

LIFE AFTER IDEA PROTECTIONS: A CALL FOR THE EXPANSION OF COMMUNITY-BASED OPPORTUNITIES FOR YOUNG ADULTS WITH INTELLECTUAL DISABILITIES*

I. INTRODUCTION

Katelyn just turned twenty-one, which is an exciting milestone in the life of any young adult.¹ Yet Katelyn's twenty-first birthday comes with uncertainty as she has a diagnosis of autism. The twenty-first birthday of most individuals with autism or other intellectual disabilities brings uncertainty, as these young adults become ineligible for educational services after age twenty-one.² For Katelyn, this means she will officially graduate high school at the end of the year. And after that, her future path is quite uncertain. The services that provided the normalcy she has known since kindergarten will disappear, and she must find a new way to participate in her community. After high school, many individuals enroll in postsecondary education or begin their careers. But for Katelyn, there is no clear path forward; a life fully integrated in her community will be costly.³ Some refer to this sudden lack of government support for educational services and community integration as the phenomenon of "falling off the cliff."⁴

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1. The story of Katelyn is based on the real-life experience of a young adult with autism.

2. The Individuals with Disabilities Education Act requires states to provide a free appropriate public education to all children with a qualifying disability between the ages of three and twenty-one. 20 U.S.C. § 1412(a)(1)(A) (2018). A child with an intellectual disability is one with "significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance." 34 C.F.R. § 300.8(c)(6) (2018).

3. Ronnie Polaneczky, *Falling Off the Cliff Part 1: A Crisis for the Disabled*, PHILA. INQUIRER (Dec. 2, 2017, 5:00 AM), http://media.philly.com/storage/special_projects/intellectual-developmental-disabilities-caregivers-abuse-falling-off-the-cliff-part-1.html [http://perma.cc/4L55-NSY8] [hereinafter Polaneczky, *Falling Off the Cliff Part 1*] ("To parents of these children, looking out for them is not just a lifelong obligation . . . It takes money—for most parents, more than they can earn in a lifetime.").

4. Ronnie Polaneczky, *Falling Off the Cliff Part 3: Finding Work*, PHILA. INQUIRER (Dec. 2, 2017), http://media.philly.com/storage/special_projects/intellectual-developmental-disabilities-employment-falling-off-the-cliff-part-3.html [http://perma.cc/4MH4-TE56] [hereinafter Polaneczky, *Falling Off the Cliff Part 3*] ("After 21 . . . the entitlement ends and it's on parents to find new ways to fill their grown children's days. The shift is so abrupt, parents grimly call it 'falling off the cliff.'").

After high school graduation, many young adults with intellectual disabilities have difficulty finding and maintaining employment.⁵ For some individuals, employment is impossible without a support system, such as a job coach to assist with daily job functions or a family member to prepare them for the work day.⁶ For most, this form of supported employment is dependent on Medicaid waiver funding.⁷ Medicaid waivers provide funding for home- and community-based support services⁸ like a job coach or daily medical services.⁹ Unfortunately, the number of Medicaid waivers within each state is limited, and waiting lists to receive funding can be years long.¹⁰ The lack of Medicaid waiver funding to support individuals with disabilities in their jobs is a problem for all of society, as the ability to work enables young adults with intellectual disabilities to participate in their communities and increases their economic self-sufficiency.¹¹

If Katelyn receives enough waiver funding, she will have the opportunity to work in her community with the support of a job coach. Katelyn's parents will be able to use the waiver funding to pay for her daily job coach, job-related transportation, and any other support she needs to fully participate in her community. Without waiver funding, Katelyn will not be able to work full-time—if at all. Katelyn's parents must find ways for her to stay active in the community. Because she cannot go out into her community without support, however, her parents will likely have to sacrifice their own time and earning capacity to accompany Katelyn whenever she decides to venture into her community.

Without a connection to the community, individuals with disabilities have trouble fostering relationships with nondisabled individuals and may lose the basic communication and social skills developed throughout their education.¹² Without a chance at employment, young adults with disabilities are deprived of the opportunity to achieve economic self-sufficiency during their postsecondary

5. See *id.* (“Even the most thoughtful school counselors and savviest parents have a hard time finding appropriate employment for adults . . . who can independently handle activities of daily living (like eating, bathing, toileting, walking, and dressing) but whose disabilities keep employers from seeing what they might contribute to a workplace.”).

6. See Sharon Lurye, *For Adults with Autism, a Struggle To Find Jobs*, PHILLYVOICE (Apr. 28, 2016), <http://www.phillyvoice.com/autistic-adults-struggle-find-jobs> [http://perma.cc/5FXT-MBY8] (“[I]t’s not enough for employers to commit to hiring those with autism if they’re not also prepared to support them.”).

7. See Polaneczky, *Falling Off the Cliff Part 3*, *supra* note 4 (“[T]hey needed to have Eric’s IQ tested to make sure he was eligible for the type of Medicaid waiver that would fund the job supports he’d need at APS.”).

8. See *infra* notes 175–85 and accompanying text.

9. See *infra* notes 199–200 and accompanying text.

10. See *infra* notes 239–44 and accompanying text.

11. See Polaneczky, *Falling Off the Cliff Part 3*, *supra* note 4 (discussing how, without employment and money, one cannot live independently).

12. See *id.* (noting that high school graduates with disabilities can go years without finding work, “their hard-earned social and behavioral skills regressing as their isolation from the world increases”).

years.¹³ Most importantly, these individuals miss the chance to develop the personal dignity and autonomy associated with employment.¹⁴ For family members and society as a whole, it is best to have individuals with disabilities involved in their communities.¹⁵ Employment allows people to earn the income they need to support themselves, pursue their own interests, and contribute to the tax base.¹⁶

Despite congressional findings that all people are “presumed to be capable of engaging in gainful employment,”¹⁷ individuals with serious intellectual disabilities face barriers to obtaining and maintaining meaningful employment. One barrier to employment is the lack of funding for long-term job support, which many individuals with intellectual disabilities require.¹⁸ Although the primary method of funding long-term support is Medicaid Home- and Community-Based Services Waivers, states limit the number of waivers available to their residents and leave many people on waiting lists for funding.¹⁹ Unfortunately, states are not required to provide a waiver to every eligible individual, as the Medicaid statute does not require that states give funding for community-based services to all.²⁰ This lack of entitlement to a waiver results in an administrative failure and denial of equal employment opportunities for individuals with intellectual disabilities.²¹ To remedy this problem, this Comment proposes making waivers an “entitlement” rather than an option and introduces an alternative funding method for long-term supported employment.

This alternative funding method would encourage employers to hire both individuals with disabilities and their job coaches to perform daily job tasks. To incentivize employers to take on both employees, the alternative method proposes funding the job coach’s work through a combination of employer compensation and state waiver funding. This system affords employers the benefit of two employees, and the waiver recipient receives the benefit of a job coach without paying a large sum of money for that daily support.

Although waivers are a creation of Congress, each state has discretion in implementing its own waiver programs. This discretion results in considerable variability among the states. To illustrate the way waiver funding is allocated to individuals with disabilities, this Comment highlights features of Pennsylvania’s

13. See Dawn Hendricks, *Employment and Adults with Autism Spectrum Disorders: Challenges and Strategies for Success*, 32 J. VOCATIONAL REHABILITATION 125, 125–26 (2010).

14. See Malynn Kuangparichat, Note, *Legal Rights of Young Adults with Autism: Transitioning into Mainstream Adulthood*, 16 WIDENER L. REV. 175, 184 (2010).

15. Carol Beatty, Symposium, *Implementing Olmstead by Outlawing Waiting Lists*, 49 TULSA L. REV. 713, 744 (2014).

16. See Hendricks, *supra* note 13, at 126; see also Polaneczky, *Falling Off the Cliff Part 3*, *supra* note 4 (“Employment is key. Without money, you can’t live independently in the community.” (quoting Cheryl Bates-Harris, “senior advocacy specialist with the National Disability Rights Network”)).

17. 29 U.S.C. § 720(a)(3)(A) (2018).

18. See *infra* notes 153–59 and accompanying text.

19. See *infra* notes 205–08 and accompanying text.

20. See *infra* notes 206–09 and accompanying text.

21. See *infra* notes 298–301 and accompanying text.

waiver programs. In order to remedy the problems highlighted by this Comment, changes must be made to all states' waiver programs.

II. OVERVIEW

Congress has repeatedly recognized that all individuals with intellectual disabilities have the right to participate in our society and contribute to their local communities.²² Individuals may participate in their communities through employment, but they may also participate through group activities like volunteer opportunities or community art and music programs.²³ Efforts to integrate individuals with disabilities into their local communities began with the Rehabilitation Act of 1973 and continued with the Americans with Disabilities Act (ADA).²⁴ To prepare children with disabilities for the later integration ensured by the ADA, Congress created the Individuals with Disabilities Education Act (IDEA).²⁵ Through the IDEA, Congress has tried to ensure that young adults with disabilities are well prepared for future employment and able to obtain that employment upon graduation from high school.²⁶ Most recently, Congress passed the Workforce Innovation Opportunity Act (WIOA), which also prepares children with disabilities for later integration and employment in the community.²⁷ Unfortunately, these codifications of the right to community integration have not led to the provision of the full range of services individuals with disabilities need to succeed.²⁸ This is because an individual with intellectual disabilities may be unable to work independently and lacks the state funding needed for supported employment services.²⁹ This bars some individuals from contributing to their community and gaining the benefits of employment.³⁰

Medicaid waivers are the main source of funding for long-term participation in the community.³¹ In a state like Pennsylvania, where the need for community-based services outweighs the availability of Medicaid funding, people

22. See, e.g., 20 U.S.C. § 1400(c)(1) (2018); 42 U.S.C. § 12101(a)(1) (2018).

23. See NAT'L DISABILITY SERVS. & NAT'L DISABILITY INSURANCE SCHEME, COMMUNITY PARTICIPATION IN ACTION: A RESOURCE GUIDE FOR DISABILITY SERVICE PROVIDERS 14 (2016), http://www.nds.org.au/images/resources/resource-files/CIH_Community_Participation_in_Action_Guide_2016.pdf [<http://perma.cc/WUQ7-BVJU>].

24. See *infra* notes 53–59 and accompanying text.

25. See 20 U.S.C. § 1400(c)(14) (“[P]roviding effective transition services to promote successful post-school employment or education is an important measure of accountability for children with disabilities.”).

26. See *infra* Part II.C.

27. See *infra* Part II.D.

28. See, e.g., Carli Friedman & Mary C. Rizzolo, “Get Us Real Jobs:” Supported Employment Services for People with Intellectual and Developmental Disabilities in Medicaid Home and Community Based Services Waivers, 46 J. VOCATIONAL REHABILITATION 107, 108 (2017) (noting that people with disabilities are employed at lower rates than nondisabled individuals).

29. See Polaneczky, *Falling Off the Cliff Part 3*, *supra* note 4.

30. *Id.*

31. See *infra* notes 174–81 and accompanying text. Additionally, some short-term services exist to assist individuals with disabilities in community participation. See *infra* notes 123–26 and accompanying text.

must wait to become full participants in their community.³² Unfortunately, this waitlist structure remains unchallenged by the courts or the legislature and results in a lack of employment for young adults with intellectual disabilities who cannot work without long-term support.

This Comment argues that individual states should make waivers an entitlement, granting all individuals with disabilities the funding needed to live and work in their local communities rather than remain segregated in institutions. In support of this argument, this Comment highlights society's current distaste toward institutional care and notes that statutes such as the ADA, IDEA, and WIOA are based in a public policy that values making individuals with disabilities full participants in society. This Comment continues by explaining that Medicaid offers a solution for states to fund the community participation of individuals with disabilities. Finally, this Comment draws on past case law that recognizes unjustified segregation of individuals with disabilities as discrimination and notes that recent case law is expanding the right to community participation.

A. *Life for Individuals with Disabilities in Traditional Institutions*

Prior to the second half of the twentieth century, people with intellectual disabilities relied on services provided by public institutions or received care from family members.³³ The placement of individuals with disabilities in segregated institutions increased at the fastest rate from 1925 to 1969.³⁴ People living in segregated public institutions resided in public, overcrowded facilities with little education or opportunity for community participation.³⁵ Living conditions in segregated institutions were poor and residents suffered inhumane treatment.³⁶ Yet waitlists to enter the institutions were often lengthy.³⁷ Although parents typically felt guilty about institutionalizing their children, they often had no other choice, as there was no other way to secure a permanent home for their children.³⁸

The civil rights movement of the 1960s and 1970s increased society's focus on personal rights and individual autonomy.³⁹ The movement also inspired the

32. See *infra* Part II.B.1.

33. Sandra L. Yue, *A Return to Institutionalization Despite Olmstead v. L.C.? The Inadequacy of Medicaid Provider Reimbursement in Minnesota and the Failure To Deliver Home- and Community-Based Waiver Services*, 19 L. INEQ. 307, 312 (2001).

34. *Id.*

35. Beatty, *supra* note 15, at 717.

36. See Yue, *supra* note 33, at 313 (“[C]laims of poor living conditions, neglect and inhumane treatment grounded legal challenges to institutionalization.”); see also *Wyatt v. Aderholt*, 503 F.2d 1305, 1315 (5th Cir. 1974) (“[T]he state may not fail to provide treatment for budgetary reasons alone.”); Joseph Shapiro, *WWII Pacifists Exposed Mental Ward Horrors*, NPR (Dec. 30, 2009, 2:00 PM), <http://www.npr.org/templates/story/story.php?storyId=122017757> [<http://perma.cc/S72U-6Y9A>] (describing Philadelphia State Hospital, known as Byberry, as “brutal and chaotic”).

37. Beatty, *supra* note 15, at 717–18.

38. *Id.*

39. *Id.* at 718.

idea that individuals with intellectual disabilities could improve and benefit from living in less restrictive settings than traditional institutions.⁴⁰ In addition to segregated institutions, discrimination against individuals with disabilities included intentional exclusion and barriers stemming from a failure to modify preexisting facilities in areas like housing and public transportation.⁴¹ Inspired by the Supreme Court's decision in *Brown v. Board of Education*,⁴² disability advocates began a movement toward deinstitutionalization, relying on the theory that separation from society was inherently unequal.⁴³ The deinstitutionalization movement was premised on the idea that individuals with disabilities "could benefit, and even thrive, in less restrictive settings."⁴⁴

Deinstitutionalization involved three essential elements: "releasing people from institutional settings, reducing or preventing admissions to institutional settings, and creating or expanding alternative services in the community."⁴⁵ From 1980 to 2010, the number of people with intellectual and developmental disabilities living in traditional institutional settings decreased by 76.7%.⁴⁶ In 1994, annual spending for services provided outside of institutions exceeded the amount spent for institutional care for the first time.⁴⁷ By 2010, fourteen states had closed all of their public institutions for people with intellectual and developmental disabilities.⁴⁸ Unfortunately, the movement toward deinstitutionalization was not accompanied by the simultaneous development or expansion of comprehensive services to help individuals with disabilities engage in daily community life.⁴⁹

B. *Statutory Protections for Individuals with Disabilities Under the ADA*

Since its enactment in 1990, the ADA has played a critical role in reducing discrimination against individuals with disabilities.⁵⁰ The purpose of the ADA was to address the fact that society "tended to isolate and segregate individuals

40. *Id.* at 718–19.

41. Melody M. Kubo, Note, *Implementing Olmstead v. L.C.: Defining "Effectively Working" Plans for "Reasonably Paced" Wait Lists for Medicaid Home and Community-Based Services Waiver Programs*, 23 U. HAW. L. REV. 731, 740 (2001); *see also* 42 U.S.C. § 12101(a)(5) (2018) (noting current exclusionary effects stem from intentional exclusion, failure to modify existing facilities and practices, and lesser services and opportunities in jobs and other activities).

42. 347 U.S. 483 (1954).

43. Yue, *supra* note 33, at 313.

44. *Id.*

45. Beatty, *supra* note 15, at 718.

46. *Id.* at 720.

47. *Id.* at 729.

48. *Id.* at 720.

49. *See* Joseph Shapiro, *A New Nursing Home Population: The Young*, NPR (Dec. 9, 2010, 12:02 AM), <http://www.npr.org/2010/12/09/131912529/a-new-nursing-home-population-the-young> [<http://perma.cc/EG7E-AL34>] (noting that young people must receive care in nursing homes when states lack programs that allow them to receive care in their own homes).

50. *See* 42 U.S.C. § 12101(b)(1) (2018); *see also* Jane Perkins & Randolph T. Boyle, *Addressing Long Waits for Home and Community-Based Care Through Medicaid and the ADA*, 45 ST. LOUIS U. L.J. 117, 135 (2001).

with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue[d] to be a serious and pervasive social problem.”⁵¹ Prior to enactment of the ADA, individuals with disabilities rarely had legal recourse to address discrimination.⁵²

The ADA expanded upon the ideas set forth in the Rehabilitation Act of 1973,⁵³ which prohibited discrimination against individuals with disabilities by programs receiving federal funding⁵⁴ and was considered the “civil rights bill of the disabled.”⁵⁵ The ADA enhanced the Rehabilitation Act by prohibiting discrimination against disabled individuals by any private entity or employer open to the public.⁵⁶ The ADA’s legislative history indicates that the ADA’s supporters intended that the Act would finally extend “[t]he right to be treated with respect and dignity” to all disabled Americans.⁵⁷

As detailed in the following parts, the ADA requires that individuals with disabilities are integrated into their community and receive care in the least restrictive settings possible.⁵⁸ However, there are limitations to this integration requirement. As discussed in Part II.B.2, the steps that an employer must take to ensure that an individual with disabilities is a full community participant are not unrestricted.⁵⁹

1. The Integration Mandate: The ADA Requires that Individuals with Disabilities Have the Opportunity To Participate in Their Local Communities

The ADA protects the right of disabled individuals to access employment, public services, transportation, public accommodations, and communication.⁶⁰ The ADA requires public entities to “administer services, programs, and

51. 42 U.S.C. § 12101(a)(2).

52. *See id.* § 12101(a)(4).

53. 29 U.S.C. § 794 (2018).

54. *Id.*; Sara Rosenbaum et al., *Olmstead v. L.C.: Implications for Medicaid and Other Publicly Funded Health Services*, 12 HEALTH MATRIX 93, 95–96 (2002).

55. Yue, *supra* note 33, at 315 (quoting *Ams. Disabled for Accessible Pub. Transp. v. Skinner*, 881 F.2d 1184, 1187 (3rd Cir. 1989)).

56. Rosenbaum et al., *supra* note 54, at 96; *see also* 42 U.S.C. § 12101(a)(3).

57. 135 CONG. REC. S10,732 (daily ed. Sept. 7, 1989) (statement of Sen. Mitchell); *see also* Paul Wehman, *Part I: Definitions and Expectations of the ADA*, in THE ADA MANDATE FOR SOCIAL CHANGE 1 (Paul Wehman ed., 1993) (noting that the ADA aimed to promote freedom and choice for people with disabilities and abolish the presumption that people with disabilities are second- or third-class citizens).

58. *See infra* Part II.B.1.

59. *See infra* Part II.B.2.

60. Title I of the Act prohibits employers from discriminating in job application procedures, hiring, advancement, training, and other employment practices. 42 U.S.C. §§ 12111–12117. Title II prohibits discrimination in the provision of public services, programs, and activities provided by state or local governments. *Id.* §§ 12131–12165. Title III prohibits discrimination by places of public accommodation, such as hotels, restaurants, and movie theaters. *Id.* §§ 12181–12189. Title IV of the Act provides for telecommunications services for hearing- and speech-impaired individuals. 47 U.S.C. § 255 (2018). Title V includes miscellaneous provisions, such as the limitation that no individuals with disabilities are required to accept the accommodations ensured by the Act. 42 U.S.C. §§ 12201–12213.

activities in the most integrated setting appropriate to the needs of the qualified individuals with disabilities.”⁶¹

In *Helen L. v. DiDario*,⁶² the Third Circuit Court of Appeals highlighted that integration mandate by holding that the Pennsylvania Department of Welfare violated the ADA by requiring a plaintiff with disabilities to receive care in a segregated nursing home rather than her own home.⁶³ The plaintiff was capable of living without the institutional-level care provided in her nursing home, and a contractor of the Pennsylvania Department of Welfare had previously found that she was eligible for in-home care services.⁶⁴ But a lack of state funding for those in-home services resulted in the plaintiff’s placement on a waitlist for the less restrictive in-home care services.⁶⁵ The court noted that in response to the ADA, “the Department of Justice stated ‘[i]ntegration is fundamental to the purposes of the Americans with Disabilities Act.’”⁶⁶ In granting judgment in favor of the plaintiff, the court reasoned that “the ADA and its attendant regulations clearly define unnecessary segregation as a form of illegal discrimination against the disabled.”⁶⁷ Although the state lacked funding for the plaintiff’s less restrictive placement, the court still found that a denial of services in the most integrated setting appropriate violated the ADA.⁶⁸ As a result, the state was required to provide the plaintiff services in the least restrictive setting possible.⁶⁹

2. Reasonable Employment Accommodations: A Limitation on the ADA’s Integration Mandate

Title I of the ADA prohibits discrimination against qualified individuals in job application procedures, hiring, promotion, discharge, compensation, training, or any other term, condition, or privilege of employment.⁷⁰ As noted in *Helen L.*, the ADA was meant to ensure that people with disabilities are treated “with basic human dignity” and not in “a manner which shunts them aside, hides, and ignores them.”⁷¹ The ADA defines a disability as “a physical or mental impairment that substantially limits one or more major life activities,”⁷² such as caring for oneself, communicating, working, and performing manual tasks.⁷³

61. 28 C.F.R. § 35.130(d) (2018).

62. 46 F.3d 325 (3d Cir. 1995).

63. *Helen L.*, 46 F.3d at 327.

64. *Id.* at 328–29.

65. *Id.* at 329.

66. *Id.* at 332–33 (alteration in original) (quoting 28 C.F.R. § 35.130).

67. *Id.* at 333; *see also* Yue, *supra* note 33, at 316 (noting that the Third Circuit Court of Appeals found that a denial of services in the most integrated setting appropriate for the plaintiff violated the ADA, despite the state’s limited funding).

68. *Helen L.*, 46 F.3d at 338; Yue, *supra* note 33, at 316.

69. *Helen L.*, 46 F.3d at 339.

70. 42 U.S.C. § 12112(a) (2018).

71. *Helen L.*, 46 F.3d at 335.

72. 42 U.S.C. § 12102(1)(A).

73. *Id.* § 12102(2)(A).

Individuals with intellectual disabilities are protected by Title I of the ADA⁷⁴ and are therefore entitled to protections from discrimination in employment.

In an effort to prohibit discrimination, the ADA requires employers to make reasonable accommodations for qualified applicants with disabilities that would not impose undue hardship on the business.⁷⁵ The ADA also requires that employers provide employment opportunities to an individual with disabilities regardless of the individual's need for reasonable accommodations in the workplace.⁷⁶ A "reasonable accommodation" requires an employer to make the workplace readily accessible and usable to individuals with disabilities, restructure work schedules, modify training materials or policies, provide qualified readers or interpreters, and provide other similar accommodations.⁷⁷

Such reasonable accommodations are limited to those that do not place an employer under undue hardship.⁷⁸ An undue hardship is a significant difficulty or expense considering the accommodation needed, and the resources, size, and functions of the employer.⁷⁹ Based on these provisions, Title I of the ADA "opens employment opportunities and requires employers to provide reasonable accommodations in order that a person with a disability can perform a job."⁸⁰ The ADA, however, does not "put people with disabilities in a position to apply and be qualified for jobs in the first place."⁸¹ The ADA protects individuals with disabilities from discrimination in hiring and employment practices, but it fails to assist these individuals in training or preparing to apply for jobs.

A "reasonable accommodation" may include allowing an individual to bring a "job coach" to the job site to provide instruction and support.⁸² A job coach will typically be the primary method of support for an individual with significant disabilities throughout their term of employment.⁸³ Job coaches provide one-on-one training to assist individuals with disabilities in learning and performing their job duties.⁸⁴ Other methods of support may include assistive

74. *Id.* § 12102(1).

75. *Id.* § 12112(b)(5).

76. *Id.*

77. *Id.* § 12111(9).

78. *Id.* § 12112(b)(5).

79. *Id.* § 12111(10).

80. Perkins & Boyle, *supra* note 50, at 135; *see also* 42 U.S.C. §§ 12111–12117.

81. Samuel R. Bagenstos, *The Future of Disability Law*, 114 *YALE L.J.* 1, 23 (2004).

82. Darlene D. Unger, *Workplace Supports: A View from Employers Who Have Hired Supported Employees*, 14 *FOCUS ON AUTISM & OTHER DEVELOPMENTAL DISABILITIES* 167, 167 (1999); *see also* Press Release, U.S. Equal Emp't Opportunity Comm'n, EEOC Sues Comfort Suites for Disability Discrimination (Sept. 16, 2010), <http://www1.eeoc.gov/eeoc/newsroom/release/9-16-10b.cfm?renderforprint=1> [<http://perma.cc/WHX5-J3ES>] (noting that the Equal Employment Opportunity Commission filed a disability discrimination lawsuit against an employer who denied an employee with autism access to and assistance from his state-funded job coach).

83. Unger, *supra* note 82, at 167.

84. JOB ACCOMMODATION NETWORK, *ACCOMMODATION & COMPLIANCE SERIES: JOB COACHING IN THE WORKPLACE 2–3* (2018), <http://askjan.org/publications/topic-downloads.cfm?pubid=969650> [<http://perma.cc/U2M6-GJ6B>].

technology, mentoring programs, or assistance from fellow employees.⁸⁵ Although it is not typical for employers to pay for employees to have a long-term job coach, paying for a temporary job coach may not always be too costly to qualify as a reasonable accommodation.⁸⁶

A “reasonable accommodation” under the ADA would “not require the employer to provide in-home personal-assistance services or transportation to enable an individual with a disability to get to work.”⁸⁷ Employers of individuals with disabilities have no obligation to “make accommodations for personal needs of daily living, such as hygiene, nutrition, and transportation.”⁸⁸ Those extensive accommodations would pose an undue hardship on most, if not all, employers. Unfortunately, those are the types of accommodations necessary for some adults with disabilities to participate in long-term employment.⁸⁹

Because of the limitations on accommodations that an employer must make, some find that the ADA’s prohibition of discrimination does little to “safeguard the quality of life of individuals with disabilities, and particularly individuals with intellectual disabilities.”⁹⁰ Scholars focusing on disability see a need for more positive interventions and social programs that remove the structural barriers that prevent individuals with disabilities from participating in employment.⁹¹ Such programs would require legislation at both the federal and state levels, and implementation would depend on cooperation and understanding from employers and other members of the local community.⁹² Although the ADA provided protections for individuals with disabilities in hiring and employment, the statute failed to provide the support services needed to prepare individuals with disabilities for future employment. Through the IDEA, Congress made progress toward providing such preparatory services.

C. *Transition Services Under the Individuals with Disabilities Education Act*

In 1990 Congress created the IDEA “in response to Congress’ perception that a majority of handicapped children in the United States ‘were either totally excluded from schools or [were] sitting idly in regular classrooms awaiting the time when they were old enough to “drop out.””⁹³ To adequately prepare young adults with disabilities for postgraduation employment, they must receive training and services during their time in school.⁹⁴ To ensure that children with disabilities were developing the necessary skills for future employment, Congress

85. Unger, *supra* note 82, at 168.

86. See JOB ACCOMMODATION NETWORK, *supra* note 84, at 4–5.

87. Bagenstos, *supra* note 81, at 4.

88. Stephanie R. Hoffer, *Making the Law More ABLE: Reforming Medicaid for Disability*, 76 OHIO ST. L.J. 1255, 1259 (2015).

89. *Id.*

90. *Id.* at 1267.

91. *E.g., id.* at 1268.

92. See *id.* (noting that integration of people with disabilities depends on society as a whole).

93. Bd. of Educ. v. Rowley, 458 U.S. 176, 179 (1982) (alteration in original) (quoting H.R. REP. NO. 94-332, at 2 (1975)).

94. See 20 U.S.C. § 1400(c)(14) (2018).

amended the IDEA in 2004 to assist children in the transition from school to adulthood.⁹⁵

The IDEA aims to ensure that children with disabilities have an education that prepares them for “further education, employment, and independent living.”⁹⁶ The IDEA recognizes that “providing effective transition services to promote successful post-school employment or education is an important measure of accountability for children with disabilities.”⁹⁷ The goal of IDEA transition services is to “foster self-sufficiency and independence among students with disabilities by providing them with equal educational opportunities.”⁹⁸

The IDEA requires that all states receiving federal assistance provide a free appropriate public education (FAPE) to all children with disabilities.⁹⁹ A FAPE requires a school to “offer an [Individualized Education Plan (IEP)] reasonably calculated to enable a child to make progress appropriate in light of the child’s circumstances.”¹⁰⁰ A FAPE is provided through a child’s IEP,¹⁰¹ which consists of a written plan for the child that is developed, reviewed, and revised, and includes a statement of the child’s present level of academic achievement and functional performance, a statement of measurable academic and functional goals, and services or accommodations that will be provided to assist the child in meeting these goals.¹⁰²

Critically, the IEP for a child aged sixteen or older requires measurable postsecondary goals related to training and employment.¹⁰³ The IEP should also provide for the transition services needed to assist the child in reaching any goals related to future employment.¹⁰⁴ For a child with disabilities, the transition services should include coordinated activities that assist in moving to postschool activities such as competitive integrated employment, supported employment, and community participation.¹⁰⁵ The services could include instruction,

95. Margaret Condit, Comment, *Remember the IDEA: A Call for Courts To Apply a Piecemeal Approach to Transition Litigation*, 38 T. JEFFERSON L. REV. 6, 10 (2015); see also *Individuals with Disabilities Education Improvement Act of 2004*, Pub. L. No. 108-446, § 101, 118 Stat. 2647, 2647–799 (codified as amended at 20 U.S.C. §§ 1400–1482).

96. 20 U.S.C. § 1400(d)(1)(A).

97. *Id.* § 1400(c)(14).

98. Kevin Golembiewski, *Disparate Treatment and Lost Opportunity: Courts’ Approach to Students with Mental Health Disabilities Under the IDEA*, 88 TEMP. L. REV. 473, 480 (2016).

99. 20 U.S.C. § 1412(a)(1).

100. *Andrew F. v. Douglas Cty. Sch. Dist.*, 137 S. Ct. 988, 999 (2017).

101. 20 U.S.C. § 1401(9)(D); see also *Bd. of Educ. v. Rowley*, 458 U.S. 176, 181 (1982) (“The ‘free appropriate public education’ required by the Act is tailored to the unique needs of the handicapped child by means of an ‘individualized educational program’ (IEP).”).

102. 20 U.S.C. § 1414(d)(1)(A)(i).

103. *Id.* § 1414(d)(1)(A)(i)(VIII).

104. *Id.*; Kuangparichat, *supra* note 14, at 177–78.

105. 20 U.S.C. § 1401(34)(A). With competitive integrated employment, individuals with disabilities work in a community setting with other nondisabled individuals, receive the employer’s customary pay rate, and have opportunities for advancement that mirror those of their nondisabled coworkers. 34 C.F.R. § 361.5(c)(9) (2018). With supported employment, the employee receives the ongoing supports needed to stay in the workplace based on that individual’s unique needs. See *id.* § 361.5(c)(54).

community experiences, development of employment objectives, and acquisition of daily living skills.¹⁰⁶ Parents, school personnel, and outside agencies may participate in a student's transition.¹⁰⁷ The transition services should also consider the student's goals, strengths, and needs.¹⁰⁸ For students with disabilities, these services facilitate the switch from a supported school environment to the less structured world of adult employment.¹⁰⁹

D. The Impact of the Workforce Innovation and Opportunity Act

In 2014 Congress amended the Rehabilitation Act of 1973 and replaced the previous Workforce Investment Act with the Workforce Innovation and Opportunity Act (WIOA).¹¹⁰ Congress passed the WIOA to increase access to and opportunities for the employment, education, training, and support services people need to succeed in the labor market.¹¹¹ The WIOA aims to provide assistance to all eligible individuals, not just those who are under twenty-one.¹¹² The WIOA is particularly concerned with those individuals who face barriers to employment, including individuals with disabilities.¹¹³ Overall, the WIOA aims to increase the economic self-sufficiency of workers in the United States.¹¹⁴

For individuals with disabilities, the WIOA "requires each state to provide, or otherwise arrange for the provision of, pre-employment transition services for all eligible students with disabilities."¹¹⁵ These transition services may include job exploration counseling, integrated work-based learning experiences, counseling related to transition or postsecondary education, workplace readiness training, and instruction in self-advocacy.¹¹⁶ The amended Rehabilitation Act aims to assist states in operating accountability programs of vocational rehabilitation.¹¹⁷ These vocational rehabilitation programs should be "designed to assess, plan, develop, and provide vocational rehabilitation services for individuals with disabilities . . . so that such individuals may prepare for and engage in gainful employment."¹¹⁸ Importantly, the Rehabilitation Act declares

106. 20 U.S.C. § 1401(34)(C); Kuangparichat, *supra* note 14, at 178.

107. Condit, *supra* note 95, at 21.

108. Kuangparichat, *supra* note 14, at 178.

109. Condit, *supra* note 95, at 20.

110. THE ARC OF THE U.S., WIOA: WHAT IT MEANS FOR PEOPLE WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES (I/DD) 2 (2015), <http://www.thearc.org/document.doc?id=5183> [<http://perma.cc/S2BM-N5X2>]; *see also* Workforce Innovation and Opportunity Act, Pub. L. No. 113-128, 118 Stat. 1425 (2014) (codified as amended in scattered sections of 29 U.S.C.).

111. 29 U.S.C. § 3101(1) (2018).

112. *See id.* § 722(a)(1).

113. *Id.* §§ 3101(1), 3102(24).

114. *Id.* § 3101(6).

115. THE ARC OF THE U.S., *supra* note 110, at 5.

116. *Id.* Work-based learning experiences may include in-school or after-school opportunities such as internships. 29 U.S.C. § 733(b)(2). Workplace readiness training should aim to build social skills and independent living. *Id.* § 733(b)(4).

117. 29 U.S.C. § 720(a).

118. *Id.* § 720(a)(2)(B).

a national policy that even “individuals with the most significant disabilities” are presumed capable of gainful employment.¹¹⁹

To receive assistance under the Rehabilitation Act, an individual must have a disability and require vocational rehabilitation to “prepare for, secure, retain, advance in, or regain employment.”¹²⁰ For a state to receive federal funding for its vocational rehabilitative services, it must have a plan in place to comply with federal requirements.¹²¹ These state plans must require state agencies to take affirmative steps to employ and advance employment of individuals with disabilities.¹²²

In order to provide the necessary services, the state agency must work with the individual to create an “individualized plan for employment,” which includes a goal employment outcome, a description of the services needed to achieve that outcome, and evaluative criteria to measure employment progress.¹²³ The vocational rehabilitation services provided through the individualized employment plan could include counseling and guidance, vocational training, transportation, interpretation, supported employment services, and transition services for students.¹²⁴ For purposes of the Rehabilitation Act, supported employment services are “ongoing support services . . . needed to support and maintain an individual with a most significant disability in supported employment.”¹²⁵ But an individual cannot use the supported employment services provided through a state agency for more than twenty-four months.¹²⁶

The WIOA also encourages competitive integrated employment and promotes greater emphasis on transition services for youth with disabilities.¹²⁷ To achieve the goal of competitive integrated employment, the WIOA requires coordination between schools and vocational rehabilitation agencies.¹²⁸ The WIOA also requires schools providing IDEA services to students to provide preemployment transition services.¹²⁹ The required transition services include

119. *Id.* § 720(a)(3)(A).

120. *Id.* § 722(a)(1).

121. *Id.* § 721(a)(1)(A). The federal requirements include, among other things, that each state designate a single agency to administer that state’s vocational rehabilitative services and prepare an individualized plan for employment for each eligible individual. *Id.* § 721(a)(2)–(9).

122. *Id.* § 721(a)(6)(B).

123. *Id.* § 722(b)(4).

124. *Id.* § 723(a).

125. *Id.* § 705(39).

126. *Id.* The WIOA increased the provision of supported employment services from eighteen to twenty-four months, which may be extended when necessary to achieve an individual’s goal employment outcome. THE ARC OF THE U.S., *supra* note 110, at 7.

127. THE ARC OF THE U.S., *supra* note 110, at 5. “Competitive integrated employment” refers to full- or part-time work performed in a space where the employee with disabilities interacts with nondisabled coworkers and receives the employer’s customary pay rate. 29 U.S.C. § 705(5).

128. 29 U.S.C. § 733(a); THE ARC OF THE U.S., *supra* note 110, at 5. These agencies are run by the state or contract with the state to provide the appropriate vocational services. 29 U.S.C. § 705(24).

129. THE ARC OF THE U.S., *supra* note 110, at 5 (noting that vocational rehabilitation officers are required to attend a student’s IEP meeting and work with schools to ensure provision of preemployment transition services); *see also* 29 U.S.C. § 733(a).

job exploration counseling, integrated work-based learning experiences, secondary education counseling, training in social skills and independence, and self-advocacy instruction.¹³⁰ Funds may also be used to develop strategies for individuals with intellectual disabilities to live independently and obtain and retain competitive integrated employment.¹³¹

Each state is required to allocate 15% of its WIOA federal grant funding for vocational rehabilitative services to transition services for students with disabilities.¹³² Although a state receiving federal funds must provide these transition services, there is no guarantee that an individual with disabilities will have the chance to utilize their skills in future employment.¹³³

E. “Falling Off the Cliff”: An Abrupt End to Transitional Support Services Followed by the Waiver Waiting Period

The Centers for Medicare and Medicaid Services (CMS) recognizes that employment is a fundamental part of life that provides individuals with disabilities a sense of purpose and the opportunity to contribute to the community.¹³⁴ Employment is associated with positive mental and physical health benefits, as well as positive self-esteem and well-being.¹³⁵ The CMS also recognizes that all people, regardless of disability and age, can work and build their own economic self-sufficiency.¹³⁶ Without employment and community participation, individuals with disabilities and their families may suffer. Without Medicaid-funded supports, parents may sacrifice their own careers and relationships to care for their children.¹³⁷ The switch from full-day educational services provided through the IDEA to a day without structure and certainty can be shocking for both parents and their newly graduated children.¹³⁸

Unfortunately, the reality is that “people with disabilities are employed at significantly lower rates than nondisabled people.”¹³⁹ Employment rates create one of the largest gaps between people with and without disabilities.¹⁴⁰ Maintaining employment becomes difficult for people with intellectual

130. 29 U.S.C. § 733(b).

131. *Id.* § 733(c).

132. *Id.* § 730(d); THE ARC OF THE U.S., *supra* note 110, at 5.

133. Although the WIOA aims to increase access to and opportunities for employment, it fails to guarantee actual employment. *See* 29 U.S.C. § 3101(1).

134. *Medicaid Employment Initiatives*, MEDICAID.GOV, <http://www.medicaid.gov/medicaid/ltss/employment/index.html> [<http://perma.cc/USQ7-M3YJ>] (last visited May 15, 2019).

135. *Id.*; *see also* Wendy Parent, *Quality of Life and Consumer Choice*, in *THE ADA MANDATE FOR SOCIAL CHANGE*, *supra* note 57, at 28.

136. *Medicaid Employment Initiatives*, *supra* note 134.

137. Polaneczky, *Falling Off the Cliff Part 1*, *supra* note 3.

138. *See id.* (“One day your kid is getting what she needs. You’re able to go to work because she’s being looked after. The day she turns 21—boom—the help ends.” (quoting Audrey Coccia, cofounder of Vision for Equality, “an advocacy group that helps families of disabled relatives access services for their loved ones”)).

139. Friedman & Rizzolo, *supra* note 28, at 108.

140. *Id.*

disabilities like autism, which causes communication and social difficulties with supervisors and coworkers.¹⁴¹ But individuals with all levels of cognitive, behavioral, and social functioning have the ability to work with support.¹⁴² Often, individuals with intellectual disabilities have strengths that make them more successful in job tasks than typical individuals. For example, employees with autism show “attention to detail and intense focus that result in increased work output.”¹⁴³ They may also “enjoy performing jobs often shunned by others due to social isolation or the repetitive nature of the task.”¹⁴⁴

Supported employment may be required for people with intellectual disabilities to utilize their skills. Supported employment can take different forms, depending on the skills of the individual and the employment location. Typical employment options include integrated employment and segregated workshops.¹⁴⁵ As opposed to segregated workshops where the majority of individuals have disabilities, integrated employment allows for interaction with coworkers who are not disabled.¹⁴⁶ This type of supported employment provides payment in an integrated work setting to individuals who were previously excluded from working in their own communities.¹⁴⁷

Community integrated employment could include self-employment, group supported employment, or competitive, individual employment with ongoing support.¹⁴⁸ Supports for integrated employment might involve job placement assistance, help from supervisors and coworkers, workplace modifications, and long-term support.¹⁴⁹ Job coaches are often used in the long term to assist an individual with disabilities at no cost to the employer.¹⁵⁰ They assist in finding a job, developing the skills needed to perform the job, and provide ongoing support while an individual performs the job.¹⁵¹ These job coaches come from vocational rehabilitation agencies and supported employment programs.¹⁵²

141. Hendricks, *supra* note 13, at 127.

142. *Id.* at 131–32.

143. *Id.* at 126.

144. *Id.* (endnote omitted).

145. *Id.*; see also THE ARC OF THE U.S., *supra* note 110, at 3; Paul Wehman, *Employment Opportunities and Career Development* [hereinafter Wehman, *Employment Opportunities*], in THE ADA MANDATE FOR SOCIAL CHANGE, *supra* note 57, at 58.

146. THE ARC OF THE U.S., *supra* note 110, at 3.

147. Rose A. Daly-Rooney, *Designing Reasonable Accommodations Through Co-Worker Participation: Therapeutic Jurisprudence and the Confidentiality Provision of the Americans with Disabilities Act*, 8 J.L. HEALTH 89, 103 n.53 (1993–94).

148. JEAN WINSOR ET AL., PARTNERSHIPS IN EMPLOYMENT: SUPPORTING ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN THEIR COMMUNITIES 3 (2015), http://scholarworks.umb.edu/cgi/viewcontent.cgi?article=1057&context=ici_pubs [<http://perma.cc/4PQ7-Q97Y>].

149. Friedman & Rizzolo, *supra* note 28, at 109; Hendricks, *supra* note 13, at 128.

150. ADA COMPLIANCE GUIDE, INTERPRETERS AND ASSISTANCE ¶ 353 (2018).

151. *Employment Options Before/After Graduation for Individuals with Intellectual Disabilities (Fact Sheet #1)*, EMP’T 1ST, http://s3-us-west-2.amazonaws.com/palms-aws3-repository/MyODP_Content/Course+Content/SELN/Comp+Inter+4/PA-employment-options.pdf [<http://perma.cc/7YXA-9L4K>] (last visited May 15, 2019).

152. *Id.*

In Pennsylvania, the Office of Vocational Rehabilitation (OVR) provides services and assistance to people with disabilities who experience substantial barriers to employment.¹⁵³ OVR services are provided to people who can benefit from and need assistance to prepare for, enter, engage in, or retain employment.¹⁵⁴ OVR employment placement services are provided at no cost to individuals with physical, mental, or emotional disabilities that result in barriers to employment.¹⁵⁵

OVR services are allocated according to an individualized plan and may include diagnosis, vocational counseling, job skills training, and job placement.¹⁵⁶ Job coaching is available to individuals who need on-site job training. OVR will hire and pay for the skills training and ensure that the job coach works with the employee to learn the job to the employer's satisfaction.¹⁵⁷ Unfortunately, this accommodation is not a long-term support option. OVR-funded job coaches are only intended to train the employee and then provide occasional follow-up support when needed.¹⁵⁸ OVR job coaches are not intended to provide support for individuals with disabilities working in a long-term employment setting.¹⁵⁹

OVR will provide a student between the ages of fourteen and twenty-two with preemployment transition services prior to the student's transition out of high school.¹⁶⁰ These transition services include job exploration counseling, work-based learning experiences, counseling for post-secondary education, work-readiness training, and self-advocacy.¹⁶¹ Based on need, OVR may also provide students with a work-based learning experience, which provides an opportunity to develop the knowledge and skills needed for later competitive integrated employment.¹⁶² Individuals participating in a work-based learning experience are paid for their work and may receive on-site support, depending on the need.¹⁶³

Although the OVR programs provide the services needed to start a young adult with disabilities in their search for employment, it is not a long-term solution. Individuals needing more individualized, long-term support will often

153. PA. OFFICE OF VOCATIONAL REHAB., EMPLOYMENT SERVICES FOR PERSONS WITH DISABILITIES (2013), <http://www.dli.pa.gov/Individuals/Disability-Services/ovr/Documents/OVR-600.pdf> [<http://perma.cc/6M65-Q7XL>].

154. *Id.*

155. *Vocational Rehabilitation Services*, PA. DEP'T OF LABOR & INDUS., <http://www.dli.pa.gov/individuals/disability-services/ovr/pages/default.aspx> [<http://perma.cc/9VQS-ED8W>] (last visited May 15, 2019).

156. PA. OFFICE OF VOCATIONAL REHAB., *supra* note 153.

157. *Vocational Rehabilitation Services*, *supra* note 155.

158. *Id.*

159. *Id.*

160. Ja'Netta Kennedy, Vocational Rehab. Counselor, Norristown OVR, PowerPoint Presentation: Pennsylvania Office of Vocational Rehabilitation (Jan. 26, 2016).

161. *Id.*

162. *Id.*

163. *Id.*

need more services than OVR can provide to become full participants in their communities.¹⁶⁴

In addition to the services provided through OVR, Pennsylvania is an “employment first” state. On March 10, 2016, Governor Tom Wolf signed Executive Order 2016-03, called “Establishing ‘Employment First’ Policy and Increasing Competitive-Integrated Employment for Pennsylvanians with a Disability.”¹⁶⁵ This new policy urges agencies like OVR to provide competitive integrated employment as the first consideration and preferred outcome for all working-age individuals in Pennsylvania.¹⁶⁶ The executive order defines competitive integrated employment according to the WIOA as

work performed on a full or part-time basis (including self-employment) for which a person is:

- (1) Compensated at not less than federal minimum wage requirements or State or local minimum wage law (whichever is higher) and not less than the customary rate paid by the employer for the same or similar work performed by people without a disability;
- (2) At a location where the employee interacts with people without a disability (not including supervisory personnel or people who are providing services to such employee); and
- (3) Presented, as appropriate, opportunities for similar benefits and advancement like those for other employees without a disability and who have similar positions.¹⁶⁷

The executive order was signed at a time when only 20% of individuals with disabilities participated in the labor force.¹⁶⁸ Along with the new policy, the executive order came with a recognition that the monetary cap on Pennsylvania’s Person/Family Directed Support Waiver precluded waiver participants from pursuing competitive employment.¹⁶⁹ Since the executive order was issued, the cap for these waiver services has been increased by \$15,000 for supported employment services.¹⁷⁰ Moving forward, Pennsylvania is “actively committed to promoting improved competitive integrated employment outcomes” with the

164. See Paul Wehman, *Supported Employment and Opportunities for Integration* (concluding that individuals with autism and other serious disabilities would not be able to hold jobs without permanent, long-term support in the workplace), in *THE ADA MANDATE FOR SOCIAL CHANGE*, *supra* note 57, at 71–72.

165. PA. DEP’T OF LABOR & INDUS., EXECUTIVE ORDER 2016-03: RECOMMENDATIONS 1 (2016), <http://www.dli.pa.gov/Documents/EstEmpFirstPolicy-for-Pennsylvanians-with-a-Disability.pdf> [<http://perma.cc/MV78-2PRQ>].

166. *Id.*

167. *Id.* at 22.

168. *Id.* at 2 (comparing the 20% of people with disabilities participating in the labor force with the 63% of all people participating in the labor force).

169. *Id.* at 9.

170. *Person/Family Directed Support Waiver*, PA. DEP’T OF HUMAN SERVS., <http://www.dhs.pa.gov/learnaboutdhs/waiverinformation/personfamilydirectedsupportwaiver/> [<http://perma.cc/NM2H-MS86>] (last visited May 15, 2019).

hope of remedying the unemployment rate for disabled Pennsylvanians that is twice the unemployment rate for all individuals.¹⁷¹

F. *The Role of Medicaid*

Congress created Medicaid through the Social Security Amendments of 1965.¹⁷² Medicaid is a joint federal- and state-funded program that is designed to fund the provision of health care services to eligible individuals below a designated income level.¹⁷³ Each state can design and administer its own version of a Medicaid program in compliance with broad federal rules.¹⁷⁴ The Federal Medicaid program reimburses states for a portion of the cost of care provided to low-income individuals through the state's Medicaid program.¹⁷⁵ Because each state designs its own Medicaid program, there is no dollar limit on the amount of federal reimbursement a state can receive.¹⁷⁶ The amount of federal dollars allocated to a state depends on the overall expansiveness of that state's program, which depends on the eligibility rules, number of participants, benefits offered, and health care reimbursement rates defined by the state.¹⁷⁷ The federal share—which ranges from 50% to 83%—depends on the difference between the per capita personal income levels of the state and the national average.¹⁷⁸

After several years of Medicaid's operation, Congress became concerned about the high cost of the program.¹⁷⁹ Congress responded by creating the Medicaid waiver program as a way to replace “expensive institutional care [for individuals with disabilities] with economical services provided in homes and in the community.”¹⁸⁰ In addition to the cost-savings benefit, the waiver program provides services to individuals in their home or community rather than in a hospital or institutional facility.¹⁸¹

The waiver program is optional for states.¹⁸² Under 42 U.S.C. § 1396n(c)(1), states can opt into the program by obtaining a waiver of typical Medicaid

171. PA. DEP'T OF LABOR & INDUS., *supra* note 165, at 21.

172. 42 U.S.C. § 1396 (2018); Beatty, *supra* note 15, at 721.

173. Kubo, *supra* note 41, at 735.

174. ELICIA J. HERZ, CONG. RESEARCH SERV., RL33202, MEDICAID: A PRIMER 1 (2012).

175. Pa. Dep't of Pub. Welfare v. U.S. Dep't of Health & Human Servs., 647 F.3d 506, 508 (3d Cir. 2011) (noting that the federal government reimburses states between 50% and 83% of the cost of Medicaid patient care); HERZ, *supra* note 174, at 1.

176. *Id.* at 9.

177. *Id.*

178. *Id.*

179. Kubo, *supra* note 41, at 735.

180. Beatty, *supra* note 15, at 726. Waivers were created as part of the 1981 Omnibus Reconciliation Act. Helen L. Rapp, Comment, *Funding Long-Term Services and Supports (LTSS) for Working Aged Disabled Americans*, 29 J.L. HEALTH 302, 310 (2016).

181. Pa. Dep't of Pub. Welfare v. U.S. Dep't of Health & Human Servs., 647 F.3d 506, 508 (3d Cir. 2011) (“Medicaid is ‘a cooperative, jointly funded, federal-state program to financially assist low income persons in securing medical care.’” (quoting *Klein v. Califano*, 586 F.2d 250, 253 (3d Cir. 1978))).

182. *See infra* notes 192–95 and accompanying text.

program requirements from the Secretary of Health and Human Services.¹⁸³ The waiver program allows states to waive the typical Medicaid requirements of “comparability” and “statewideness.”¹⁸⁴ These requirements ensure that Medicaid services are available to all individuals on an equivalent basis and that the state Medicaid plan is effective throughout the state.¹⁸⁵ Without the comparability and statewideness requirements, states can prioritize providing waivers to specific groups of people in specific areas of the state.¹⁸⁶

1. Home- and Community-Based Services Waivers

Through the waiver program, states can target Medicaid services to distinct groups of people by creating waiver programs specifically tailored to serve the needs of those populations.¹⁸⁷ One of the main ways that individuals with disabilities receive the long-term services and supports needed to live in the community is through Medicaid Home- and Community-Based Services (HCBS) waivers.¹⁸⁸ HCBS waivers allow individuals to remain in their community and avoid institutionalization.¹⁸⁹ The HCBS waivers are authorized by section 1915(c) of the Social Security Act.¹⁹⁰ Section 1915(c) authorizes the head of the CMS to approve state waiver applications so those states can receive federal matching funds to pay for the home- and community-based services.¹⁹¹

Within the guidelines of the HCBS waiver program, states have flexibility to decide the benefits they will provide, who they will provide those benefits to, and how much healthcare providers will be paid.¹⁹² The waiver program provides states with an opportunity to provide coverage and care to individuals that would not be provided through any other state plan.¹⁹³ Due to the discretion afforded to individual states, the eligibility of individuals with disabilities and the services provided varies among states.¹⁹⁴ Individual states can also revise the terms of eligibility, services, or reimbursement for their own Medicaid programs at any time.¹⁹⁵

183. See *infra* notes 190–99 and accompanying text.

184. Beatty, *supra* note 15, at 727.

185. *Id.*

186. See Rapp, *supra* note 180, at 311; see also Perkins & Boyle, *supra* note 50, at 125.

187. For example, some states have created waiver programs aimed at providing services and supports to the elderly. In Pennsylvania, the “Aging Waiver” provides in-home and community support to individuals ages sixty or above who need nursing-level care. *Aging Waiver*, PA. DEP’T OF HUMAN SERVS., <http://www.dhs.pa.gov/citizens/alternativestonursinghomes/agingwaiver/> [http://perma.cc/F373-GSN2] (last visited May 15, 2019).

188. Beatty, *supra* note 15, at 726.

189. *Id.*

190. See 42 U.S.C. § 1396n(c) (2018).

191. Beatty, *supra* note 15, at 727.

192. *Id.* at 721.

193. Rosenbaum et al., *supra* note 54, at 129.

194. Beatty, *supra* note 15, at 721–22.

195. *Id.* at 722.

The HCBS waiver program aims to provide services to people at home and in their community to avoid institutionalization.¹⁹⁶ Without the services provided through HCBS waivers, the covered individuals would require institutional-level care and could not live in their homes,¹⁹⁷ as “states must limit eligibility to individuals who would, absent HCBS services, require institutional care.”¹⁹⁸ These waiver services may provide for case management services, home health aide and personal care services, adult day health services, and habilitation services.¹⁹⁹ Waivers play a critical role in a state’s ability to provide long-term community care to individuals with intellectual disabilities.²⁰⁰

Before gaining federal approval for a HCBS waiver program, a state’s program must meet several requirements. The proposed program must be “budget neutral,” providing the waiver services must not cost more than comparable institutional services.²⁰¹ It must also ensure the protection of people’s health and welfare, provide adequate and reasonable provider standards to meet the needs of the target population, and ensure that the waiver services follow an individualized and person-centered care plan.²⁰² States must indicate the number of beneficiaries who will receive waiver services each year and request approval before expanding the number of slots available.²⁰³ Some see obtaining waiver funding as an individual waiving his or her right to institutional care in order to receive a comparable and less costly level of community care.²⁰⁴

Although Medicaid requires a state to provide institutional services to all eligible individuals, HCBS is not a mandatory benefit for Medicaid recipients.²⁰⁵ Thus states can limit the number of individuals who receive waiver funding.²⁰⁶ Due to budgetary constraints, few states are willing to provide waivers on a “full open-ended entitlement basis.”²⁰⁷ This leads to a waiting lists for waiver

196. See Perkins & Boyle, *supra* note 50, at 125; see also Skurka v. Dep’t of Pub. Welfare, No. 2167 C.D. 2011, 2013 WL 3961003, at *5 (Pa. Commw. Ct. Jan. 30, 2013) (“The Waiver is available as an alternative to institutionalization for those who wish to receive care and services in their home.”).

197. Rosenbaum et al., *supra* note 54, at 129.

198. Beatty, *supra* note 15, at 728.

199. 42 U.S.C. § 1396n(c)(4)(B) (2018).

200. Beatty, *supra* note 15, at 722.

201. See *id.* at 728; see also 42 C.F.R. § 441.302(e) (2018) (requiring a state to show that the cost of medical assistance provided through a waiver program will not exceed the cost of services provided if a waiver was not granted).

202. *Home & Community-Based Services 1915(c)*, MEDICAID.GOV, <http://www.medicaid.gov/medicaid/hcbs/authorities/1915-c/index.html> [<http://perma.cc/SH86-U7VP>] (last visited May 15, 2019).

203. 42 C.F.R. § 441.303(f)(6).

204. Desiree Kameka, *5 Things You Need To Know About Disability Housing and Advocacy*, AUTISM HOUS. NETWORK (Sept. 27, 2016), <http://www.autismhousingnetwork.org/5-things-need-know-disability-housing-advocacy/> [<http://perma.cc/W66P-4K8Y>].

205. Beatty, *supra* note 15, at 730.

206. *Id.*

207. *Id.* This unwillingness to create more waiver slots exists despite the fact that HCBS typically cost less than institutional care. See *infra* note 212 and accompanying text.

resources.²⁰⁸ The nonentitlement status of HCBS waivers means individuals may be eligible for a waiver but will still be put on a waiting list because there is not enough funding for all eligible applicants.²⁰⁹

In some states, the waitlists to receive services are long and the demand for HCBS waiver funding is growing. As of 2017, 428,151 individuals with intellectual or developmental disabilities were enrolled in a waiting list for some type of HCBS waiver.²¹⁰ Waiver slots become available when a current recipient dies, moves out of state, or stops using waiver services for thirty days.²¹¹ Occasionally, a state will create new waiver slots for a fiscal year, provided that the state has enough capital to fund the additional slot.²¹²

Due to the flexibility built into the HCBS waiver program, the funding provided varies among states.²¹³ Although this variability exists, state waiver programs inform and influence each other.²¹⁴ This Comment highlights features of Pennsylvania's waiver program to demonstrate the logistics of a state waiver program. The Comment draws on national case law, however, because existing case law is sparse and the HCBS waiver program is ultimately governed by federal standards.

2. Home- and Community-Based Services Waivers in Pennsylvania

Like all other states, Pennsylvania participates in the Medicaid program.²¹⁵ In Pennsylvania, the Department of Human Services operates nine different types of HCBS waivers.²¹⁶ Waivers that can provide home and community services for individuals with intellectual disabilities and/or autism include the Adult Autism Waiver, the Consolidated Waiver, the Person/Family-Directed Support Waiver, and the Community Living Waiver.²¹⁷ Each of these waivers

208. Perkins & Boyle, *supra* note 50, at 126.

209. Rapp, *supra* note 180, at 312.

210. *Waiting List Enrollment for Medicaid Section 1915(c) Home and Community-Based Services Waivers*, HENRY J. KAISER FAMILY FOUND., <http://www.kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D> [<http://perma.cc/YTM9-WT6S>] (last visited May 15, 2019).

211. Polaneczky, *Falling Off the Cliff Part 1*, *supra* note 3.

212. *See id.*

213. *See supra* notes 193–95 and accompanying text.

214. *See* L&M POLICY RESEARCH, AUTISM SPECTRUM DISORDERS (ASD): STATE OF THE STATES OF SERVICES AND SUPPORTS FOR PEOPLE WITH ASD 444–45 (2014), <http://www.medicaid.gov/medicaid/ltss/downloads/asd-state-of-the-states-report.pdf> [<http://perma.cc/6PTF-8ME4>] (showing that the majority of states have developed a waiver specifically aimed to provide care to individuals with autism spectrum disorders).

215. Pa. Dep't. of Pub. Welfare v. U.S. Dep't of Health and Human Servs., 647 F.3d 506, 508 (3d Cir. 2011).

216. PA. DEP'T OF HUMAN SERVS., PENNSYLVANIA'S HOME AND COMMUNITY-BASED SERVICES (HCBS) SETTINGS CMS FINAL RULE STATEWIDE TRANSITION PLAN 6 (2016), http://www.dhs.pa.gov/cs/groups/webcontent/documents/document/c_220667.pdf [<http://perma.cc/GV5L-S879>].

217. *Id.* at 7–9; *see also* *Community Living Waiver*, PA. DEP'T OF HUMAN SERVS., <http://dhs.pa.gov/learnaboutdhs/waiverinformation/communitylivingwaiver/index.htm> [<http://perma.cc/JT2Q-5GTV>] (last visited May 15, 2019).

varies in the funding available to the recipient and the services that funding can provide. These waivers exist as an alternative to institutionalization, which is estimated to cost between \$43,500 and \$60,500 per person per year in Pennsylvania.²¹⁸

Before Pennsylvania receives funding for these waivers, the Office of Developmental Programs applies to the Federal CMS to have each category of waiver approved.²¹⁹ Before approval, Pennsylvania must provide information about the eligibility criteria for each waiver, the types of services that will be provided through the waiver, assurances about the methods used to provide those services, and information about how the state will ensure the health and welfare of waiver recipients.²²⁰ After Pennsylvania receives waiver approval from CMS, the state Office of Developmental Programs must submit a renewal request after the first three years of the waiver's operation and then every five years to continue receiving waiver funding from CMS.²²¹

Pennsylvania's Adult Autism Waiver is designed for individuals over the age of twenty-one who would otherwise need institutional care.²²² To qualify for this waiver, an individual must have a diagnosis of autism spectrum disorder.²²³ Services provided through the Adult Autism Waiver include day habilitation, residential habilitation, respite care, supported employment, supports coordination, therapy, assistive technology, behavioral services, community inclusion, community transition, environmental modifications, family counseling, family training, job assessment and placement, nutritional consultation, temporary crisis assistance, and transitional work services.²²⁴ The Adult Autism Waiver received approval for a five-year renewal effective July 16, 2016, and it is meant to provide long-term support for individuals living in their communities with autism spectrum disorder.²²⁵ One of the purposes of this waiver is to “[h]elp

218. Estimates for the cost of institutional-level care vary depending on the year, even when looking at facilities that offer a similar level of skilled nursing services. In 2014, the Pennsylvania Long Term Care Commission estimated the yearly cost of care in a facility offering skilled nursing services to be \$43,500. See PA. LONG TERM CARE COMM'N, FINAL REPORT 6 (2014), http://www.dhs.state.pa.us/cs/groups/webcontent/documents/report/c_134443.pdf [<http://perma.cc/VVA9-PLWR>]. For fiscal year 2012–13, the cost of care in a skilled nursing facility was \$60,528 per person. David Gingerich et al., Pennsylvania Department of Aging, Presentation to Members of the Pennsylvania Long-Term Care Commission: Understanding the Long-Term Living Support System in Pennsylvania (Apr. 10, 2014), http://www.dhs.pa.gov/cs/groups/webcontent/documents/document/c_079845.pdf [<http://perma.cc/NR93-BLDU>]. For 2018, the yearly cost of care by a private company in a skilled nursing facility was estimated to be \$115,340 per person. *Cost of Care Survey 2018*, GENWORTH, <http://www.genworth.com/aging-and-you/finances/cost-of-care.html> [<http://perma.cc/PZ2Y-CZQD>] (last visited May 15, 2019).

219. PA. TRAINING P'SHIP FOR PEOPLE WITH DISABILITIES AND FAMILIES, FAQ #2: INTELLECTUAL DISABILITIES (ID) WAIVERS 2 (2013).

220. *Id.*

221. *Id.*

222. L&M POLICY RESEARCH, *supra* note 214, at 323.

223. *Adult Autism Waiver*, PA. DEP'T OF HUMAN SERVS., <http://www.dhs.pa.gov/citizens/autismservices/adultautismwaiver/> [<http://perma.cc/J54T-LVXD>] (last visited May 15, 2019).

224. *Id.*

225. *Id.*

adults with autism spectrum disorder reach their employment goals.”²²⁶ For the fiscal year 2016–17, there were 668 waiver slots in Pennsylvania for adults with autism.²²⁷ There is no cap placed on the funding provided to individuals through the Adult Autism Waiver, and people receive services based on their individual need.²²⁸

Pennsylvania’s Consolidated Waiver is intended to assist individuals with intellectual disabilities, developmental disabilities, and autism spectrum disorder of any age to live more independently in their homes and communities.²²⁹ The Consolidated Waiver “emphasizes deinstitutionalization” by aiming to provide support in individuals’ private homes.²³⁰ The Consolidated Waiver is often referred to as the “big waiver” in Pennsylvania, as there is no dollar cap on the services available to individuals receiving the waiver.²³¹ The services provided to an individual will vary depending upon need but may include educational support services, home and community habilitation, homemaker and chore services, licensed day habilitation, prevocational services, residential habilitation, respite care, supported employment, supports coordination, extended nursing, extended therapy services, supports broker services, assistive technology, behavioral support, companion support, home accessibility adaptations, specialized supplies, transitional work services, transportation, and vehicle accessibility adaptations.²³²

The Pennsylvania Person/Family Directed Support Waiver is available for individuals of any age with intellectual disabilities, developmental disabilities, and autism spectrum disorders.²³³ This waiver is designed to help individuals live more independently in their homes and communities and provide services that promote community living.²³⁴ Unlike the Consolidated Waiver, the Person/Family Directed Support Waiver has a cost limitation of \$33,000 per person per fiscal year, with an additional \$15,000 per year available for supported employment services.²³⁵ Due to this monetary cap, this waiver is often

226. *Id.*

227. *Id.*

228. *Id.*

229. *Consolidated Waiver*, PA. DEP’T OF HUMAN SERVS., <http://www.dhs.pa.gov/learnaboutdhs/waiverinformation/consolidatedwaiverforindividualswithintellectualdisabilities/> [http://perma.cc/7sdz-9ba8] (last visited May 15, 2019).

230. L&M POLICY RESEARCH, *supra* note 214, at 324.

231. PA. TRAINING P’SHIP FOR PEOPLE WITH DISABILITIES AND FAMILIES, *supra* note 219, at 4. Although there is limited funding for Pennsylvania’s entire waiver program, there is no dollar cap on the services the state can provide through the Consolidated Waiver. *Long Term Care Services*, PA. DEP’T OF HUMAN SERVS., <http://www.dhs.pa.gov/citizens/healthcaremedicalassistance/longtermcare/services/index.htm> [http://perma.cc/75QR-KS7K] (last visited May 15, 2019).

232. L&M POLICY RESEARCH, *supra* note 214, at 324.

233. *Person/Family Directed Support Waiver*, PA. DEP’T OF HUMAN SERVS., <http://www.dhs.pa.gov/learnaboutdhs/waiverinformation/personfamilydirectedsupportwaiver/> [http://perma.cc/ZBD9-5CJU] (last visited May 15, 2019).

234. *Id.*

235. *Id.*

referred to as the “small waiver.”²³⁶ The services available under the Person/Family Directed Support Waiver are the same as those available through the Consolidated Waiver, with the exception of residential habilitation.²³⁷

CMS approved the Community Living Waiver on December 20, 2017.²³⁸ The waiver became effective on January 1, 2018, and Pennsylvania aims to provide waiver services for 1,000 individuals with an intellectual disability or autism.²³⁹ The goal of this new waiver is to “support[] individuals . . . to live more independently in their homes and communities through the provision of a variety of services that promote community living, employment, communication, self-direction, choice and control.”²⁴⁰ The funding available to an individual through the Community Living Waiver is capped at \$70,000, and some of the services available include behavioral support, small group employment, supported employment, and transportation.²⁴¹

Although people living in Pennsylvania are “entitled to apply” for these waiver services, they are not actually entitled to receive them.²⁴² Individuals who are eligible for the waivers will be placed on the state’s waiting list when there is no current funding available.²⁴³ As of January 31, 2019, there were 13,119 people with intellectual disabilities on a waiting list for a waiver in Pennsylvania.²⁴⁴ People on the waitlist are characterized as emergency, critical, or planning, ranging from a need for services immediately to a need for services within the next five years.²⁴⁵ The Pennsylvania Department of Human Services reported that as of December 2018, 17,811 people were receiving Consolidated Waivers, 711 people were receiving the Adult Autism Waiver, and 12,377 individuals were receiving the Person/Family Directed Support Waiver.²⁴⁶ In the same month, 1,726 individuals were living in private Intermediate Care Facilities for people with disabilities, and 746 people were living in public facilities.²⁴⁷

236. PA. TRAINING P'SHIP FOR PEOPLE WITH DISABILITIES AND FAMILIES, *supra* note 219, at 3.

237. *Id.* at 7.

238. *Community Living Waiver*, *supra* note 217.

239. *Id.*

240. *Id.*

241. *Id.*

242. PA. TRAINING P'SHIP FOR PEOPLE WITH DISABILITIES AND FAMILIES, *supra* note 219, at 10.

243. *Id.*

244. *Intellectual Disabilities—As of January 31, 2019*, PA WAITING LIST CAMPAIGN, <http://pawaitinglistcampaign.org/> [<http://perma.cc/G33Z-AUFS>] (last visited May 15, 2019).

245. *Who Is Waiting for Services?*, PA. DEP'T HUMAN SERVS. (June 2017), http://dhs.pa.gov/cs/groups/webcontent/documents/document/c_262143.pdf [<http://perma.cc/JGJ6-PGDV>].

246. PA. DEP'T OF HUMAN SERVS., MONTHLY DATA REPORT: JANUARY 2019, at 22–24 (2019), http://www.dhs.pa.gov/cs/groups/webcontent/documents/document/c_213880.pdf [<http://perma.cc/vs7l-fysd>].

247. *Id.* at 24 (noting a 3% decreased enrollment in private facilities from September 2017 to September 2018 and a 11% decreased enrollment in public facilities from September 2017 to September 2018).

G. *The Court's Impact on HCBS Waivers*

The Supreme Court has addressed a state's obligation to provide individuals with disabilities with care in the least restrictive community settings. But the Court has not addressed the specific services an individual with disabilities must receive to experience community life. Specifically, the Court has not addressed a state's obligation to allocate sufficient resources to afford individuals with the opportunity to engage in meaningful employment.

Part II.G.1 begins with a discussion of the leading case on the integration mandate of the ADA. Part II.G.2 continues by discussing failed challenges aimed at eliminating states' waiver program waitlists. Finally, Part II.G.3 highlights recent cases that suggest that waiting lists themselves violate the ADA's integration mandate. These cases do not explicitly hold that waiting lists violate the integration mandate. However, the cases recognize that segregation can occur in one's own home while waiting for the funding necessary to become a community participant.

1. *The Olmstead Decision*

In *Olmstead v. L.C. ex rel. Zimring*,²⁴⁸ the Supreme Court considered whether placement of persons with mental disabilities in institutions rather than appropriate community settings resulted in discrimination.²⁴⁹ *Olmstead* followed *City of Cleburne v. Cleburne Living Center, Inc.*,²⁵⁰ in which "Justice Marshall noted that continued isolation of persons with disabilities perpetuated negative attitudes and irrational fears toward them, which in turn deprived them of 'much of what makes for human freedom and fulfillment—the ability to form bonds and take part in the life of a community.'"²⁵¹

In *Olmstead*, the Court determined that Title II of the ADA requires states to place individuals with disabilities in community settings rather than in institutions when state treatment professionals determine community placement is appropriate, the individual does not oppose the community care, and placement can be reasonably accommodated considering the state's resources and the needs of other individuals with disabilities.²⁵² Therefore, unjustified isolation results in discrimination based on disability.²⁵³ The unfair and dissimilar treatment of individuals with disabilities is rooted in the fact that people with mental disabilities must give up community life to receive needed medical care, whereas people without disabilities can receive necessary medical services without relinquishing their community participation.²⁵⁴

248. 527 U.S. 581 (1999).

249. *Olmstead*, 527 U.S. at 587.

250. 473 U.S. 432 (1985).

251. Yue, *supra* note 33, at 314 (quoting *Cleburne*, 473 U.S. at 461 (Marshall, J., concurring in the judgment and dissenting in part)).

252. *Olmstead*, 527 U.S. at 587.

253. *Id.* at 597.

254. *Id.* at 601.

In reaching its conclusion, the Court noted that “institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.”²⁵⁵ Building on Justice Marshall’s earlier conclusions,²⁵⁶ the Court underscored that institutionalization diminishes the daily activities of individuals, including family relations, social contacts, employment options, economic independence, educational advancement, and cultural enrichment.²⁵⁷

Although the Court’s holding requires community placement, it is qualified by the fact that states only have to undertake “reasonable modifications” to avoid discrimination.²⁵⁸ This allows states to avoid allocating resources to an individual’s appropriate community placement when the state can show that the allocation of those resources would be inequitable, considering the large population of persons the state is responsible for treating.²⁵⁹ A state that demonstrates a “comprehensive, effectively working plan” for community placement and a “waiting list that move[s] at a reasonable pace” meets this reasonable modification standard.²⁶⁰

2. Failed Challenges to HCBS Waiver Waiting Lists

Following *Olmstead* and the growth of waiting lists for state HCBS waivers, courts have heard challenges to the waiting periods for noninstitutional services. In *Arc of Washington State Inc. v. Braddock*,²⁶¹ the Ninth Circuit Court of Appeals considered whether a state violates the ADA by limiting the number of individuals who can participate in a Medicaid waiver program.²⁶² At the time the case was filed, the State of Washington limited its HCBS waiver to 9,977 people, but there was no indication that the state was failing to fill the allocated waiver slots with participants.²⁶³ The institutionalized plaintiffs argued that Washington needed to make the HCBS waiver program open to all individuals who qualified for institutional care in order to comply with the ADA.²⁶⁴ The court rejected the plaintiffs’ argument, using the *Olmstead* language to conclude that states have a responsibility to make reasonable modifications to their waiver programs to comply with the ADA but not modifications that would fundamentally alter the nature of the programs.²⁶⁵ Rather than evaluating the actual size of the waiver program, the court considered whether the program was an acceptable plan for

255. *Id.* at 600.

256. *See Yue, supra* note 33, at 314.

257. *Olmstead*, 527 U.S. at 601.

258. *Id.* at 603.

259. *Id.* at 604.

260. *Id.* at 605–06.

261. 427 F.3d 615 (9th Cir. 2005).

262. *Arc of Wash.*, 427 F.3d at 617.

263. *Id.*

264. *Id.*

265. *Id.* at 618.

deinstitutionalization.²⁶⁶ Although the court did not hold that the forced expansion of a state's waiver program can never be required by the ADA, it refused to order Washington to expand the state waiver program because it was comprehensive, effective, and committed to deinstitutionalization.²⁶⁷

In *Frederick L. v. Department of Public Welfare*,²⁶⁸ the Third Circuit Court of Appeals considered whether Pennsylvania's Department of Public Welfare violated the rights of a class of institutionalized plaintiffs under the ADA by failing to integrate the plaintiffs into their communities.²⁶⁹ The court pointed to *Olmstead*, which "requires that patients eligible and desirous of community placement be discharged into community-based programs if placement can be reasonably accommodated."²⁷⁰ Noting the state's ability to present a fundamental alteration defense,²⁷¹ the court stated that a comprehensive working plan toward deinstitutionalization is a necessary component of such a defense.²⁷² Although Pennsylvania attempted to construct an effective plan, the court found no such comprehensive plan for placing the institutionalized patients in community-based programs.²⁷³ Relying on *Olmstead*, the court established guidelines for the district court to use on remand to evaluate Pennsylvania's deinstitutionalization plan:

[A] viable integration plan . . . should specify the time-frame or target date for patient discharge, the approximate number of patients to be discharged each time period, the eligibility for discharge, and a general description of the collaboration required between the local authorities and the housing, transportation, care, and education agencies to effectuate integration into the community.²⁷⁴

To ensure compliance with the ADA in future cases, the court advised Pennsylvania's Department of Public Welfare to create a plan in line with these recommendations to comply with the ADA.²⁷⁵

In both *Arc of Washington* and *Frederick L.*, the appellate courts concluded that a state must have a plan working toward deinstitutionalization. The courts did not hold that every person who qualifies for a waiver must receive one immediately. Additionally, the courts did not articulate the quality or array of services required for meaningful community participation.

266. *Id.* at 620.

267. *Id.* at 621.

268. 422 F.3d 151 (3d Cir. 2005).

269. *Frederick L.*, 422 F.3d at 154.

270. *Id.* at 156–57.

271. Such a defense "would allow the State to show that, in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities." *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 604 (1999) (opinion of Ginsburg, J.).

272. *Frederick L.*, 422 F.3d at 157.

273. *Id.* at 158–59.

274. *Id.* at 160.

275. *Id.*

3. Recent Case Law Presents an Opportunity for the Expansion of *Olmstead*

After *Olmstead*, courts were uncertain of the decision's reach. Because *Olmstead* involved individuals who were institutionalized, lower courts later had to decide whether the decision applied to people living outside of traditional institutional settings.²⁷⁶ Recently, several courts across the United States have concluded that *Olmstead's* reasoning applies outside of the institutional setting.²⁷⁷ These courts recognize that individuals with disabilities can still experience segregation from the community while living inside their own homes.

The United States District Court for the District of Minnesota recently addressed whether segregation can occur outside of the traditional institutional setting in *Guggenberger v. Minnesota*.²⁷⁸ *Guggenberger* involved three plaintiffs who claimed they were experiencing unjustified segregation based on the state's administration of its waiver program.²⁷⁹ Specifically, the plaintiffs alleged "that their placement on waiting lists and their inability to access Waiver Services cause[d] feelings of isolation and segregation from society."²⁸⁰ The court denied the Minnesota Department of Human Services's motion to dismiss because the plaintiffs adequately alleged they were not living, working, or receiving services in a setting that allowed them to interact with nondisabled individuals in their community, in violation of the ADA.²⁸¹ To reach this ruling, the court concluded that the *Olmstead* holding was not limited to situations in which individuals are institutionalized.²⁸² Instead, the ADA's integration mandate applies broadly to all individuals experiencing segregation.²⁸³

Similarly, in *Lane v. Kitzhaber*,²⁸⁴ the United States District Court for the District of Oregon determined that the *Olmstead* holding applied beyond the institutional context.²⁸⁵ In *Lane*, the plaintiffs alleged they experienced segregation in sheltered workshops.²⁸⁶ The plaintiffs had the ability and preference to work in an integrated community setting.²⁸⁷ In applying *Olmstead* to the facts of *Lane*, the court reasoned that the problems with institutionalization were the same problems evident in the segregated sheltered workshops where the plaintiffs were working.²⁸⁸ As in *Olmstead*, where the court

276. Yue, *supra* note 33, at 317–18.

277. See *infra* notes 278–94 and accompanying text.

278. 198 F. Supp. 3d 973 (D. Minn. 2016).

279. *Guggenberger*, 198 F. Supp. 3d at 1029.

280. *Id.* at 987.

281. *Id.* at 1029–30, 1036.

282. *Id.* at 1026–27.

283. See *id.*

284. 841 F. Supp. 2d 1199 (D. Or. 2012).

285. *Lane*, 841 F. Supp. 2d at 1205.

286. *Id.* at 1200.

287. *Id.*

288. *Id.* at 1205 (noting that institutionalization perpetuates the assumption that people with disabilities cannot participate in the community and diminishes the quality of life of people with disabilities).

was concerned with the assumption that people with disabilities cannot participate in everyday life, life in sheltered workshops assumes that individuals with disabilities are not able to live and work in society with their typical peers.²⁸⁹

The Seventh Circuit Court of Appeals also addressed the application of *Olmstead* outside of the institutional setting in *Steimel v. Wernert*.²⁹⁰ In *Steimel*, the plaintiffs were moved from an expansive waiver service to a more limited waiver that stunted their ability to participate in community activities.²⁹¹ In considering whether isolation in the home of a person who can benefit from community integration is a violation of the integration mandate of the ADA, the court applied *Olmstead*'s reasoning.²⁹² The court pointed out that segregation inside one's home can limit the quality of life of individuals with disabilities.²⁹³ The Seventh Circuit held "that the integration mandate is implicated where the state's policies have either (1) segregated persons with disabilities within their homes, or (2) put them at serious risk of institutionalization."²⁹⁴

Although *Olmstead* involved institutionalized individuals, courts have recognized that its reasoning applies outside of the visibly segregated institutional setting.²⁹⁵ This extension of *Olmstead* shows courts' willingness to recognize that segregation of individuals with disabilities is not completely solved through deinstitutionalization.²⁹⁶ Segregation can still occur when individuals live outside of traditional institutions, yet are unable to participate fully in community life.

Unfortunately, no statute or judicial opinion currently mandates that young adults with disabilities receive the resources needed for them to become full, working participants in their own communities. Practically, funding such a mandate may be expensive and resource intensive. As society moves toward deinstitutionalization, it is important to note that courts are willing to reiterate

289. *Id.*

290. 823 F.3d 902 (7th Cir. 2016).

291. *Steimel*, 823 F.3d at 908.

292. *Id.* at 910.

293. *Id.* at 911.

294. *Id.* at 914.

295. *See supra* notes 278–94 and accompanying text.

296. *See Ball v. Kasich*, 244 F. Supp. 3d 662, 679 (S.D. Ohio 2017) ("*Olmstead* relief is not limited to individuals currently institutionalized but also applies to persons at serious risk of institutionalization or segregation."). The Department of Justice has also noted that *Olmstead* can apply to individuals outside of a traditional institution. U.S. DEP'T OF JUSTICE, CIVIL RIGHTS DIV., STATEMENT OF THE DEPARTMENT OF JUSTICE ON ENFORCEMENT OF THE INTEGRATION MANDATE OF TITLE II OF THE AMERICANS WITH DISABILITIES ACT AND *OLMSTEAD V. L.C.* 5 (2011), http://www.ada.gov/olmstead/q&a_olmstead.pdf [<http://perma.cc/9D6G-QMWK>] ("[T]he ADA and the *Olmstead* decision extend to persons at serious risk of institutionalization or segregation and are not limited to individuals currently in institutional or other segregated settings. . . . [A] plaintiff could show sufficient risk of institutionalization to make out an *Olmstead* violation if a public entity's failure to provide community services or its cut to such services will likely cause a decline in health, safety, or welfare that would lead to the individual's eventual placement in an institution.").

the ADA's important finding that isolation and segregation of individuals with disabilities "continue[s] to be a serious and pervasive social problem."²⁹⁷

III. DISCUSSION

The prospect of not receiving funding from a state waiver program is a source of stress for families and individuals with intellectual disabilities.²⁹⁸ Building on *Olmstead* and *Guggenberger*, which recognized the importance of community integration,²⁹⁹ the needs of individuals with disabilities would best be met through a waiver entitlement program that ensures they can remain in their community and have an opportunity to experience the fulfillment of employment. The certainty of waiver funding would provide young adults with disabilities and their families a sense of security and allow them to focus on planning for the future, rather than dreading the future after high school graduation. The certainty would also allow individuals with disabilities to participate in the workforce at a rate that more closely aligns with rates of employment for individuals without disabilities.

The unique federal-state partnership structure of Medicaid presents an opportunity for states to treat HCBS waiver as if they were an entitlement for all eligible individuals. But even if waiver funding becomes an entitlement, there are still budgetary constraints on states that may limit the amount of funding available for each person.³⁰⁰ To lessen the amount of waiver funding it takes for young adults with disabilities to work in their community, we should consider alternative methods of funding supports such as job coaches. An alternative method of funding job supports would lessen the percentage of waiver funding spent on employment and encourage employers to hire young adults with disabilities.

This Comment argues that waivers should be treated as an entitlement for three main reasons. First, waiting lists for waiver funding and small amounts of funding segregate individuals with disabilities from their communities. Second, case law demonstrates a pattern tending toward recognition that waiver waiting lists violate the ADA's integration mandate. Finally, the dual federal-state structure of Medicaid presents an opportunity for states to act independently and recognize that all individuals with disabilities should be entitled to waiver funding for community participation without time for young adults to "fall off the cliff" and lose the skills gained through their education.

A. *People with Disabilities Need Waivers To Avoid Segregation and Regression*

The ADA alone fails to provide intellectually disabled individuals with supported employment. For individuals requiring the short-term support of a job

297. See *supra* Part II.G.3; see also 42 U.S.C. § 12101(a)(2) (2018).

298. See Polaneczky, *Falling Off the Cliff Part 3*, *supra* note 4.

299. See *supra* notes 275–80 and accompanying text.

300. See *supra* Part II.F.2 for a discussion of Pennsylvania's budgetary constraints that limit the current HCBS waiver program.

coach to learn basic job tasks, the ADA may ensure an equal opportunity to gain employment.³⁰¹ Requiring an employer to pay for long-term supported employment, however, is not typically a reasonable accommodation an employer will always be required to undertake.³⁰² Without incentives or government assistance, few employers would be willing to pay for long-term services or supports in the form of a job coach or other one-on-one support.³⁰³ Individuals requiring extensive support need more services and more funding to participate in the employment that will grant them human dignity and the chance for economic self-sufficiency.

After high school graduation, many of the support services an individual has been receiving are suddenly discontinued.³⁰⁴ Despite the services and resources used to prepare students for their transition out of high school, students leave school and encounter unemployment and underemployment, along with economic instability and social isolation.³⁰⁵ The school and transition services provided through the IDEA provide more than just training—they provide students with a sense of purpose and belonging that disappears with graduation.³⁰⁶ To replace those lost services and the lost sense of community participation, individuals with disabilities often look to HCBS waivers.³⁰⁷ HCBS waivers are the largest sources of funding for long-term supports and services for people with disabilities in the United States.³⁰⁸ In 2013, HCBS waivers were responsible for more than two-thirds of all supported employment spending for people with intellectual disabilities.³⁰⁹

Without HCBS waiver funding, home and community care is “a financial drain on families” of individuals with disabilities.³¹⁰ “Most people who require long-term services live in families with very limited income, and receive their personal care under the ‘informal support model,’ in which uncompensated services are provided by family members and friends.”³¹¹ These informal caregivers may forego economic and personal responsibilities due to the needs of a loved one with disabilities.³¹² An alternative to the provision of waiver funding is to require parents to stay home and care for a young adult with disabilities.

301. See *supra* notes 123–26 and accompanying text.

302. See *supra* Part II.B.2.

303. See *supra* Part II.B.2.

304. Kuangparichat, *supra* note 14, at 181.

305. See Condit, *supra* note 95, at 22.

306. Polaneczky, *Falling Off the Cliff Part 3*, *supra* note 4 (“The services provide more than tailored academic or life-skills instruction: They give a child a place to be each day and a feeling of belonging . . .”).

307. See Kuangparichat, *supra* note 14, at 181.

308. Friedman & Rizzolo, *supra* note 28, at 108.

309. *Id.* at 109.

310. Perkins & Boyle, *supra* note 50, at 119; see also Wehman, *Employment Opportunities*, *supra* note 145, at 55.

311. Andrew I. Batavia, *A Right to Personal Assistance Services: “Most Integrated Setting Appropriate” Requirements and the Independent Living Model of Long-Term Care*, 27 AM. J. L. MED. 17, 18 (2001).

312. *Id.*

This may lead to an emotional burden on the parent, as well as financial strain on the family and society as a whole.³¹³

Without waivers that are provided promptly after the discontinuation of school services, individuals with disabilities cannot make a smooth transition into their communities. When all supports and services are suddenly discontinued upon high school graduation, there is a possibility of regression in the skills learned and invested in during school.³¹⁴ The transition period from school age to adulthood is a critical time for individuals with intellectual disabilities,³¹⁵ and we should not allow regression in invested skills just because of a state's unwillingness to allocate the necessary resources to provide supported employment.³¹⁶ The transition services provided through the IDEA and the WIOA are wasted by a government that fails to provide recipients with an opportunity to utilize their transition-preparedness skills in a way that adds to their quality of life and facilitates their economic self-sufficiency.

Alternatively, if young adults with disabilities graduate from high school and are able to utilize their entitlement to Medicaid waiver funding, they could use that funding to immediately begin supported employment. This way, the skills they learned through IDEA transition services will not be lost or wasted. Rather than having to stay home and lose the skills developed during high school, they can use and continue to master their job skills on a regular basis. Of course, this is only possible if the waiver funding provided is large enough to pay for employment support.³¹⁷ In Pennsylvania, getting a small amount of waiver funding forces parents to focus on daily living needs rather than employment.³¹⁸

Today's waiver system creates perverse incentives toward segregated institutionalization. Although states are required to provide all qualified individuals with institutional care through Medicaid, states are not required to provide waivers to all qualified individuals.³¹⁹ For some families, this forces a choice between two unappealing alternatives: placing their family member with disabilities in an institution to receive guaranteed services or waiting an

313. See Wehman, *Employment Opportunities*, *supra* note 145, at 56 (stating that wages earned by individuals with disabilities typically flow back into the state and local economies).

314. Kuangparichat, *supra* note 14, at 176.

315. THE ARC OF THE U.S., *supra* note 110, at 3.

316. Friedman & Rizzolo, *supra* note 28, at 114 (“[P]eople with IDD ‘spend the first two decades of their lives preparing to be full members of the community. We should not break that promise just as it is about to be achieved. A guarantee of supported employment services would help to keep that promise.’” (quoting Samuel R. Bagenstos, *The Disability Cliff*, 35 *DEMOCRACY* 55, 67 (2015))).

317. See *supra* Part II.F.2 for a discussion of how some state waivers have smaller financial allotments than others.

318. When forced with the choice of allocating waiver money from a limited budget to medically necessary care and employment supports, it is likely that parents will forgo the employment services. See *supra* Part II.F.2 for a discussion of how Pennsylvania waivers can be used for a range of different services.

319. Beatty, *supra* note 15, at 730.

unknown amount of time to receive HCBS waiver services.³²⁰ As society moves away from institutionalization, we should not force parents to give up their right to prompt services in order to keep their child out of institutional care.³²¹ Currently, the institutional services a young adult with disabilities is entitled to can cost up to five times as much as home- and community-based waiver services.³²²

The forced choice between guaranteed institutional care and uncertain home care reflects a different undesirable choice parents were forced to make in the past. In December of 2014 Congress passed the Achieving a Better Life Experience (ABLE) Act to allow individuals with disabilities and their families to save money without impacting Medicaid eligibility.³²³ Prior to the creation of the ABLE Act, parents often had to choose between providing their children with financial resources or making their children dependent on government funding in order to receive Medicaid funding.³²⁴ Medicaid eligibility rules required that recipients fell below a certain income level, causing individuals with disabilities to choose low-wage jobs for themselves and causing family members to avoid providing Medicaid recipients with groceries and other necessities.³²⁵ With the ABLE Act, individuals with significant disabilities and their families can now save a certain amount of money for necessities without impacting Medicaid eligibility.³²⁶ Although the amount an individual can receive without losing their Medicaid eligibility is fixed at \$15,000,³²⁷ the ABLE Act takes away the Catch-22 feeling of family members of those with disabilities.

Just as Congress implemented the ABLE Act to limit a choice between two evils, states should eliminate the choice between institutionalization and home- and community-based services by broadening access to Medicaid waivers. Considering it costs a state more to fund an individual's entitlement to an institution,³²⁸ it makes sense for the government to create an entitlement to home- and community-based services. With an entitlement to a waiver, families

320. *Id.* at 714; Perkins & Boyle, *supra* note 50, at 128; *see also* Polaneczky, *Falling Off the Cliff Part 1*, *supra* note 3 (noting the frustration of a parent of a young adult with disabilities who “feels like the state plays chicken” with parents who do not want to institutionalize their children).

321. *See* Polaneczky, *Falling Off the Cliff Part 1*, *supra* note 3 (“The irony is that, if forced, they could exercise the boys’ entitlement to care in an institutional setting, at a cost to taxpayers about five times higher than what a waiver would provide.”); *see also* Parent, *supra* note 135, at 21 (explaining that, in the past, “the opportunity to make choices concerning [one’s] life, work, and recreation has been limited or nonexistent for individuals who have disabilities”).

322. *See* Polaneczky, *Falling Off the Cliff Part 1*, *supra* note 3.

323. Hoffer, *supra* note 88, at 1261.

324. *Id.*

325. *Id.*

326. *Id.*

327. Bob Casey, Opinion, *Let’s Lower the Barriers for Young People with Disabilities*, PHILA. INQUIRER (Dec. 8, 2017, 5:00 AM), <http://www.philly.com/philly/opinion/commentary/intellectual-developmental-disabilities-americans-with-disabilities-act-bob-casey-pa-20171208.html> [http://perma.cc/TW2Y-DZY2].

328. *See supra* notes 215–18 and accompanying text.

would feel more secure and more inclined to avoid placing their loved ones in an expensive institutional setting.

B. Broad Interpretation of Olmstead and the ADA's Integration Mandate Could Require a Waiver Entitlement

Unfortunately, *Olmstead* does little to combat waiver waiting lists. Under *Olmstead*, a state can use a waiting list to allocate waiver funding as long as the waiting list moves at a reasonable pace.³²⁹ As case law shows, it seems that courts are more concerned with segregation when an individual is institutionalized and could benefit from a less-restricted form of care.³³⁰ Courts are reluctant to intervene when individuals are sitting at home waiting for services.³³¹ Although an individual at home may be less physically isolated than an individual in an institution, both are equally segregated from community participation without home- and community-based services.

Even in states aiming to provide the necessary waiver services and employment support, efforts fall short. In Pennsylvania, where the state policy is “employment first” and waivers are provided to many individuals, people still struggle to secure equal opportunities for employment and a positive quality of life.³³² Based on *Frederick L.*, which required that a state have a working plan toward deinstitutionalization,³³³ states like Pennsylvania should be working to implement a system that effectuates full community integration. State progress toward community integration should not plateau just because that state complies with the minimum requirements of *Olmstead*.

In Pennsylvania, even some people who receive waiver services are not receiving enough resources to maintain gainful employment. Pennsylvania previously recognized that the Person/Family Directed Support Waiver may not be enough for individuals with disabilities to become employed.³³⁴ The monetary cap on the waiver places a restriction on the services available to recipients of the Person/Family Directed Support waiver.³³⁵ Especially in scenarios where a waiver recipient requires medical treatment or daily home care, supported employment services are low on the list of things that are necessary.³³⁶ These “small waivers” are a short-term solution that makes services available to more individuals, but they fail to provide all people with the full range of services needed to avoid segregation and isolation.³³⁷

Fortunately, lower courts have been willing to recognize the policy goal of integration that underlies the ADA. In *Guggenberger*, the District of Minnesota

329. See *supra* Part II.G.1.

330. See *supra* Part II.G.1.

331. See *supra* Part II.G.1.

332. See *supra* notes 165–71, 239–42 and accompanying text.

333. See *supra* notes 265–72 and accompanying text.

334. See *supra* notes 169–70 and accompanying text.

335. See *supra* notes 169–71 and accompanying text.

336. See *supra* notes 217–23 and accompanying text.

337. See *supra* notes 230–34 and accompanying text.

recognized that failure to provide individuals with the disability resources to achieve *full* community participation can still result in segregation.³³⁸ Moving forward, courts and legislatures must recognize that waiting for waiver services does result in isolation from the community and can result in violations of the ADA's integration mandate. Courts must also recognize that the ability to work is an essential aspect of community participation. As both lower courts and society recognize the necessity of including individuals with disabilities in daily community life, the Supreme Court must revisit the standards it imposed on states through its 1999 *Olmstead* decision.

C. The Medicaid Structure Presents States with an Opportunity for Change

Through statutes banning discrimination based on disability, Congress has recognized that all people have the ability to participate in gainful employment.³³⁹ Congress provides antidiscrimination protections and financing for short-term supports for individuals with disabilities who seek employment.³⁴⁰ But the current legal landscape lacks an adequate solution for individuals with more serious intellectual disabilities.³⁴¹ Such individuals have a lessened opportunity to enjoy the benefits of employment without long-term support and long-term funding.³⁴²

Our Medicaid structure does some work to address this problem through HCBS waivers, as these waivers are a major source of funding for long-term supports.³⁴³ But these waivers are limited in number and come with waiting lists.³⁴⁴ Individuals with serious intellectual disabilities should not be denied the ability to work because of a state's unwillingness to allocate resources for their benefit. It is not unreasonable to ask a government to provide all individuals with an opportunity to work, regardless of their disability. To remedy this failure, HCBS waivers should be an entitlement, rather than an option.³⁴⁵

Due to the complex structure of Medicaid, it is unlikely that Congress will soon act to make HCBS waivers an entitlement for all individuals with qualifying disabilities. However, the ability of states to design unique Medicaid programs presents an opportunity for individual states to grant an adequate amount of Medicaid waiver funding to all eligible participants. This would result in states treating HCBS waivers as if they were an entitlement like institutional care. If society is willing to bear the cost of segregated institutional care, it should be willing to bear the cost of integrated, community-based care. State legislatures

338. See *supra* notes 275–80 and accompanying text.

339. See, e.g., 42 U.S.C. § 12101 (2018).

340. See *supra* Parts II.B, II.D.

341. See *supra* notes 123–26 and accompanying text for a discussion of how vocational rehabilitation services are available for twenty-four months only for employment training, not for long-term daily supports.

342. See *supra* Part II.E.

343. Beatty, *supra* note 15, at 722–23.

344. See *supra* notes 203–09 and accompanying text.

345. See *supra* notes 207–09 and accompanying text.

should also consider alternative methods of paying for supported employment. Such an alternative method should incentivize employers to hire disabled individuals and decrease the percentage of waiver funding that must be allocated toward employment supports.

Disability rights advocates argue that home- and community-based services must receive entitlement status.³⁴⁶ Currently, individuals with disabilities who qualify for institutional-level care are entitled to those services.³⁴⁷ This entitlement means that if a parent of a young adult with disabilities decides that institutionalization is necessary for that young adult, the state must provide and pay for the institutional care.³⁴⁸ Alternatively, if that same parent decides that institutional care is not the right placement for their son or daughter, the state has no obligation to provide prompt or comprehensive home- and community-based services.³⁴⁹ This dichotomy exists despite the fact that home- and community-based services cost a state less than institutionalization.³⁵⁰

In response to the waitlists, several members of Congress have introduced the Disability Integration Act (DIA), which models a potential solution to the lack of resources for community participation.³⁵¹ This proposed legislation was introduced with the understanding that, while Congress expected for the ADA to provide long-term services and supports to those eligible for them, “that expectation has not been fulfilled.”³⁵² The DIA would ensure that disabled individuals have the right to live and receive services in their own homes.³⁵³ Expanding HCBS to entitlement status through legislation like the DIA would ensure that disabled individuals have the funding needed to become full participants in their communities, which could include the ability to work with long-term support and ensure economic stability. Although state action likely presents a quicker solution, eventual congressional legislation like the DIA is necessary, as we move further away from the trend of institutionalization toward a society that values the individual rights and autonomy of all.³⁵⁴

346. Casey, *supra* note 327 (“To make it possible for people with disabilities to live in the community with the supports they need, we need to amend the 1965 law that created Medicaid so that community-based supports are a right, enabling people with disabilities to choose to live in the community that will best enable them to succeed and to thrive.”).

347. *See supra* notes 205–08 and accompanying text.

348. *See supra* notes 205–08 and accompanying text.

349. *See supra* notes 205–08 and accompanying text.

350. *See supra* notes 216–18 and accompanying text.

351. *See The Disability Integration Act*, DISABILITYINTEGRATIONACT.ORG, <http://www.disabilityintegrationact.org/wp-content/uploads/2017/07/DIA-Fact-Sheet.pdf> [<http://perma.cc/4CWT-J3JF>] (last visited May 15, 2019).

352. Disability Integration Act, S. 910, 115th Cong. § 2 (2017); *see also* Disability Integration Act, S. 117, 116th Cong. § 2 (2019).

353. *The Disability Integration Act*, *supra* note 351.

354. *See supra* Parts II.A, II.B.

D. Alternative Methods for Providing Individuals with the ADA's Promised Dignity and Inclusion

Statutes like the ADA and the Rehabilitation Act prohibit discrimination against individuals with disabilities, but they do little to incentivize positively employers to hire a person with autism spectrum disorder or other intellectual disability.³⁵⁵ The unfortunate reality is that some employers are unlikely to go out of their way to hire intellectually disabled young adults without some benefit in return. To provide this benefit, some states provide tax incentives to employers for implementing accommodations for individuals with disabilities.³⁵⁶ The hope is that employers will be more willing to hire people with disabilities with some encouragement from the government.³⁵⁷

To encourage employers to hire individuals with disabilities and make supported employment more affordable, this Comment proposes an alternative way of paying for supported employment. For individuals who require a high level of support in employment, the job coach or one-on-one support professional shadow is usually not an additional employee at the job site.³⁵⁸ The job coach will simply assist the disabled employee in performing job tasks.³⁵⁹ In this scenario, the job coach is entirely funded through the disabled employee's HCBS funding, and the only burden on the employer is allowing the job coach to be physically present in the employment facility. Here, there is a high cost burden on the disabled individual and little if no increased benefit to the employer in having a disabled employee rather than a typical employee.

As an alternative for all individuals with disabilities who want to work, state agencies should train job coaches to provide support to the disabled employee while also working as an additional employee for the employer. Because the job coach would be providing support for the disabled employee while also doing work for the employer, the job coach would be paid by both the employer and the HCBS waiver funding. The job coach's wages would not increase in this scenario. The job coach would receive the same wage as when he or she was functioning only as a job coach. This way, the cost of supported employment will take less from HCBS waiver funding and decrease the need for large waiver funding for all individuals with serious intellectual disabilities. At the same time, the employer will have two employees performing job duties; however, the employer will pay less than the typical wages of two employees because the job coach will dedicate some of his or her time to assisting the disabled employee, resulting in slightly less productivity than two typical employees. The job coach will serve as both an employee and guide to his or her disabled coworker.

In addition to reducing the cost of supported employment, this model would provide job coaches with opportunities for their own career advancement in the employer's business. In an ideal situation, the job coach could enhance his or her

355. *See supra* Parts II.B, II.D.

356. Kuangparichat, *supra* note 14, at 188.

357. *Id.* at 187.

358. *See supra* notes 82–86 and accompanying text.

359. *See supra* notes 82–86 and accompanying text.

own skills and take the disabled employee forward to new opportunities. Currently, individuals who have minimal intellectual disabilities receive similar supports in the workplace.³⁶⁰ But the job coach is simply a coworker or supervisor who is trained to assist the disabled employee with occasional needs. The coworker is meant to serve as a problem solver for the disabled employee, as the disabled employee should largely work independently. Unfortunately, this model of supported employment does not work for individuals with more serious intellectual disabilities who need more one-on-one assistance.³⁶¹ With a model that hires a trained job coach as a coworker, individuals will receive more one-on-one support from a person who is trained to provide such support in the employment context.

IV. CONCLUSION

As society moves further into an age of deinstitutionalization, our federal and state governments must provide feasible alternatives for people who want to use home- and community-based care. Economically, it makes sense for the federal government to grant waiver funding entitlement status because waivers cost state governments less money than institutional care. If we can guarantee waiver funding, we may be able to eliminate the need for expensive institutional-level care.

It is time to recognize that individuals with disabilities deserve to be full participants in our local and national communities. Not only does community participation benefit these individuals, but it also benefits all of society, as people with disabilities bring tremendous value to our communities. To facilitate this full participation, the government must consider new, less expensive ways to fund the supports individuals with disabilities need to live and work in their own neighborhoods.

360. *See supra* notes 141–49 and accompanying text.

361. *See supra* notes 82–90 and accompanying text.