income of the beneficiary.²⁰⁴ Again, upon the beneficiary’s death, any trust assets that haven’t been spent must be used to repay the state for Medicaid expenditures of the beneficiary.²⁰⁵

Legal strictures on the beneficiary’s ability to demand trust funds or to use them for many common expenses limit the usefulness of Medicaid payback trusts to beneficiaries. Specifically, trust funds may be used only for supplemental expenses. In Ohio, for instance, supplemental expenses are those that ordinarily would not be covered by some form of government assistance.²⁰⁶ In other words, if the beneficiary incurs expenses for which a government program is available, such as housing or food, trust funds may not be used to cover the expenses. In fact, the law is even more explicit. It provides that trust funds may not be used for “basic necessities” including “essential food, clothing, shelter, education, and medical care.”²⁰⁷ Instead, funds must be used for expenses not covered by government programs (a claim denied by Medicaid or habilitative services not available through the government, for instance), or they may be used for extras such as vacations, hobbies, cable television, companionship, and cosmetic surgery.²⁰⁸ The normative legitimacy of these spending restrictions is truly questionable if payback trusts are meant to improve the quality of life of individuals with qualifying disabilities, particularly if one assumes that quality of life depends, in part, on the satisfaction of an individual’s preferences for basic necessities that may not be included in programs for government assistance. For example, a beneficiary may prefer, and have trust resources sufficient to obtain, nonsubsidized housing. So while they are an incredibly important component of special needs planning, Medicaid payback trusts provide neither sufficient assurance to worried families nor adult decision-making power to individuals with disabilities *even when those individuals directly earned, through labor, the funds in the trust*. As a result, Medicaid payback trusts are a suboptimal answer to normative and pragmatic concerns raised by means-tested access to government-coordinated habilitative care.

²⁰² *Id.* § 1396p(d)(4)(A).

²⁰³ *Id.*

²⁰⁴ *Id.* § 1396p(d)(4)(B).

²⁰⁵ *Id.*

²⁰⁶ OHIO ADMIN. CODE § 5123:1-5-01(C)(c) (Supp. 2015). For a more thorough description of the law on supplemental needs trusts, see generally Rosenberg, *supra* note 196.

²⁰⁷ OHIO ADMIN. CODE § 5123:1-5-01(C)(1)(b).

²⁰⁸ *Id.* § 5123:1-5-01(C)(2).

2. Pooled Trusts

A second form of Medicaid protection trust, the pooled trust, was also codified in 1993.²⁰⁹ The pooled trust is similar to an ordinary payback trust, with three prominent distinctions. First, the trust must be administered by a charitable organization that pools and invests funds for the benefit of persons with disabilities while maintaining separate accounting for each beneficiary.²¹⁰ Second, upon the death of the beneficiary, the remaining trust corpus may either be retained by the charitable organization for the benefit of its mission, or it may be repaid to the state in an amount equal to the amount of Medicaid benefits received by the beneficiary.²¹¹ Third, unlike an ordinary payback trust, a pooled trust may be settled by the beneficiary herself.²¹²

Although this form of trust is somewhat less paternalistic in its conception of the individual with a disability—she may settle the trust herself and may choose a charitable remainderman—it is subject to the same spending restrictions as the Medicaid payback trusts described above.²¹³ As a consequence, the trust funds cannot be used for food, housing, or basic medical care even though they may be used for a trip to Disney World or porcelain veneers on one's teeth.²¹⁴ While this structure is superior to one in which an individual with a disability must choose between financial stability and Medicaid eligibility, it is obviously flawed as a means of achieving normative goals of autonomy and dignity for individuals with disabilities or as a means of providing assurance to worried family members.

3. Common Law Discretionary Trusts

Like Medicaid payback trusts and pooled trusts, discretionary trusts (also known as supplemental needs trusts) are designed to supplement rather than supplant government benefits provided to the beneficiary who has a disability.²¹⁵ Like Medicaid payback trusts, these trusts restrict the trustee from making distributions of funds to cover basic needs such as food and housing.²¹⁶ Unlike Medicaid payback trusts and pooled trusts, however, discretionary trusts are not enshrined in federal law. Rather, they are governed by state law.²¹⁷ As a result, they need not contain the Medicaid payback

²⁰⁹ See 42 U.S.C. § 1396p(d)(4)(C).

²¹⁰ *Id.*

²¹¹ *Id.*

²¹² *Id.*

²¹³ *Id.*

²¹⁴ See, e.g., OHIO ADMIN. CODE § 5123: 2-18-01(C)(2) (Supp. 2015).

²¹⁵ See JOHN W. NADWORNÝ & CYNTHIA R. HADDAD, *THE SPECIAL NEEDS PLANNING GUIDE* 203 (2007).

²¹⁶ *Id.* at 204.

²¹⁷ See Rosenberg, *supra* note 196, at 123–30 (surveying state statutes authorizing supplemental needs trusts).

provision required by federal statute. Upon the beneficiary's death, the remainder of trust funds is distributed to remaindermen designated by the settlor rather than to the government or to the pooled trust administrator.²¹⁸

A number of states have codified discretionary trust law. Ohio's provision is typical. By state statute, the trust must be irrevocable, and distributions may be made "only at the trustee's discretion."²¹⁹ Furthermore, the trust may not include "any standards to guide the trustee in exercising its discretion to make distributions to or for the benefit of the beneficiary."²²⁰ As a result, a discretionary trust must not contain a support standard that would permit a beneficiary to compel distributions. In addition, state law prohibits withdrawals by the beneficiary.²²¹ Finally, to preserve Medicaid eligibility, the trust must contain "[p]recatory language regarding its intended purpose of providing supplemental goods and services to or for the benefit of the beneficiary, and not to supplant benefits from public assistance programs."²²² It also must contain a "prohibition against providing food, clothing, and shelter to the beneficiary."²²³ New York's law also permits the use of such language,²²⁴ and Minnesota requires it.²²⁵

B. *Protection Trusts Are Not Enough*

In light of the goals of promoting autonomy, assisting integrated living to the extent desired and practical, and alleviating harm caused by the improper reliance on norms of the typically-abled in Medicaid eligibility law, protection trusts are better than nothing. In contrast to a world that permits no asset protection, the current system provides some measure of autonomy by providing a source of funding for the discretionary expenses of an individual with an intellectual or other qualifying disability, who now may choose to eat out, take a class, go on vacation, or engage in other life-enriching activities.²²⁶ Protection trusts may assist in integrated living by allowing purchases of items as simple as gifts for friends or as important as adaptive equipment, such as a

²¹⁸ *Id.*

²¹⁹ OHIO REV. CODE ANN. § 5801.01(Y)(1)(a)–(b) (West 2007). This language is also required in California, Illinois, and Wisconsin, among others. *See Rosenberg supra* note 196, at 125 (describing discretionary trust law in those states).

²²⁰ OHIO REV. CODE ANN. § 5801.01(Y)(1)(e).

²²¹ *Id.*

²²² *Id.* § 5801.01(Y)(5)(a).

²²³ *Id.* § 5801(Y)(5)(b).

²²⁴ *See Rosenberg, supra* note 196, at 124 (describing the language forbidding distributions for food, clothing, shelter, and medical care used in New York to preserve a beneficiary's access to government benefits).

²²⁵ *Id.* at 126 (citing MINN. STAT. § 501B.89(2)(d) (2000)).

²²⁶ *Id.* at 124–25 (stating that a trust must be settled for intended purpose of providing supplemental goods and services to or for the benefit of the beneficiary and in some states must contain a prohibition against providing food and shelter to the beneficiary).

communication device, not covered by Medicaid.²²⁷ In addition, protection trusts address, to some extent, norms of the able-bodied that are woven into the Medicaid eligibility requirements. The government's approval of protection trusts pushes back against the assumption that a person who has the use of assets does not require public assistance. In addition, by placing assets beyond the control of the individual with a disability, the protection trust addresses (albeit in a grossly paternalistic way) the assumption that Medicaid applicants are fully able to understand and independently comply with the law. Finally, the protection trust regime formalizes the government's recognition of the role of family or friend relationships in the life of an individual with a disability, pushing back on the assumption of a stark dichotomy between dependent and independent living.

Regardless of the superiority of a protection trust regime to one in which individuals with disabilities are permitted no asset protection, current law deviates substantially from a normative account of the provision of government-coordinated habilitative care to individuals with qualifying disabilities. Imagine once again the parents of Thomas, the infant with Down Syndrome. Because of their anticipation that Thomas may require access to habilitative care as an adult, they create a discretionary trust as part of their estate plan. The law, in essence, forces them to publicly express a desire to impoverish their son, requiring him to make claims on food assistance, public housing, and other government programs. His choices about what to eat, where to live, and how to get to work all will be limited by this fact. He will be saddled with the stigma that accompanies life as a comprehensive lifelong public claimant.²²⁸ Furthermore, as an adult, Thomas will be forced to ask permission from a trustee to use trust funds for discretionary expenses. If he wants to take a girlfriend out on a special date, purchase a movie collection that reminds him of his parents, or take a class on photography, he must seek the assent of another person as if he were still a child. No right-minded legislator would propose such a regime for children who are typically-abled. The parent of a typically-abled child may make such a choice, but the government would never mandate it. The fact that the law is so starkly different for individuals with significant disabilities indicates an embodiment in the law of assumptions about the nature of those with disabilities; namely, that they are childlike. There can be no question that the trust regime, which allows no support standard, grants absolute discretion to the trustee, and permits the adult beneficiary no independent judgment in ordinary matters of adult life, imposes dignitary harms on adults with qualifying disabilities.

²²⁷ *Id.*

²²⁸ See Anne L. Alstott, *The Earned Income Tax Credit and the Limitations of Tax-Based Welfare Reform*, 108 HARV. L. REV. 533, 565 (1995) (“[S]tigma and social isolation [are] associated with welfare.”); John F. Muller, *Disability, Ambivalence, and the Law*, 37 AM. J.L. & MED. 469, 513–14 (2011) (stating that direct payments for disability “tend to be a marker of powerlessness and shame”).

The protection trust regime also fails on normative grounds because it impinges on autonomy and interferes in interpersonal relationships that have the potential to improve quality of life. In doing so, it imposes dignitary costs on individuals with disabilities. Where a protection trust is involved, an individual with a disability is literally unable to act independently. So while the use of protection trusts may appear to be autonomy increasing from an outsider's perspective because trust funds allow a greater variety of personal expenditures, this may not be the perspective of an individual with a disability. Although the use of protection trusts may improve autonomy in cases where the trustee is a trusted friend who is truly guided by the choices of the individual with a disability, it militates against autonomy in cases where the trustee deviates from that individual's preferences. Requiring the individual with a disability to request funds is, almost by definition, the opposite of autonomy. In addition, if the settlor of the trust is someone other than the beneficiary, and if that person wants the beneficiary to have some measure of independence, the settlor's autonomy is also compromised by the current law.

Another failure of the trust regime is that requiring the individual with a disability to request permission for discretionary expenditures embodies, in law, a message that the government (as a voice of collective society) does not believe that the individual is competent to handle his or her own affairs. While this may be true in some cases, enshrinement of this assumption in federal law makes little normative sense. Instead, to protect the dignity of individuals with disabilities, government should work from the premise that these individuals are competent to handle financial matters and let families, case workers, or guardians decide when this is not the case. Categorical relegation of individuals with disabilities on the basis of a characteristic that may not affect financial sophistication is an unduly restrictive approach.

Yet another problem with the trust regime is that its prohibition on the use of a support standard imposes uncompensated emotional cost on the family members of individuals with disabilities. Stated more dryly, the protection trust regime interferes with interpersonal relationships between the individual with a disability and anyone who might be willing to provide financial assistance to that person, once again wrongly assuming, as does the Medicaid eligibility regime, that independent living is not consistent with interpersonal dependency. Think again of Thomas's parents and the pain they must have felt when told that they would not be permitted to support their son in adulthood without jeopardizing his access to services that would permit him to live in the community instead of in an institution. Can we truly say that the emotional cost imposed by the government in this case is justified by the fact of Thomas's disability?

A final shortcoming of the trust regime is that imposing these costs only on a subset of individuals with significant disabilities may be conceived of as discriminatory because it places those individuals in an inferior position on the basis of their disabilities. To state it colloquially, imagine two children. One is gullible, or a criminal, or a substance abuser. The other has a developmental

disability. Both are beneficiaries of trusts settled by loving and concerned parents. The trust for the child with an addiction will contain a support standard requiring the trustee to see that the child has adequate shelter, clothing, and food. The trust for the child with the disability, by law, cannot, because if it does, the child will lose access to needed habilitative care. This discrepancy, which arises under law solely as a result of the second child's disability, makes little sense. There simply is no reasoned connection between the need for coordinated habilitative care and the ability to pay for one's own housing and food.

V. THE ABLE ACT: A STEP FORWARD

A. A Brief Description of the ABLE Act

A better attempt to alleviate the adverse impact of Medicaid eligibility on individuals with intellectual or other qualifying disabilities is the Achieving a Better Life Experience Act, generally referred to as the ABLE Act.²²⁹ The ABLE Act creates a tax-preferred savings account under newly enacted section 529A of the Internal Revenue Code, similar to a college savings account.²³⁰ ABLE accounts may be created by the account beneficiary, or by the parent or legal guardian of a beneficiary who lacks capacity, and the account beneficiary must have a qualifying disability.²³¹ Anyone can contribute to the account, so long as the contributions are made in cash or a cash equivalent.²³² Contributions to the account, investment earnings inside of the account, and funds distributed for "qualified disability expenses" will not count against eligibility for means-tested federal programs, including Medicaid, except that distributions for housing expenses and account balances above \$100,000 will reduce the beneficiary's supplemental security income

²²⁹ See ABLE Act of 2014, Pub. L. No. 113-295, 128 Stat. 4056 (codified at I.R.C. §§ 529A, 3511, 7705 (West Supp. 2015)).

²³⁰ I.R.C. § 529A. For a description of college savings accounts, see Kerry A. Ryan, *Access Assured: Restoring Progressivity in the Tax and Spending Programs for Higher Education*, 38 SETON HALL L. REV. 1, 25 (2008).

²³¹ I.R.C. § 529A(e)(1) (stating that an individual is eligible to be an ABLE beneficiary if "(A) the individual is entitled to benefits based on blindness or disability under title II or XVI of the Social Security Act, and such blindness or disability occurred before the date on which the individual attained age 26, or (B) a disability certification with respect to such individual is filed with the Secretary for such taxable year"); *id.* § 529A(e)(6) (requiring an account to be established by an eligible individual); Prop. Treas. Reg. § 1.529A-2(c)(1), 80 Fed. Reg. 35,602, 35,613 (June 22, 2015) (clarifying that a parent or legal guardian may establish and take actions with regard to an ABLE account for the benefit of a beneficiary who lacks capacity). Proposed regulations provide a default rule requiring annual redetermination of eligibility, but they allow states to choose their own recertification periods based on type of disability. *Id.* § 1.529A-2(d).

²³² I.R.C. § 529A(b)(2) (not limiting source of contribution but specifying cash equivalency).

(SSI) payment, if any.²³³ Each beneficiary may have only one account.²³⁴ Like college savings accounts, ABLE accounts are subject to an aggregate contribution limit pegged, strangely, to the cost of college tuition rather than any projection of the beneficiary's disability-related expenses.²³⁵ In addition, yearly contributions to the account cannot exceed the annual gift tax exemption,²³⁶ which is \$14,000 in 2015.²³⁷ Again, this amount bears no relation to an individual's estimated yearly expenses, disability related or otherwise.

Funds in an ABLE account may be used for "qualified disability expenses" without jeopardizing a beneficiary's Medicaid eligibility.²³⁸ The definition of "qualified disability expenses" is broad and includes many of the everyday expenses that mark passage into adulthood, such as housing, transportation, and medical insurance.²³⁹ Specifically, the law provides that "qualified disability expenses" are expenses made for the benefit of an individual that are related to the individual's disability.²⁴⁰ The law provides several categories of qualified expenses: education; housing; transportation; employment training and support; assistive technology and personal support services; health, prevention, and wellness; financial management and administrative services; legal fees; expenses for oversight and monitoring; funeral and burial expenses; and other expenses that are approved by the Secretary of the Treasury.²⁴¹ Proposed regulations issued in June of 2015 clarify that basic living expenses may be treated as qualified disability expenses.²⁴² For example, the cost of a smart phone with navigation features is disability related.²⁴³ Funds that remain unused at the end of the beneficiary's life are transferred to the state to reimburse it for assistance provided to the

²³³ ABLE Act of 2014 § 103, 128 Stat. at 4063. Funds in excess of \$100,000 would not terminate a beneficiary's eligibility for SSI; rather, excess funding would suspend the beneficiary's collection of SSI benefits. *Id.* This suspension would not affect Medicaid eligibility in states where SSI eligibility is a prerequisite for Medicaid eligibility. *Id.*

²³⁴ I.R.C. § 529A(b)(1)(B).

²³⁵ *Id.* § 529A(b). For purposes of this limitation, rollovers or program-to-program transfers from another qualified ABLE account are treated as contributions. Prop. Treas. Reg. § 1.529A-2(g), 80 Fed. Reg. at 35,614.

²³⁶ I.R.C. § 529A(b)(6). Rollovers or program-to-program transfers from another qualified ABLE account are not treated as contributions for purposes of applying this limitation. Prop. Treas. Reg. § 1.529A-2(g).

²³⁷ See Rev. Proc. 2014-61, 2014-47 I.R.B. 860.

²³⁸ I.R.C. § 529A(c)(1)(B) (describing tax treatment of distributions for qualified disability expenses); ABLE Act of 2014 § 103, 128 Stat. at 4063 (describing relationship between ABLE accounts and eligibility for federal benefits programs).

²³⁹ I.R.C. § 529A(e)(5).

²⁴⁰ *Id.*

²⁴¹ *Id.* § 529A(b).

²⁴² Prop. Treas. Reg. § 1.529A-2(h)(1), 80 Fed. Reg. 35,602, 35,614-15 (June 22, 2015).

²⁴³ *Id.* § 1.529A-2(h)(2).

beneficiary through Medicaid, but only up to the amount of that assistance.²⁴⁴ This provision mirrors the Medicaid payback requirement found in some special needs trusts.²⁴⁵

In addition to preserving a beneficiary's eligibility for Medicaid and other programs, ABLE accounts subsidize qualified disability expenses through tax preference. ABLE account contributions and distributions receive preferential gift tax treatment.²⁴⁶ In addition, distributions for qualified disability expenses are not subject to federal income tax.²⁴⁷ On the other hand, distributions to a beneficiary for nonqualified expenses do not receive any income tax preference.²⁴⁸ Instead, they are taxed as annuity payments at a rate that is ten percent higher than the beneficiary's usual rate.²⁴⁹

Overall, the ABLE Act provides individuals with disabilities the opportunity to save money for necessary costs of adult living without jeopardizing access to the very disability-related services that they require for integration into the community. The ability to save, though, is hampered by yearly and aggregate contribution limits that unnecessarily limit the usefulness of ABLE accounts. In other words, the Act provides some relief, but that relief is incomplete.

1. *The ABLE Act: A Long Awaited (Partial) Solution*

The ABLE Act is normatively superior to the protection trust regime because it both increases autonomy and facilitates integrated living when it is desired and possible. First, and foremost, an individual with a disability who places funds in an ABLE account is not required to relinquish control over those funds but can withdraw them (subject to a tax penalty) if needed.²⁵⁰ This ability to reclaim funds differs markedly from the special needs trust regime, which requires beneficiaries to completely relinquish any claim or control over contributions, even if those contributions come from a beneficiary's own wage income.²⁵¹ Second, unlike assets held in a special needs trust, assets held in an ABLE account may be used for ordinary costs of living such as housing, insurance, and transportation.²⁵² As a result, the beneficiary of an ABLE account is not constrained in his or her choices by restrictions and stigma that may be attached to government programs. In addition, it may be possible for an account owner or beneficiary to arrange direct payment to providers in a manner similar to college tuition, which would require the beneficiary to seek

²⁴⁴ I.R.C. § 529A(f).

²⁴⁵ See *supra* Part IV.A.1.

²⁴⁶ I.R.C. § 529A(c)(2).

²⁴⁷ *Id.* § 529A(c)(1)(B).

²⁴⁸ *Id.* § 529A(c)(1)(A).

²⁴⁹ *Id.* § 529A(c)(1)(A), (c)(3).

²⁵⁰ *Id.* (describing tax and ten percent penalty on non-disability-related distributions).

²⁵¹ See *supra* Part IV.A.1.

²⁵² I.R.C. § 529A(e)(5).

permission fewer times and from fewer people.²⁵³ Under law, there is a tax penalty on disbursements made for nonqualified expenses, and nonqualified expenditures will count against the income and asset limitations of Medicaid, but enactment of the tax penalty makes it clear that a beneficiary may use the funds for nonqualifying expenditures. Broader permissible use of the funds and easier access to them will allow individuals with disabilities to more easily use funds in the way best suited to their individual needs and tastes.

Another benefit of the ABLE account is that it can provide a form of income smoothing for Medicaid eligibility purposes when individuals with disabilities have earnings that follow a feast or famine model. The ability to remain eligible for benefits rather than drifting in and out of the system is important. Qualification for waiver services requires paperwork and often placement on a waiting list.²⁵⁴ Someone who is employable only in spurts may suffer from repeated disqualification from Medicaid and, therefore, also suffer from repeated application processes and waiting times. By allowing individuals with disabilities to save earnings and then use them over time for qualified expenses, ABLE accounts can provide income smoothing that will prevent repeated losses of Medicaid eligibility.²⁵⁵ This should forward integration and autonomy by preventing the disruption of an individual's waiver services.

In addition to forwarding traditional integrationist goals of autonomy and integration, the ABLE Act also addresses redistributive concerns raised by Francine Lipman and others by providing financial support in the form of a tax expenditure.²⁵⁶ Investment earnings inside of an ABLE account are exempt

²⁵³ Many plans allow direct payments or online requests. For instance, Iowa has an online claim request process. See *Withdrawals*, C. SAVINGS IOWA, <https://collegesavingsiowa.com/content/withdrawals.html> [<https://perma.cc/B466-JXGS>]; see also *FAQ: PA 529 Guaranteed Savings Plan*, PA529, <http://www.pa529.com/faqs/pa-529-guaranteed-savings-plan/account-access> [<http://perma.cc/24AU-CRUQ>]; *How to Take Money Out of Your Direct Plan Account*, NY'S 529 C. SAVINGS PROGRAM, https://www.nysaves.org/content/planbenefits_withdrawals.html [<https://perma.cc/Q2KU-C2NH>].

²⁵⁴ For a fifty-state chart on the length of waiver waitlists, see *Waiting List Enrollment for Medicaid Section 1915(c) Home and Community-Based Services Waivers*, KAISER FAM. FOUND., <http://kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers/> [<http://perma.cc/JM2N-JEVW>].

²⁵⁵ The proposed regulations provide additional protection for individuals whose disability is sporadic. Proposed Treasury Regulation section 1.529A-2(d)(3) provides that an account will retain ABLE status even though an individual's disability has ceased. 80 Fed. Reg. 35,602, 35,613 (June 22, 2015). The account can accept no contributions during the cessation, and distributions made during that time are not made for qualified disability expenses. *Id.*

²⁵⁶ See Lipman, *supra* note 26, at 410 (arguing that post-integrationism calls for more aggressive redistribution of resources to individuals with disabilities). Under the traditional definition crafted by Stanley Surrey, tax expenditures are provisions that take the place of direct government spending and that deviate from generally accepted definitions of net

from federal income taxation unless and until they are distributed for nonqualified expenses or to a nonqualified beneficiary, and this foregone federal revenue will provide beneficiaries with additional money to spend on disability-related expenses.²⁵⁷ This is precisely the sort of cost-shifting envisioned by some post-integration disability law theorists.²⁵⁸ In addition, the ABLE Act moves away from a false dichotomy between dependent and independent living by interfering to a lesser degree with interpersonal financial relationships, and in doing so, it unwinds (to the extent of the contribution cap) perverse family financial and work planning incentives created by means testing. Returning to Thomas's parents, there will be less reason to move assets into a special needs trust if they can instead be placed in an ABLE account, where they may be used to cover Thomas's groceries, rent, and other expenses that cannot be covered through use of a special needs trust.²⁵⁹ ABLE accounts funded by family members and friends of individuals with disabilities will bring interpersonal financial relationships of individuals with disabilities closer to those experienced by their typically-abled counterparts. Accounts funded by individuals with disabilities from their own earnings will increase autonomy and self-direction.²⁶⁰

Use of the accounts also should vitiate, to some extent, the waning yet widespread stereotype of individuals with waiver-qualifying disabilities as financial (or actual) wards of the state. This mischaracterization, which is embodied in the Medicaid eligibility requirements, forces individuals with disabilities to enter into a fuller relationship of dependence with the state than may be necessary. Stated more colloquially, typically-abled individuals in need of assistance may commonly look first to friends and family, and only when that fails, to the state. Means testing as a bar to access for disability-related services prevents individuals with disabilities from benefitting from

income. STANLEY S. SURREY, *PATHWAYS TO TAX REFORM 3* (1973). They may include exemptions, deductions, credits, and exclusions. *Id.*

²⁵⁷ I.R.C. § 529A(a), (c) (accounts are exempt from tax; nonqualified distributions are subject to tax and a penalty).

²⁵⁸ See Weber, *supra* note 26, at 891 (“[Post-integration theorists] have written of new ideas of social justice that take into account the realities of disability—for example, the inevitable costs that disability imposes on the individual by reducing earning capacity and increasing necessary expenses. They have proposed shifting those costs onto society as a whole.” (footnote omitted)).

²⁵⁹ See I.R.C. § 529A(e)(5) (description of disability related expenses). In addition, distributions from the account could be used to for transportation expenses such as to purchase a vehicle, make necessary modifications to it, or to cover the cost of other options such as mass transit or a taxi. *Id.* Distributions from the account could also cover the cost of financial management, legal fees, personal assistance, job training, education, and funeral expenses. *Id.*

²⁶⁰ See *ABLE Hearing*, *supra* note 180, at 31 (prepared statement of Chase A. Phillips, Financial Advisor and Advocate) (“This account will serve as a self-sufficient booster for disabled individuals to live independently, go to college, get married, and start a family. No longer would an individual have to decline a higher paying salary for fear that their assets would eclipse the \$2,000 asset limit.”).

similar relational dependence. Placing an artificial barrier between individuals with disabilities and their loved ones likely affects not only the transfer of funds but also the emotional health of the parties involved, imposing intangible costs on both the individual with a disability and those who want to assist him. But there seems to be no logical connection between imposition of this cost and the presence of a disability. The presence of a disability does not provide a line of demarcation that would justify government intrusion into preferred relationships of dependency. Rather, both avenues of resort—support of a social and familial network and support of the government—should be equally available, just as they are equally available to typically-abled individuals. The ABLE Act allows family and friends to contribute and allows beneficiaries to use those contributions for everyday expenses of adult life. As such, it is an improvement over the special needs trust regime because it recognizes and does not delegitimize natural relationships of dependency and support.²⁶¹

Of equal importance, the ABLE Act preserves dignity and improves employment opportunities of individuals with qualifying disabilities. Prior to passage of the ABLE Act, individuals with disabilities had three choices if their potential earnings would bar them from receiving waiver services. First, they could forego government-provided services in favor of private ones. This may be a viable option for some people, but for many, many others, government coordination of services is important.²⁶² In addition, private services are difficult to obtain,²⁶³ are unaffordable,²⁶⁴ and typically are not covered by private health insurance.²⁶⁵ Second, a person whose income was above the Medicaid limit could contribute her excess earnings to a Medicaid payback trust. This option is suboptimal because the individual must cede complete control of her earnings to a trustee vested with absolute discretion.²⁶⁶

²⁶¹ See I.R.C. § 529A(b) (no restrictions on identity of account contributors); *id.* § 529A(e)(5) (description of disability-related expenses).

²⁶² Case managers, who are typically not available with privately purchased care, assess an individual's needs, develop a plan for meeting those needs, coordinate care among multiple providers, link individuals with disabilities to other relevant federal and state programs, monitor the delivery of care and address problems with it, and responds to crisis situations. See CTRS. FOR MEDICARE & MEDICAID SERVS. (CMS), APPLICATION FOR A § 1915(c) HOME AND COMMUNITY-BASED WAIVER: INSTRUCTIONS, TECHNICAL GUIDE AND REVIEW CRITERIA 113–14, 141–42 (Ver. 3.5, Jan. 2015) [hereinafter HCBS INSTRUCTIONS], <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/downloads/technical-guidance.pdf> [<http://perma.cc/7SCH-344L>] (stating that coordinating care enables the state to set the standard for training and maintain a high level of care from all providers).

²⁶³ 2010 FINDS SURVEY, *supra* note 86, at iv (finding that more than 80% of families had difficulty finding care providers).

²⁶⁴ *Id.* at 24 (finding that 80% of families reported having insufficient funds to cover the costs of care).

²⁶⁵ *Id.* at 12 (finding that only 8% of families reported private insurance coverage of costs of care paid to unrelated parties).

²⁶⁶ See *supra* Part IV.A. (describing Medicaid protection trusts).

The trustee could choose never to make a distribution, and the beneficiary whose earnings are tied up would have no legal recourse. Furthermore, money in the trust cannot be used for important expenses of adult living like food and rent. Finally, an individual with earnings potential in excess of the Medicaid limit may decide to work fewer hours in order to preserve eligibility for disability-related services.²⁶⁷ For example, consider testimony before the Senate Finance Committee of Sara Wolff, a woman who happens to have Down Syndrome:

Currently, I cannot have more than two-thousand dollars in assets before the government aid that I need is cut off. In this day and age, two-thousand dollars is not a lot of money and with the rising costs of housing, transportation and medical assistance that I need, it is tough for me to be able to save. I currently work two part-time jobs, and *my employers have been gracious enough to work with me so I do not earn more than seven-hundred dollars a month*; and maintain my government benefits.²⁶⁸

Because employers may be unwilling to enter into very limited part-time arrangements and would prefer to hire individuals who have fewer scheduling restrictions, the Medicaid income and asset limitations may unduly limit employment opportunities for individuals who need government-coordinated habilitative care. Passage of the ABLE Act should alleviate this problem to an extent (although contribution caps make it a less-than-perfect fix).

The ABLE Act is, however, an incomplete solution. Like special needs trusts, it relies on private actors for its implementation, and not all individuals with disabilities will have either the capability or the outside assistance needed to access the law. It also requires segregation of finances under special rules that disempower beneficiaries with disabilities. In addition, contributions to the account are limited, which means that its ability to address perverse incentives created by current law is similarly limited. Furthermore, contribution limitations applicable to ABLE accounts seemingly bear no relationship to an individual's projected or actual disability-related expenses. So while the ABLE Act is a clear improvement over prior law, it is not normatively optimal. Congress and the states should take the next step and eliminate the means testing for waiver services.

2. Normative Weaknesses of the ABLE Act

There are three substantive problems with the ABLE Act. One of them—its contribution limit—is more pragmatic in nature, while the other two—lack of access for lower income or financially unsophisticated families and lack of self-administration by the individual with a disability—raise normative

²⁶⁷ *ABLE Hearing*, *supra* note 180, at 34 (prepared statement of Sara C. Wolff, Self-Advocate & Board Member, National Down Syndrome Society (NDSS)).

²⁶⁸ *Id.* (emphasis added).

concerns about the equitable distribution of resources in society and about dignity of the person. This is not to say that the ABLE Act is not, at the very least, a partial solution to the problems raised by means testing. Rather, the ABLE Act is a good start, but it is incomplete. Congress should go further.

a. Contribution Limits Measured by College Tuition Make No Sense In this Context

The first and most obvious flaw of the ABLE account is that its contribution limits bear no relationship to the actual qualified disability expenses that an individual might incur. Artificially low contribution limits may prevent account beneficiaries from fully covering disability-related expenses using account funds, may prevent them from saving for retirement, and may prevent families from contributing to support in ways that could lessen a beneficiary's dependence on non-disability-related government programs. And while Congress may have imposed contribution limits to control the amount of tax benefit provided under the act, it could have chosen to cap the tax benefit directly rather than limiting contributions to the account.

Two contribution limits apply to ABLE accounts. First, yearly contributions to the account may not exceed the gift tax exemption amount in effect under Internal Revenue Code section 2503(b) for any given year.²⁶⁹ In 2015, that amount is \$14,000.²⁷⁰ This amount bears no relationship to an individual's projected or actual qualified disability expenses. In many cities, the account beneficiary might spend close to this amount on rent alone. Because the amount is artificially low, it will prevent individuals with disabilities who may be capable of saving for disability-related expenses in retirement from actually doing so. Not only might this result in financial insecurity and dignitary harm to the account beneficiary, but it almost guarantees that the account beneficiary will be a claimant of government programs in retirement. Congress appears not to have considered these costs when choosing the gift tax exemption amount as an annual contribution cap. In fact, its choice demonstrates that gifts, and not earned income, were of primary concern when writing this portion of the legislation. Otherwise, it would have chosen some combination of estimated and/or actual disability-related expenses.

The \$14,000 limitation also makes no sense in the context of contributions from family members and friends. Not only is it unrelated to any reasonable estimate of disability-related expenses, but it also precludes testamentary transfers. Imagine again Thomas's family, but in a scenario where their assets are illiquid. They have a house and vehicles. When they die, these assets could be sold and the proceeds used to cover Thomas's disability-related expenses, including housing, transportation, and food. Doing so would lessen his

²⁶⁹ ABLE Act of 2014, I.R.C. § 529A(b)(2) (West Supp. 2015).

²⁷⁰ Rev. Proc. 2014-61, 2014-47 I.R.B. 860.

dependence on related government programs and give his parents the satisfaction of knowing that they had provided for him, at least in part. Instead, the ABLE Act prohibits a lump sum contribution, so Thomas's parents will direct the money to a special needs trust instead. The special needs trust will limit use of the funds to discretionary expenses not otherwise covered by the government. Thomas will be able to use the bequest to buy movie tickets and haircuts, but he will not be able to use it for rent. This problem could be easily solved by allowing testamentary transfers to ABLE accounts, a quick fix with low potential for abuse.

In addition to imposing a yearly contribution limit, the ABLE Act also imposes an aggregate contribution limit. It specifies that contributions over the life of the account cannot exceed "the limit established by the State under section 529(b)(6)."²⁷¹ Under section 529, which describes college savings accounts, states must provide "adequate safeguards to prevent contributions on behalf of a designated beneficiary in excess of those necessary to provide for the qualified higher education expenses of the beneficiary."²⁷² Consequently, states have set contribution limits based on the costs of tuition, room and board, books, and other educational expenses.²⁷³ In addition, the Treasury Regulations provide a safe harbor contribution amount based on "five years of undergraduate enrollment at the highest cost institution allowed by the program."²⁷⁴ There is no reason to believe that this amount will bear any relationship to the amount of money needed to support the lifetime "qualified disability expenses" of an ABLE account beneficiary.

Congress could easily correct the discrepancy between its seemingly random contribution limit and the amount of qualified disability expenses that an individual might incur over a lifetime. For instance, Congress could amend section 529A to allow contributions up to the amount of disability-related distributions during the year plus an amount deemed reasonable for retirement savings, like the tax-preferred IRA contribution limit in effect for the year. Amending the law in this way would allow individuals with disabilities to cover more expenses from their own wages while still allowing them to save for those expenses in retirement. Alternatively, and perhaps more easily implemented, Congress could simply remove contribution limits and cap the available tax benefit instead.

An aggregate contribution limit pegged to the cost of education raises a second very troubling problem. Congress seems to have assumed that ABLE

²⁷¹ See I.R.C. § 529A(b)(6).

²⁷² *Id.* § 529(b)(6).

²⁷³ See I.R.S. Priv. Ltr. Rul. 200134032 (May 30, 2001) (approving maximum contribution limit of four years of undergraduate and three years of "graduate school tuition, fees, books, supplies, and room and board at the most expensive graduate school eligible for the program"); I.R.S. Priv. Ltr. Rul. 200030030 (Apr. 28, 2000) (approving maximum contribution of the lesser of seven years of average undergraduate tuition, fees, room and board or the cost of a beneficiary's anticipated higher education expenses).

²⁷⁴ Prop. Treas. Reg. § 1.529-2(i)(2), 63 Fed. Reg. 45,019, 45,028 (Aug. 24, 1998).

account beneficiaries will not have both disability related expenses and qualified education expenses. Consider, for instance, Jane and Joe. Jane is typically-abled, but Joe happens to have a waiver-qualifying disability arising from cerebral palsy. As a result, he could benefit from disability-related services. Both are the owners of fully funded tax-preferred savings accounts, and both choose to attend the same private college. Both completely exhaust their account balance on tuition and other educational expenses. Jane's account is a college savings account under section 529, but Joe's is an ABLE account under section 529A. (He cannot own a regular 529 college savings account because they are countable resources for purposes of determining Medicaid eligibility.)²⁷⁵ While Jane will need no extraordinary assistance to enter the workforce and participate independently in her community, Joe will require monetary and habilitative support to remain independent. Unfortunately, the balance of his ABLE account will have been exhausted; means testing of Medicaid eligibility will prevent him from seeking a fair wage; and his family will be unable to assist him further without jeopardizing his access to habilitative care through Medicaid.

One possible explanation for the disparate treatment of Jane and Joe centers on misplaced concerns about horizontal equity—the idea that similarly situated taxpayers should bear and receive similar portions of the burdens and benefits of government.²⁷⁶ Applying college savings account contribution limits to ABLE accounts might be seen as an attempt to create parity between individuals with disabilities and those without. Individuals with disabilities, the argument may run, are currently at a disadvantage because they cannot create savings accounts for their future benefit without jeopardizing their Medicaid status. In other words, the law provides a financial advantage to Jane that is not currently provided to Joe, making his position subordinate to hers purely on the basis of his disability. To cure this slight, the ABLE Act grants to Joe the same benefit that is granted to Jane. Using this logic, the same contribution limit should apply to both forms of tax-preferred savings.

A parity-based argument in support of contribution limits is misguided in this context, though, because the two groups of beneficiaries are not similarly situated. Jane will not need lifelong access to habilitative care, while Joe will. To create true parity, Congress could simply have provided that a college savings account would not be considered an asset of its owner for Medicaid purposes (and, in the author's opinion, it should do so). Jane and Joe could then pay for their own college expenses on equal terms. But this would not achieve the goal of the ABLE Act. The purpose of the ABLE account is entirely different from the purpose of the college savings account. The stated purpose of the ABLE Act is “supporting individuals with disabilities to

²⁷⁵ POMS, *supra* note 135, at SI 01140.150 (Oct. 2009), <http://policy.ssa.gov/poms.nsf/lnx/0501140150> [<https://perma.cc/5U6V-K2X6>].

²⁷⁶ See JOEL SLEMROD & JOHN BAKIJA, TAXING OURSELVES: A CITIZEN'S GUIDE TO THE DEBATE OVER TAXES 59–60 (4th ed. 2008) (defining vertical and horizontal equity for purposes of tax policy).

maintain health, independence, and quality of life.”²⁷⁷ The legislation clarifies that it is meant to “supplement, but not supplant,” benefits provided by the government.²⁷⁸ In other words, it is meant to facilitate private support of individuals with disabilities without jeopardizing their access to Medicaid. In contrast, the college savings account was created to help families pay tuition. It is clear that the two accounts forward different goals. As a result, the concept of horizontal equity is inapposite as a justification for the ABLE account contribution limit.

Congress should carve college savings accounts out of the Medicaid eligibility calculation. The example of Jane and Joe demonstrates that as a result of embodiment of the longstanding norm of exclusion of individuals with qualifying disabilities from higher education, Joe’s position is subordinate to Jane’s. But this norm is giving way to the reality of increased educational opportunities for individuals with intellectual and developmental disabilities,²⁷⁹ and in the recent FINDS survey, over fifty-eight percent of family caregivers reported that it was very important for their loved ones with intellectual or developmental disabilities to continue their education after high school.²⁸⁰ To create true parity, Joe should be permitted ownership of both the college savings account *and* the ABLE account without jeopardizing his access to waiver services.

The disparate treatment of Jane and Joe is perhaps mitigated by the fact that although Joe cannot own a college savings account, he can be the beneficiary of one.²⁸¹ Of course, his potential status as a beneficiary of a college savings account makes Congress’s choice of the section 529 aggregate account limitation even more bizarre. Finally, notice the dignitary harm present here. Joe can benefit from a college saving account, but only if he does not create or own it. Because Joe has a disability, the law forces him to trade ownership and control (i.e., self-determination and independence) for the very services that he needs to remain independent in the community.

A second possible justification for aggregate and annual contribution limits may be Congress’s desire to avoid tax sheltering. Although contributions to ABLE accounts are not federally deductible, investment earnings inside of the account are exempt from tax.²⁸² Distributions for

²⁷⁷ See ABLE Act of 2014, Pub. L. No. 113-295, § 101, 128 Stat. 4056, 4056 (codified at I.R.C. § 529A (West Supp. 2015)) (statement of legislative purpose).

²⁷⁸ *Id.*

²⁷⁹ See, e.g., *Find a College*, THINK COLLEGE!, <http://www.thinkcollege.net/component/programsdatabase/?view=programsdatabase&Itemid=339> [<http://perma.cc/3R5V-QUA6>] (containing a database of 227 college programs available to students with intellectual disabilities).

²⁸⁰ 2010 FINDS SURVEY, *supra* note 86, at 7.

²⁸¹ See *supra* note 275 and accompanying text.

²⁸² See I.R.C. § 529A(a) (qualifying ABLE programs are exempt from federal income tax).

qualified disability expenses are also exempt.²⁸³ In addition, the owner of the account may change the beneficiary designation without incurring any tax if the new beneficiary is a member of the original beneficiary's family who also has a qualifying disability.²⁸⁴ If contributions to ABLE accounts were unlimited, permissive tax treatment might enable wealthy families to shelter investment earnings from tax, allowing them to accumulate in the ABLE account for the duration of the beneficiary's life. This problem could be solved easily, though, by capping the maximum tax benefit available in a year or over the lifetime of the account rather than by capping contributions. Furthermore, the presence of Medicaid payback language in the ABLE Act is likely to discourage families from contributing more money to an ABLE account than a beneficiary might actually use. Because the potential for sheltering is low and easily dealt with in other ways, Congress should repeal the annual and aggregate contribution limits currently applicable to ABLE accounts.

b. Placing the ABLE Account in the Internal Revenue Code Restricts Access but May Produce Structural Gains.

A second problem with the ABLE account—its inclusion in the Internal Revenue Code—raises normative concerns about equity and equal access. First, limiting availability of benefits to taxpayers who are able to save (i.e., have disposable income) creates disparities across socioeconomic strata. Beneficiaries who are able to save more will have more untaxed investment earnings inside of their ABLE accounts. Greater earnings will provide them with both greater tax benefit and greater purchasing power. And it is likely that beneficiaries who are able to save more are either more able-bodied and therefore able to earn higher wages than their low-savings counterparts, or, alternatively, they come from wealthier families than their low-savings counterparts.

Those with low or no income may realize little or no benefit from the ABLE Act due to a combination of lower marginal tax rates and income uncertainty, whereas those at higher levels will benefit from both tax subsidization and easier access to waiver services. Deborah Schenk and Andrew Grossman have demonstrated that “[a]s with the other tax incentives, taxpayers with no tax liability cannot benefit from the use of a 529.”²⁸⁵ In addition, they observe that the return on savings in a 529 account must compete not only with other reasons for saving, “such as for a house or car, but also must compete with day-to-day consumption. The utility from savings simply cannot compete with the utility from essential expenditures.”²⁸⁶ This is also true in the ABLE Act context. Families who earn no more than is needed

²⁸³ *Id.* § 529A(c) (distributions for qualified disability expenses are not subject to tax).

²⁸⁴ *Id.* § 529A(c)(1)(C)(ii).

²⁸⁵ Deborah H. Schenk & Andrew L. Grossman, *The Failure of Tax Incentives for Education*, 61 TAX L. REV. 295, 350 (2008).

²⁸⁶ *Id.* at 350–51.

to cover essential expenses will be excluded from participation in the ABLE structure and instead will have to rely on estate planning options such as special needs trusts to protect Medicaid eligibility of heirs who are individuals with disabilities.

Inclusion of the ABLE Act in the Internal Revenue Code may also create complexity that could bar access by less sophisticated taxpayers. As Anne Alstott has noted with regard to the earned income tax credit, “the traditional tax policy goal of exempting the poor from income taxation” not only means that families at low income will realize no tax benefit but also will be less likely to participate overall.²⁸⁷ Lower participation may occur in the context of the ABLE Act because a taxpayer may be reticent to work with a bank, may be reluctant to place money under even nominal state control, may not know about the ABLE Act or be able to understand it, or simply may lack disposable income.

Some commentators also have suggested that moving social safety net programs into the Internal Revenue Code may reduce aggregate complexity by shifting them into a more efficient wing of the overall bureaucracy, but this argument is inapposite in the case of the ABLE Act, which layers a new program on top of an existing one.²⁸⁸ In other words, an ABLE Act beneficiary cannot avoid the state’s Medicaid administration bureaucracy through use of the account. The beneficiary still must apply and be approved for Medicaid in order to receive waiver services (although perhaps he will experience some bureaucratic relief through avoidance of other welfare-related agencies if he substitutes ABLE account funds for government benefits such as housing assistance).

It is possible, though, that concerns about inclusion of the ABLE Act in the Internal Revenue Code are offset by gains that may accompany the enactment of nontax provisions in the tax code. For instance, Susannah Camic Tahk has noted that provisions are easier to enact if they are included in the tax code because lower procedural hurdles apply to tax legislation.²⁸⁹ In addition, “tax-embedded programs are situated in a web of tax law that makes them hard to excise cleanly.”²⁹⁰ As a result, they are less likely to be repealed than programs that may be legislated in a more free-standing fashion.²⁹¹ Social

²⁸⁷ Alstott, *supra* note 228, at 585 (stating that participation may be lower because “the poor typically do not have to file tax returns”).

²⁸⁸ *See id.* at 565 (suggesting that tax-based transfers may be more efficient because “[w]elfare administration is labor-intensive, expensive, and heavily dependent on ‘street-level’ bureaucrats”); David A. Weisbach & Jacob Nussim, *The Integration of Tax and Spending Programs*, 113 *YALE L.J.* 955, 958 (2004) (“Putting a program into the tax system makes the tax system look more complicated, but there is unseen simplification elsewhere.”).

²⁸⁹ *See* Susannah Camic Tahk, *Everything Is Tax: Evaluating the Structural Transformation of U.S. Policymaking*, 50 *HARV. J. ON LEGIS.* 67, 81–92 (2013) (describing the relative ease of procedures applicable to tax legislation).

²⁹⁰ *Id.* at 88.

²⁹¹ *Id.* at 90 n.157.

programs housed in the tax code also expand and contract automatically over time as the number of claimants filing returns waxes and wanes.²⁹² In contrast, direct spending programs generally require Congressional action for expansion.²⁹³

Benefits may also arise from redundancy.²⁹⁴ Nancy Staudt has observed that “[r]edundancy in effort and control can provide a measure of reliability in the face of uncertainty.”²⁹⁵ In addition, redundancy may spark competition and innovation among administrators.²⁹⁶ This certainly may be the case with regard to the ABLE Act, which allows the Internal Revenue Service to determine which expenses are qualified disability expenses, perhaps in contravention to the determination of some states as to whether assets or services purchased for an individual with a disability may constitute countable income or assets.

In the end, while there are legitimate arguments in favor of crafting the ABLE Act as a tax provision, it would be normatively superior to simply eliminate means testing as a bar to accessing government-coordinated habilitative care. Elimination of means-tested access to waiver services would eliminate the need for redundancy in income and asset determinations for some claimants, as these would no longer be relevant to eligibility. Second, it would eliminate distributional concerns raised by the ABLE Act’s status as a tax expenditure for families with disposable incomes. Although some may argue that granting non-means-tested waivers would create a second distributional concern by unduly redistributing to the wealthy, that argument is normatively and pragmatically unfounded. If we assume, realistically, that wealthier families of individuals with disabilities will successfully shelter assets with or without an ABLE account (in other words, because they have access to sophisticated legal counsel, individuals with disabilities from wealthy backgrounds will always qualify for waiver services), removal of means testing will not directly affect the overall distribution of waiver resources. The number of wealthy claimants will not change. For them, the question is not whether they will have access, but whether the government will continue to demand dignitary and emotional sacrifices as the cost of access. So, to summarize, the ABLE Act’s redistributive feature—the provision of a tax benefit solely to families with disposable income—raises normative concerns that would be more fully addressed by the removal of means testing, and structural gains from inclusion of the ABLE Act in the Internal Revenue Code may be outweighed by normative losses related to distributive justice.

²⁹² *Id.* at 98.

²⁹³ *Id.* at 88.

²⁹⁴ See Nancy Staudt, *Redundant Tax and Spending Programs*, 100 NW. U. L. REV. 1197, 1200 (2006) (“[I]f one agency fails, another can thrive.”).

²⁹⁵ *Id.* at 1222.

²⁹⁶ *Id.*

c. Dignitary Concerns

A third set of concerns raised by the ABLE Act regard the dignity of the beneficiary with a disability. With the ABLE Act, Congress has, in theory recognized the needs of individuals with disabilities both to earn a wage and to receive social supports that will enable integrated living. And yet, the ABLE account requires a beneficiary to hand her wages over to a manager who will give them back only upon request. Furthermore, only some of the beneficiary's expenses will receive the government's imprimatur. Although this structure was undoubtedly designed to control the ABLE Act's tax expenditure side, it nonetheless relies on assumptions about disability rather than starting from the premise that individuals with disabilities are individuals first.

One example of harm to dignity comes from the need of an account beneficiary to repeatedly interact with the state with regard to her expenditures. Repeated interaction with a trustee differs markedly from the way in which an adult ordinarily would spend money. In addition to creating transactional costs, it imposes dignitary harm by placing *all* adults with qualifying disabilities in a subjugated position when only some need intensive financial intervention, which could be provided through normal channels like guardianship or protective trust. In addition, the requirement of repeated interaction with a trustee may impose financial costs in the form of lost opportunity. For example, a beneficiary who has limited borrowing power and limited funds outside of the account may not be able to take advantage of something like a special one-day sale price on an expensive item because her interaction with the trustee simply will not be fast enough. In short, forcing individuals with disabilities into segregated disability-only trust or account planning subjects them to paternalism on the basis of a characteristic that is not always determinative of the need for paternalism. A far less intrusive means of safeguarding access to government-coordinated habilitative care would be to simply make it available to everyone regardless of income or asset holding.

A final dignitary concern arising from the ABLE Act stems from law's function as a repository of social norms. The inclusion of the ABLE Act as a corollary to section 529, a section of the Internal Revenue Code meant to help families pay for their children's education, suggests that we view individuals with waiver-qualifying disabilities as childlike. In fact, adults with significant disabilities may choose to establish their own ABLE accounts to serve as repositories for wages earned. Formalization of the longstanding cliché of the individual with a developmental disability as childlike imposes a moral cost on society. It creates a collective relegation of adults of diverse abilities and backgrounds to a group of people—juveniles—that, by definition, are unable to adequately navigate the financial responsibilities of adult life. And while some, or many, adults with qualifying disabilities may not fit comfortably within the norms established for adulthood by typically-abled society,

formalization of the stereotype of individuals with disabilities as juveniles grants federal imprimatur to society's collective discomfort with disability and, in particular, intellectual disability.

VI. REMOVAL OF MEANS TESTING FOR WAIVER SERVICES IS NORMATIVELY SUPERIOR TO ABLE ACCOUNTS OR ASSET PROTECTION TRUSTS

The distributional and dignitary concerns raised by asset protection trusts and ABLE accounts could be eliminated if Congress and the states simply ended means testing for access to waiver services. Unlike prior solutions that rely on the participation and funding of private actors, the elimination of means testing is a public solution available to all. Elimination of means testing would be a superior solution from a normative standpoint because it would preserve autonomy, facilitate integration to the fullest extent desired or possible, remove perverse incentives in family financial planning, and work around norms of the typically-abled that are embedded in Medicaid eligibility rules.

A. Normative Considerations Favor Removal of Means Testing

1. Increased Autonomy

Allowing individuals with disabilities to access waiver services regardless of ability to pay protects autonomy by allowing those individuals to have control, to the extent that they are able, over their own finances. In contrast, a legal system that relies solely on the special needs trust and ABLE account intrudes upon individuals' decision-making and requires them to rely on third parties for distributions of their own funds.²⁹⁷ Even typical support trusts (which are currently countable assets for purposes of Medicaid) are less draconian than special needs trusts because the trustee is, at the very least, required to make distributions for support and maintenance of the beneficiary.²⁹⁸ Unlike the beneficiaries of support trusts, beneficiaries of special needs trusts may be forced to become claimants of stigmatized government programs, such as housing and food assistance, which are

²⁹⁷ See Rosenberg, *supra* note 196, at 108 (describing how a trustee has "complete discretion to decide when and how to distribute income and principal or to withhold distributions completely").

²⁹⁸ See William H. Lyons & John M. Gradwohl, *Discretionary Trusts, Support Trusts, Discretionary Support Trusts, Spendthrift Trusts, and Special Needs Trusts Under the Nebraska Uniform Trust Code*, 86 NEB. L. REV. 231, 238 (2007) (describing support trusts and observing that "a support trust would give a trustee discretion to make payments for the 'support and maintenance' of the beneficiary").

completely unrelated to disability services.²⁹⁹ In addition, the personal choices of individuals with disabilities regarding fundamental life decisions, such as what to eat and where to live, must be made with reference to government strictures and in some cases will be stalled by government bureaucracy. ABLE accounts improve this situation somewhat because they lessen the degree to which waiver recipients must claim social supports unrelated to disability, but the ABLE Act still has a contribution cap and limits the ways in which individuals can spend funds.³⁰⁰ Removal of means testing would address these problems.

2. *Less Reliance on Norms of the Able-Bodied*

Removal of means testing also reduces government reliance on norms of the typically-abled that are embedded in the Medicaid eligibility rules. The practice of denying Medicaid access to individuals with sufficient income likely arises from the assumption that these individuals are able-bodied enough for regular employment. Regular employment may signal access to employer-provided health insurance, or sufficient resources to purchase health insurance on the private market. In the case of individuals with qualifying disabilities, one or both of these assumptions are likely to fail. The first assumption—that an individual with income is able-bodied enough for regular employment—fails to account for the importance of habilitative services in the continued employment of individuals with disabilities. To take the analysis a step further, the rules assume that work is a necessary precondition to income, which may not be the case. The second assumption—that a person with sufficient resources can purchase assistance on the private market—is faulty in at least three ways. First, the income and asset limitations applicable to Medicaid eligibility are very low, so there is likely a vast raft of individuals who are not poor enough to qualify for Medicaid but are too poor to purchase disability-related services outside of Medicaid. Second, it may be difficult for someone with a qualifying disability to coordinate her own care, whereas a waiver program generally provides some modicum of central coordination.³⁰¹ Third, correctness of the assumption depends on the existence of a robust private

²⁹⁹ See Rosenberg, *supra* note 196, at 108 (describing how a trustee has “complete discretion to decide when and how to distribute income and principal or to withhold distributions completely”).

³⁰⁰ See *supra* Part V.A. Nonqualified expenditures of a waiver claimant made with ABLE account funds will count against Medicaid’s income and asset limitations. See ABLE Act of 2014, Pub. L. No. 113-295, § 103, 128 Stat. 4056, 4063 (stating that “any amount (including earnings thereon) in the ABLE account (within the meaning of section 529A of the Internal Revenue Code of 1986) of such individual, any contributions to the ABLE account of the individual, and any distribution for qualified disability expenses (as defined in subsection (e)(5) of such section) shall be disregarded” for the purpose of determining eligibility for federal benefits).

³⁰¹ Because the waiver is administered by a state agency, there will be a case worker of some sort at the very least.

market, but the relatively small number of individuals with significant disabilities, in combination with the prevalence of government in the coordination of and payment for habilitative care, may preclude the development of such a market. Put more plainly, because governments are so heavily involved in coordinating care for a relatively small population, it may be difficult to find nongovernmental providers who work in a coordinated fashion. If most people seek care through government coordination, the private market may be hobbled by its use of the government as a middleman. If access to the private market for care is underdeveloped, access to disability-related services through Medicaid is crucial (and perhaps allowing an income insensitive buy-in would lead to increased service capacity and options in communities). Finally, removal of means testing for access to waiver services is normatively superior because it prevents assumptions about ability, income, and access from affecting Medicaid eligibility of individuals with disabilities.

Removal of means testing also addresses the embodiment in Medicaid eligibility requirements of a false dichotomy between dependent and independent living. Current law embraces the cultural assumption that adult financial independence equates to an ability to live independently. It penalizes individuals with disabilities who have resources by withdrawing needed disability-related services. But the equation is false. Possession of resources does not connote an ability to find and privately purchase those disability-related services needed for community living.³⁰² In other words, financial need and dependence upon disability-related services need not be correlated.

Family dependence also creates difficulty for an individual who wishes to remain Medicaid eligible. The law penalizes in-kind gifts from family members or friends when they stand in for something that could have been provided by government assistance.³⁰³ In other words, the law punishes adults with disabilities who enter into relationships of dependency with family and friends. In contrast, it rewards those who replace dependence on family and friends with dependence on the government. By placing severe financial restrictions on access to disability-related services, the government is unintentionally engaging in financial custodialism. In doing so, it perversely incentivizes family and friends of an individual with a qualifying disability to forego financial assistance that could be autonomy-preserving for both the person providing support and the person receiving it. This, in turn, limits the life choices of the individual with a disability.

3. Potential for Cost Savings

From a more pragmatic and utilitarian perspective, eliminating means testing for waiver services also may be cost effective and utility-increasing.

³⁰² Gifts of cash or gifts in kind of items that could have been covered by government assistance are counted against income limitation.

³⁰³ *Id.*

One source of cost savings may result from increased competitive employment of individuals with significant disabilities. Susan Stefan has written that while increasing employment-related services is “cost-intensive at the front end,” supported employment programs provide a net benefit to taxpayers in the form of taxes paid by individuals with disabilities beginning in the fourth year of the program.³⁰⁴ In addition, integrated living has been linked to better health outcomes and a reduction in healthcare costs.³⁰⁵ Additional tax revenue and healthcare savings could offset some or all of the cost of providing government-coordinated habilitative care to individuals with significant disabilities without regard to income.

Another form of savings may arise to the extent that individuals with disabilities are willing and able to substitute private support for government support. Consider, one final time, Thomas and his parents. Although they do not have disposable income for ABLE account contributions, they could leave a portion of their assets to Thomas through their wills. Let us assume that as an adult, Thomas has no objection to receiving family support (one can imagine objections based on dignity and autonomy in some cases). Put more plainly, both they and he would prefer to avoid public housing, food stamps, and other interactions with bureaucracy that may be unpleasant and stigmatizing.³⁰⁶ Because current law continues to rely heavily on trust planning, if Thomas hopes to preserve his access to government-coordinated habilitative care, he may be forced to choose government dependence. His choice will impose an unnecessary cost on taxpayers in the form of food and housing assistance, even though that assistance is unwanted. With the removal of means testing, however, Thomas is not forced to make this choice. Instead, he may choose to receive waiver services and decline other forms of public assistance. This choice is utility-increasing for Thomas and his family because it satisfies their preferences. In addition, it prevents the infliction of emotional harm on Thomas’s parents, who otherwise would be forced to disinherit him in his infancy. Finally, the situation is pragmatically superior because it prevents the expenditure of scarce government resources on goods and services that are unwanted by the recipient.

Of course, the extent to which utility is increased and cost is reduced as a result of voluntary relinquishment of offered benefits depends on the

³⁰⁴ Susan Stefan, *Beyond Residential Segregation: The Application of Olmstead to Segregated Employment Settings*, 26 GA. ST. U. L. REV. 875, 933 (2010).

³⁰⁵ See Samuel R. Bagenstos, *The Disability Cliff*, 35 DEMOCRACY J. 55, 66 (2015) (“[E]vidence shows that Medicaid costs decline—by up to \$15,000 per person per year—when individuals with significant disabilities move into competitive work.”); Stefan, *supra* note 304, at 934–35 (reviewing cost studies and finding support for claim that increased spending on workplace integration leads to increased tax revenue, better health outcomes, and fewer welfare claims for individuals with disabilities).

³⁰⁶ See Alstott, *supra* note 228, at 565 (“[S]tigma and social isolation [are] associated with welfare.”); Muller, *supra* note 228, at 513–14 (stating that direct payments for disability “tend to be a marker of powerlessness and shame”).

soundness of two assumptions. First, it assumes that individuals with disabilities are not averse to waiving their entitlement to government assistance in favor of private support. Second, it assumes that family and friends of individuals with disabilities are willing and able to provide such support, but are unable to settle ABLE accounts with disposable income (not an unfair assumption given the cost of caring for a family member with a disability). The soundness of these assumptions presents an empirical question on which no research has yet been done. I hope that this Article will provide a basis for such future research.

4. *Parity Among Families*

Finally, provision of waiver services regardless of income or asset holding is autonomy-maximizing for the families of individuals with disabilities, and it creates parity for estate planning purposes between these families and families whose children are all typically-abled. Like most parents, those of a child with a significant disability want to secure the child's financial future to the greatest extent possible. The family of a typically-abled child may do this by creating a college savings account for the child, naming the child as the beneficiary of retirement accounts or life insurance policies, or leaving a bequest of property, such as the family home or savings. Families may not do this for a child who will require government-coordinated habilitative care.³⁰⁷ For example, consider a family in which one child is typically-abled and another has autism. If the family hopes to preserve waiver eligibility of the child with autism, it must treat the two children differently. One will be named in the parents' will, and the other will be disinherited. Forcing parents to face this moral dilemma—should they disinherit one child while favoring the other, particularly when that other is far more likely to need support—imposes an emotional cost on the parents solely on the basis of a child's disability. In this situation, parental autonomy is diminished, as is the future autonomy of the child. The family is forced to push the child's future adult self into stigmatized public support programs in order to preserve access to waiver services, and that future adult will exercise no control over spending decisions. If waiver eligibility were not affected by income and asset holding, however, the autonomy of the family members and the child would be maximized. The parents could choose a run-of-the-mill support trust, an outright gift to the child, or even intestate succession without jeopardizing the child's waiver access. In this scenario, the family's options for planning with regard to the typically-abled child and the child with a disability are identical. This, as one father described to the Senate Finance Committee, "is about fairness."³⁰⁸ He added,

³⁰⁷ See *supra* Part III.C (describing income and asset holding restrictions on Medicaid eligibility).

³⁰⁸ *ABLE Hearing*, *supra* note 180, at 11 (statement of Robert D'Amelio, Volunteer Advocate, Autism Speaks, Charlotte, NC).

If Christi and I can use a college savings account to provide for our [typically-abled] daughter Lindsey's future, why can't we use something similar to take care of Nicholas and Christopher [who have autism]? I would love to sleep at night knowing that I was doing everything I could to secure the future of my children.³⁰⁹

Although the ABLE Act has alleviated this concern to some extent for families with disposable income, ABLE accounts cannot accept testamentary transfers in excess of the gift-tax exempt amount.³¹⁰ As a result, the problem of family end-of-life planning remains unsolved under current law.

B. Possible Objections to the Removal of Means Testing for Waiver Services

There are two primary objections to providing broader access to waiver services. First, some may argue that providing broader access will result in redistribution toward the wealthy. Evidence suggests, however, that providing appropriate services would actually reduce government costs through reduced claims of non-disability-related services and through increased income tax revenue.³¹¹ Second, in a world of limited resources, increased spending on waiver services for individuals with disabilities may divert resources from other groups who would derive similar utility from those resources. Stated more colloquially, why should an individual with a disability whose assets place him among middle class or wealthy individuals have non-means-tested access to government-coordinated habilitative care when others do not?

My claim in this paper is not that individuals with disabilities should have exclusive access to habilitative or vocational services or that their needs are more important than the needs of other government constituents. Rather, my claim is narrower. The needs of individuals with disabilities are different from the needs of other groups, and the distinctive characteristics of significant disability justify the provision of government-coordinated habilitative care, regardless of income or asset holding, in the absence of a robust and accessible market for privately coordinated habilitative care. Alternatively, distributive concerns could be addressed by an unrestricted form of Medicaid buy-in applicable to disability-related services. But denying access to government-

³⁰⁹ *Id.* at 11–12.

³¹⁰ See ABLE Act of 2014, I.R.C. § 529A(b)(2)(B) (West Supp. 2015).

³¹¹ See *supra* note 304; see also Bagenstos, *supra* note 305, at 66 (“[E]vidence shows that Medicaid costs decline—by up to \$15,000 per person per year—when individuals with significant disabilities move into competitive work.”); Stefan, *supra* note 304, at 934–35 (reviewing cost studies and finding support for claim that increased spending on workplace integration leads to increased tax revenue, better health outcomes, and fewer welfare claims for individuals with disabilities).

coordinated habilitative care entirely on the basis of income, which is not an indicator of disability, makes no sense.³¹²

Horizontal, equity-based objections to non-means-tested waiver services are only valid to the extent that two claimants are similarly situated, and whether this is the case may depend upon the characteristics that one chooses to compare. The argument that an individual with a disability and a typically-abled individual with equal asset holdings are similarly situated is a straw man. Income and asset ownership are not the only relevant comparators for purposes of assessing equity. To demonstrate how thoroughly the horizontal equity argument fails, consider two individuals whose situations—housing, employment, etc.—are identical in every way except that Individual A has autism. Would Individual B be indifferent to assuming the life of Individual A? Clearly not. Because our society is so thoroughly oriented toward the typically-abled, Individual B would be left worse off as a result of the trade, even if his income and asset holdings did not change because of it. In other words, A and B are not similarly situated after all.

Furthermore, income and asset holdings are largely unmoored from an individual's actual need for services. There is statistical support for the assertion that disability has a profound effect on individuals who live with it, *regardless of socioeconomic status*.³¹³ Adults with intellectual or developmental disabilities are almost three and a half times more likely than those without such disabilities to need help or supervision with one or more activities of daily living, such as bathing, dressing, eating, using a toilet, and getting in and out of bed.³¹⁴ In addition, “[a]fter controlling for gender, age, health status, race, and economic status, adults with disabilities were significantly less likely to be in the labor market than those without disabilities.”³¹⁵ Nearly 40% of individuals with intellectual or developmental disabilities have functional limitations in language compared to 0.2% of people without them.³¹⁶ Over 61% of individuals with intellectual or developmental disabilities have functional limitations with self-direction (i.e., are able to do daily activities without prompting) compared to 1% of people without them.³¹⁷ And 88% of individuals with intellectual or developmental disabilities have functional limitations with regard to economic self-sufficiency compared to 1.7% of people without them.³¹⁸ Unlike their

³¹² See Larson et al., *supra* note 6, at 5 (comparing functional limitations in the disability versus nondisability community).

³¹³ *Id.*

³¹⁴ Sheryl Larson et al., *Service Use by and Needs of Adults with Functional Limitations or ID/DD in the NHIS-D: Difference by Age, Gender, and Disability*, DD DATA BRIEF (Research & Training Ctr. on Cmty. Living & Inst. on Cmty. Integration (UCEDD), Minneapolis, Minn.), Dec. 2003, at 5.

³¹⁵ *Id.* at 3.

³¹⁶ *Id.* at 8, tbl.5.

³¹⁷ *Id.*

³¹⁸ *Id.*

typically-developed counterparts, individuals with significant disabilities may need adaptive tools such as wheelchairs, motorized scooters, home modifications for accessibility, picture communication software, and communication board devices.³¹⁹ These needs present a unique set of challenges that present themselves across socioeconomic lines.³²⁰ As a result, a horizontal equity argument against non-means-tested provision of waiver services must fail: there simply is no similarly situated comparator.

A second argument against non-means-tested provision of waiver services—that it will redistribute public resources to middleclass and wealthy families that do not need them—fails on pragmatic grounds for two reasons. First, comparable services are available on the private market only to people with substantial disposable income,³²¹ and second, it is likely that most middle-class and wealthy families already have secured Medicaid eligibility for their loved one through financial planning and are accessing not only Medicaid but also other social safety net programs. For these families, reform does not increase access. Instead, it increases autonomy and may decrease overall government dependency. The following paragraphs address each point in turn.

Unless an individual with a disability (or, more likely, that individual's family) is very wealthy, there may be no reasonable private market corollary to government-coordinated waiver services in many parts of the county. There are at least two reasons why equivalent private services may be scarce. First, private care is not affordable to families of average means,³²² and most private health insurance plans do not cover habilitative care.³²³ Second, waiver services may be coordinated by a case manager, which is typically not the case for care purchased on the private market. For an individual with an intellectual or developmental disability, coordination may be an important aspect of waiver services. A case manager assesses an individual's needs, develops a plan for meeting those needs, coordinates care among multiple providers, links individuals with disabilities to other relevant federal and state programs, monitors the delivery of care and addresses problems with it, and responds to

³¹⁹ 2010 FINDS SURVEY, *supra* note 86, at 18–19.

³²⁰ See generally Larson et al., *supra* note 314 (comparing need for and use of habilitative services across age, gender, race, and socioeconomic status).

³²¹ MEDICAID PRIMER, *supra* note 7, at 10 (reporting that individuals with disabilities often are unable to obtain adequate coverage on the private market, and Medicaid allows them to access and pay for services needed for community living and employment).

³²² THE ARC, *supra* note 4, at 8 (finding that eighty percent of families report that they do not have enough money to pay for care that their family member with a disability needs); MEDICAID PRIMER, *supra* note 7, at 10 (reporting that individuals with disabilities are unable to obtain adequate private coverage and require Medicaid to access and afford habilitative care).

³²³ See Bagenstos, *supra* note 13, at 27 (“[P]rivate insurance—on which most nondisabled people rely for their health needs—fails to cover the services people with disabilities most need for independence and health.”).

crisis situations.³²⁴ For an individual with multiple care providers who address various aspects of daily living or employment, coordination by a third party expert may be essential to effective delivery of habilitative services. Notably, the needs for habilitative services and coordination of care do not decrease as a person's income and asset holdings increase. As a result, it makes little sense to restrict access to government-coordinated habilitative care on the basis of income or asset holdings.

Limiting government coordination and payment for waiver services to the very poor also cannot be justified on the basis that broader access will unduly burden taxpayers. First, access to government-coordinated habilitative care should be permissible as a matter of distributive justice, although as Ruth Colker has noted, this area is undertheorized.³²⁵ Second, the cost of offering waiver services to individuals who previously failed to meet the income and asset limitations may be offset by gains in other parts of the social safety net. Removal of means testing for waiver services would eliminate perverse incentives that cause family and friends of individuals with qualifying disabilities to withdraw support and that cause individuals with disabilities to refrain from full employment for fair pay.³²⁶ Providing broader access to waiver services in favor of individuals with significant disabilities may increase support from family and friends and may increase employment.³²⁷ Increased support and employment may, in turn, reduce the number of claimants for nonwaiver benefits such as housing and food assistance. Finally, studies have indicated that increased employment-related services have the potential to both increase tax revenue and decrease healthcare costs.³²⁸ The interrelationship of these moving parts is complicated. Consequently, I do not argue without qualification that the removal of means testing would be cost neutral or cost saving. I do, however, take the position that it is not obviously cost increasing and that further study is warranted.

Finally, arguments that focus on the injustice of redistribution in the form of waiver services to middle-class or wealthy individuals with disabilities assume that broader access will result in increased claims from the middleclass and wealthy. It is more likely, however, that given the importance of waiver services to quality of life, individuals with disabilities who have means (or whose families have means) are almost uniformly eligible for waiver services

³²⁴ HCBS INSTRUCTIONS, *supra*, note 262, at 113–14.

³²⁵ Colker, *supra* note 26, at 1415. I do not attempt, in this paper, to fill the gap.

³²⁶ For examples of the effect of these perverse incentives, see *ABLE Hearing*, *supra* note 180, at 34 (prepared statement of Sara C. Wolff, Self-Advocate & Board Member, National Down Syndrome Society (NDSS)) (describing arrangements with employers to minimize work hours in order to protect Medicaid eligibility); *id.* at 30–31 (prepared statement of Chase A. Phillips, Financial Advisor and Advocate) (describing adverse financial planning results).

³²⁷ See generally *id.*

³²⁸ See *supra* note 311 and accompanying text.

as a result of trust planning or other financial planning.³²⁹ The issue for these families is not a lack of access, but rather the financial, emotional, and dignitary costs of that access. Finally, as mentioned above, broadening access to waiver services does not necessarily require costless provision of those services. The government could simultaneously ensure access and address redistributive concerns by permitting individuals with significant disabilities to buy into the Medicaid waiver regardless of their employment status.

In summary, arguments against the removal of means testing on the basis of opposition to redistribution do not rest on solid ground in this context because the needs of individuals with disabilities are distinctive. In addition, it is not clear that the removal of means testing would result in a drain on resources. By reducing the demand for other social safety net support and increasing the potential for wage-earning work, elimination of means testing may even result in savings.

VII. CONCLUSION

Medicaid eligibility is crucially important for people with qualifying disabilities because it provides nearly exclusive access to habilitative care that improves quality of life, facilitates independent living (if possible and desired), and preserves dignity. Means testing, through the imposition of income and asset limitations on eligibility, limits access to these necessary services. Means testing fails on normative grounds because it does not recognize the private market's failure to provide affordable services and coordination among service providers. In addition, there is no relationship between an individual's financial outlook and that individual's need for coordinated habilitative care. As a result, placing income and asset holding limitations on the provision of care denies free and equal access to community living to individuals with significant disabilities who are too far above the federal poverty line to claim Medicaid and too far below the level of income or wealth needed to pay the market price for care. Means testing thus creates perverse incentives for individuals with disabilities to limit their hours of employment and their wages, which in turn, may limit their employability. The law also perversely incentivizes families and friends of individuals with disabilities to withdraw support, and in doing so, it interferes with natural relationships of dependency while simultaneously guaranteeing an increase in claims for other public benefits such as housing and food assistance.

Attempts to alleviate the adverse impact of Medicaid eligibility rules on individuals with disabilities, such as the creation of special needs trusts, Medicaid buy-in programs, and ABLE accounts, are unquestionably improvements in access to integrated living, but they continue to restrict autonomy and impose their own dignitary, emotional, and financial costs. In

³²⁹ Once again, it is worth noting that there has been no empirical research to support this assumption.

addition, they are impartial solutions because they rely on private actors and funds for their implementation. A public solution is needed. Providing non-means-tested access to government-coordinated habilitative care is a normatively superior solution. It recognizes the uniqueness of individuals with disabilities, allowing them and their families to autonomously create an appropriate and individually tailored financial support structure without jeopardizing access to care that is necessary for quality of life and integration into the broader community and workplace.