

ESSAY

SURVEILLING DISABILITY, HARMING INTEGRATION

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Scholars, policymakers, and the media acknowledge that surveillance can threaten privacy and increase the risk of discrimination. Surveillance of people with disabilities, however, is positioned as being a convenient way of averting a host of problems: It can be seen as a way to protect people with disabilities from abuse and neglect, to prevent Medicaid fraud, and to proactively protect school communities from mass shootings. Increasingly, as surveillance systems become more sophisticated, state and federal laws have begun sanctioning, and occasionally mandating, the surveillance of people with disabilities for these purposes.

This Essay interrogates narratives that justify the increased surveillance of people with disabilities by analyzing them through the lens of the Americans With Disabilities Act (ADA) and its integration mandate. The ADA expresses a clear goal of preventing the unnecessary segregation and isolation of people with disabilities. To achieve this aim, states must provide services, programs, and activities in the most integrated setting possible. Looking at laws and policies that mandate surveillance through the lens of integration draws attention to their oppressive and isolating effects.

This Essay breaks new ground by centering disability discrimination in its analysis of surveillance. It is the first to demonstrate how ostensibly benevolent surveillance systems embed punitive, carceral practices within therapeutic and community-based settings. It yields new insights about how surveillance systems deployed within a community can result in a constrained and superficial, rather than expansive, idea of integration.

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INTRODUCTION

In February 2022, New York City Mayor Eric Adams unveiled a new plan to get unhoused people off the streets, out of the subway system, and into hospital beds.¹ The plan is multipronged and involves “grow[ing] the number of acute psychiatric beds” at hospitals,² criminalizing conduct like sleeping in subway cars,³ and increasing police presence in subway stations.⁴ This plan expands surveillance of unhoused people with disabilities in New York City by increasing police oversight in public spaces⁵ and permitting information sharing between city agencies to facilitate hospitalization and treatment of people who are deemed unable to meet their “basic needs.”⁶ It could result in the involuntary institutionalization

1. City of N.Y., The Subway Safety Plan 4 (2022), <https://www.nyc.gov/assets/home/downloads/pdf/press-releases/2022/the-subway-safety-plan.pdf> [<https://perma.cc/9F7T-4V4S>] [hereinafter City of N.Y., Subway Safety Plan] (“We must immediately help New Yorkers struggling to take the first step towards a better future—a journey that the City will coordinate every step of the way, from their first moment out of the station to ongoing care and a permanent home.”); see also Eric Adams & Jessica Katz, Housing Our Neighbors: A Blueprint for Housing and Homelessness 47 (2022), <https://www.nyc.gov/assets/home/downloads/pdf/office-of-the-mayor/2022/Housing-Blueprint.pdf> [<https://perma.cc/Q64P-EUEN>] (“In February 2022, with the release of the Subway Safety Plan, the Adams administration announced cross-agency outreach initiatives to better connect with unsheltered residents and help them access shelter options that work for them.”).

2. City of N.Y., Subway Safety Plan, *supra* note 1, at 13.

3. See *id.* at 6–7 (noting that there will be increased police presence at subway stations to enforce Metropolitan Transit Authority (MTA) and New York City Transit Authority (NYCTA) rules that prohibit “[l]ying down, sleeping, or outstretching in a way that takes up more than one seat per passenger or interferes with fellow passengers”).

4. See *id.* at 7 (“More than 1,000 additional officers have already been deployed across the system.”); see also Adams & Katz, *supra* note 1, at 47 (noting that “the Adams administration announced cross-agency outreach initiatives to better connect with unsheltered residents”).

5. See City of N.Y., Subway Safety Plan, *supra* note 1, at 7.

6. See Mental Health Involuntary Removals, City of N.Y. (Nov. 28, 2022), <https://www.nyc.gov/assets/home/downloads/pdf/press-releases/2022/Mental-Health-Involuntary-Removals.pdf> [<https://perma.cc/4PVW-QZ32>] [hereinafter City of N.Y., Involuntary Removals] (“If the circumstances support an objectively reasonable basis to conclude that the person appears to have a mental illness and cannot support their basic

of many people who do not pose a danger to the community.⁷ In proffering this plan, Adams's rhetoric is a curious mix of punitive and therapeutic. The program will, he argues, discharge a duty of care toward vulnerable people with disabilities.⁸ But targeted New Yorkers will not have a choice about whether to accept the government's intervention. Rather, Adams ominously informed unhoused New Yorkers: "No more just doing whatever you want. No, those days are over."⁹

Mayor Adams is not alone in his impulse to watch and control. Actors at all levels of government are increasingly pursuing policies that use surveillance mechanisms to manage people with disabilities. Over the past decade, state and federal laws have started to permit, and occasionally mandate, the increased surveillance of people with disabilities. These surveillance practices are a continuation of a historical trend of the oversurveillance of people with disabilities. Branded as criminals¹⁰ and scrutinized with suspicion because of their dependence on public aid,¹¹

human needs to an extent that causes them harm, they may be removed for an evaluation."); see also City of N.Y., Subway Safety Plan, *supra* note 1, at 8 (outlining New York City's multiagency effort to "expand[] services to reach those experiencing homelessness or severe mental illness").

7. See City of N.Y., Involuntary Removals, *supra* note 6 ("[New York law] authorize[s] the removal of a person who appears to be mentally ill and displays an inability to meet basic living needs, even when no recent dangerous act has been observed.").

8. See Press Release, Off. of the Mayor, Mayor Adams Releases Subway Safety Plan, Says Safe Subway Is Prerequisite for New York City's Recovery (Feb. 18, 2022), <https://www.nyc.gov/office-of-the-mayor/news/087-22/mayor-adams-releases-subway-safety-plan-says-safe-subway-prerequisite-new-york-city-s#/0> [<https://perma.cc/PDR6-QV9P>] ("It is cruel and inhumane to allow unhoused people to live on the subway The days of turning a blind eye to this growing problem are over" (internal quotation marks omitted) (quoting Eric Adams, Mayor, N.Y.C.)).

9. Gwynne Hogan, Adams, Hochul Roll Out Subway Safety Plan to Crack Down on Homeless People on Trains and in Stations, *Gothamist* (Feb. 18, 2022), <https://gothamist.com/news/adams-hochul-roll-out-subway-safety-plan-crack-down-homeless-trains-and-stations> (on file with the *Columbia Law Review*) (internal quotation marks omitted) (quoting Eric Adams, Mayor, N.Y.C.).

10. See, e.g., Kim E. Nielsen, *A Disability History of the United States* 102 (2012) (noting that institutions like the Indiana Reformatory were developed to manage the population of the "degenerate class," which included "most of the insane, the epileptic, the imbecile, [and] the idiotic," among others (internal quotation marks omitted) (quoting Jennifer Terry, *An American Obsession: Science, Medicine, and Homosexuality in Modern Society* 82 (1999))); Susan M. Schweik, *The Ugly Laws: Disability in Public* 10 (2009) (describing the broad network of public ordinances that were passed in various major U.S. cities criminalizing disability in public spaces, which were rooted in early poorhouse laws used to confine convicted people in police stations or county poorhouses); James W. Trent, Jr., *Inventing the Feeble Mind: A History of Intellectual Disability in the United States* 13 (2017) (observing that intellectual disability was historically linked to a multitude of sins requiring oversight and management, including "intemperance, poverty, consanguinity (meaning marriage between cousins), insanity, scrofula, consumption, licentious habits, failed attempts at abortion, and overwork in the quest for wealth and power").

11. One of the earliest institutions was the workhouse or poorhouse, created to confine various diverse but poor populations, including the "disabled, widowed, orphaned,

those labeled as disabled were subject to surveillance, removed from public spaces,¹² and funneled into penitentiaries, prisons, residential schools, and workhouses to be managed, worked, and treated.¹³ Once within these institutionalized spaces, surveillance was critical to the mission of correcting or rehabilitating “abnormal” behavior.¹⁴ Those who were excluded from the workhouse, including enslaved and colonized people, were wrapped up in other punitive systems of “unrestrained violence” that also used totalizing surveillance to control and manage.¹⁵ Policies that promoted the isolation and segregation of people with disabilities remained in place until well into the twentieth century.¹⁶

In the mid-twentieth century, social policy shifted from isolating people with disabilities in large institutions to closing those institutions

and sick.” See Chris Chapman, Allison C. Carey & Liat Ben-Moshe, *Reconsidering Confinement: Interlocking Locations and Logics of Incarceration*, in *Disability Incarcerated: Imprisonment and Disability in the United States and Canada* 3, 3–4 (Liat Ben-Moshe, Chris Chapman & Allison C. Carey eds., 2014).

12. Schweik, *supra* note 10, at 26 (“With an almshouse in place, street cleaning could proceed, justified—when proper—as caretaking.”). Professor Liat Ben-Moshe provides a more modern example of surveillance of people with disabilities in public spaces, namely the deliberate counting and categorizing of the “homeless mentally ill.” Liat Ben-Moshe, *Decarcerating Disability: Deinstitutionalization and Prison Abolition* 140–43 (2020) [hereinafter Ben-Moshe, *Decarcerating Disability*]. This is a “constructed category of analysis” that is part of a process of justifying the incarceration of this population in hospitals and prisons. *Id.* at 140.

13. See Chapman et al., *supra* note 11, at 4–5 (noting that the purpose of confining people with disabilities changed in the nineteenth century from undifferentiated placement in the poorhouse to more intentional placement in places like asylums, hospitals, and residential schools, where people with disabilities could be treated and cured); David J. Rothman, *The Discovery of the Asylum* 79 (Aldine de Gruyter 2002) (1971) (writing that reformation was the goal of the penitentiary, which was built to house people deemed “deviant” and had the lofty aims of reforming criminality and thereby stabilizing American society).

14. Asylums and schools for people with intellectual and developmental disabilities were sites of constant monitoring. See, e.g., Dolly MacKinnon, *Hearing Madness and Sounding Cures: Recovering Historical Soundscapes of the Asylum*, *Politiques de Communication* (Special Issue), no. 1, 2017, at 77, 78 (Fr.) (“[W]omen and men were physically segregated, and their medical appraisal and diagnosis involved an account of their visual and auditory symptoms of madness. The soundscape within the asylum was monitored at all times, as the watchful eyes and ears of both attendants and doctors made notes of any changes.”).

15. Chapman et al., *supra* note 11, at 4. For a more detailed analysis of the surveillance practices employed against enslaved people, see Simone Browne, *Dark Matters: On the Surveillance of Blackness* 21 (2015) (noting that at the time of slavery, “citizenry (the watchers) was deputized through white supremacy to apprehend any fugitive who escaped from bondage (the watched), making for a cumulative white gaze that functioned as a totalizing surveillance”).

16. Laura I. Appleman, *Deviancy, Dependency, and Disability: The Forgotten History of Eugenics and Mass Incarceration*, 68 *Duke L.J.* 417, 440 (2018) (noting that laws in the early twentieth century still called for the incarceration of “feebleminded” adults “in hopes of preventing crime, insanity and prostitution”).

and integrating people with disabilities into the community.¹⁷ Integration was first codified in section 504 of the Rehabilitation Act of 1973 (Section 504)¹⁸ and then in the Americans With Disabilities Act of 1990 (ADA).¹⁹ These statutes mandated that states and entities receiving federal funding provide people with disabilities services within the “most integrated setting” appropriate for the individual’s needs.²⁰ The move toward community integration was given an additional boost when the Supreme Court decided *Olmstead v. L.C. ex rel. Zimring*, a landmark case interpreting the ADA’s integration mandate.²¹ The Court held unequivocally that people with disabilities have a right to live within their communities and receive services in the most integrated setting possible.²² Integration entailed a seismic shift in thinking about the position, both geographical and social, occupied by people with disabilities in society.²³ If surveillance was an important characteristic of the institutions that warehoused people with disabilities to control and cure them,²⁴ integration called for protecting the privacy, autonomy, and freedom of people with disabilities so that they could live a “normal” life within the community.²⁵

17. See, e.g., Ben-Moshe, *Decarcerating Disability*, supra note 12, at 44 (noting that mental health and intellectual and developmental disability (I/DD) policy changes that culminated in deinstitutionalization began with broader social welfare reforms in the 1960s, including the establishment of Medicare and Medicaid); cf. *State ex rel. Goddard v. Coerver*, 412 P.2d 259, 261–62 (Ariz. 1966) (discussing the state legislature’s approval of new funds for an “Insane Asylum” in 1885).

18. Rehabilitation Act of 1973, Pub. L. No. 93-112, § 504, 87 Stat. 355, 394 (codified as amended at 29 U.S.C. § 794(a) (2018)).

19. Americans With Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327 (codified as amended at 42 U.S.C. §§ 12101–12213 (2018)).

20. See 42 U.S.C. § 12182(b)(1)(B).

21. 527 U.S. 581 (1999).

22. See *id.* at 597 (“Unjustified isolation, we hold, is properly regarded as discrimination based on disability.”).

23. Ben-Moshe, *Decarcerating Disability*, supra note 12, at 39 (referring to deinstitutionalization as “a *social* movement, an ideology opposing carceral logics, a mindset”).

24. See, e.g., Erving Goffman, *On the Characteristics of Total Institutions, in Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* 1, 7 (Routledge 2017) (1961). Dr. Erving Goffman, a psychiatrist and prominent thinker, wrote about the characteristics common to a wide range of “total institutions” like psychiatric hospitals and prisons. See *id.* at 4–7. Chief among these characteristics was a lack of privacy, as “each phase of the member’s daily activity [was] carried on in the immediate company of a large batch of others, all of whom [were] treated alike and required to do the same thing together.” *Id.* at 6. Goffman noted that surveillance was a critical part of policing these spaces. Inmates were subjected to “a seeing to it that everyone does what he has been clearly told is required of him, under conditions where one person’s infraction is likely to stand out in relief against the visible, constantly examined compliance of the others.” *Id.* at 7.

25. See Wolf Wolfensberger, *The Principle of Normalization in Human Services* 28 (1972). See generally *id.* at 27. Psychiatrist Dr. Wolf Wolfensberger promoted the principle of normalization—a Scandinavian concept that referred to making available to people with intellectual and developmental disabilities “patterns and conditions of everyday life which

This Essay's contribution is twofold. It first tracks the historical development of surveillance mechanisms over time, highlighting the carceral logic underpinning those practices. It then uncovers the tension between the integration mandate and modern surveillance policies that have the potential to isolate and segregate. Specifically, this Essay analyzes three modern examples of surveillance. First, it considers state laws that permit the installation of sophisticated surveillance technology in group homes for people with disabilities.²⁶ Second, it considers surveillance mechanisms adopted by states under federal laws such as the 21st Century Cures Act, a federal law requiring all states to implement Electronic Visit Verification (EVV) systems to screen for Medicaid fraud.²⁷ Finally, it considers state laws and regulations that mandate surveillance of students with disabilities through threat-assessment processes as part of a proactive school-shooting-prevention strategy.²⁸

A careful look at these modern surveillance policies and the reasons underpinning them demonstrates how the use of surveillance continues to promote and reproduce the same carceral logic that once drove the historical warehousing of people with disabilities. Surveillance can be deployed in service of *carceral ableism*—"the praxis and belief that people with disabilities need special or extra protections, in ways that often expand and legitimate their further marginalization and incarceration."²⁹ Legislation that permits, and in some circumstances requires, the

are as close as possible to the norms and patterns of the mainstream of society." *Id.* at 27 (internal quotation marks omitted) (quoting Bengt Nirje, *The Normalization Principle and Its Human Management Implications*, in *Changing Patterns in Residential Services for the Mentally Retarded* 179, 181 (Robert B. Kugel & Wolf Wolfensberger eds., 1969)). A critical part of normalization was protecting the ability of people with disabilities to take risks: "We do 'say something' to the person who lives in the building that we build for them. We can say: 'We will protect you and comfort you—and watch you like a hawk!' Or we can say: 'You are a human being and so you have a right to live as other humans live, even to the point where we will not take all dangers of human life from you.'" *Id.* at 199.

26. See, e.g., *Ariz. Rev. Stat. Ann.* § 36-568 (2022).

27. See 21st Century Cures Act, Pub. L. No. 114-255, sec. 12006, 130 Stat. 1033, 1275 (2016) (codified as amended at 42 U.S.C. § 1396b(1) (2018)) (noting that Electronic Visit Verification (EVV) systems gather detailed information about Medicaid-funded personal care services).

28. See, e.g., Marjory Stoneman Douglas High School Public Safety Act, ch. 2018-3, § 2, 2018 Fla. Laws 6, 10. This Act requires each district, school board, and charter school governing board to establish a threat-management team responsible for assessing and intervening when someone's behavior "poses a threat of violence or physical harm." Fla. Stat. Ann. § 1006.07(7)(b), (e) (West 2023). Once threatening behavior is identified, threat-assessment teams have broad powers to share this information with law enforcement and other government agencies. *Id.* § 1006.07(7)(e), (g)–(h) (requiring the sharing of records or information with "other agencies involved with the student and any known service providers to share information and coordinate any necessary followup actions").

29. Ben-Moshe, *Decarcerating Disability*, *supra* note 12, at 17; see also Wolfensberger, *supra* note 25, at 18 (noting corollaries of this belief, including the "need for extraordinary control, restriction, or supervision" and "denial of citizenship rights and privileges").

installation of cameras in the homes of people with disabilities is an example of an ostensibly protective measure that undermines and dehumanizes people with disabilities. Surveillance can also be deployed as a means of identifying and punishing the *disability con*—“the cultural anxiety that individuals fake disabilities to take advantage of rights, accommodations, or benefits.”³⁰ EVV systems are the outgrowth of a carceral logic that is suspicious of recipients of public benefits; the systems monitor and punish people with disabilities and their home health aides out of suspicion that they are committing fraud. Finally, surveillance may be driven by *carceral humanism*—a term coined by activist and scholar James Kilgore to describe a discourse that repackages punishment as part of service provision and entrenches the role of law enforcement, sheriffs, and corrections officers as caring service providers.³¹ Threat-assessment processes are an example of a surveillance structure that feeds a culture of punishment involving “heavy monitoring of a person’s behavior”³² coupled with a threat of exclusion and incarceration for exhibiting behavior deemed risky or problematic.³³

The integration mandate provides a framework to expose and challenge the carceral logic at play within these systems. *Olmstead* jurisprudence increasingly reflects the recognition that the integration mandate is not merely about the location of services but about the right to self-determination, choice, and the ability to freely interact with other members of the community.³⁴ But surveillance can isolate and segregate,

30. For a discussion of the “disability con,” see Doron Dorfman, *Fear of the Disability Con: Perceptions of Fraud and Special Rights Discourse*, 53 *Law & Soc’y Rev.* 1051, 1053–56 (2019).

31. See James Kilgore, *Repackaging Mass Incarceration*, Counterpunch (June 6, 2014), <https://www.counterpunch.org/2014/06/06/repackaging-mass-incarceration/> [<https://perma.cc/JC2M-XH95>].

32. *Id.*; see also Broward Cnty., Fla., Sch. Bd. Policy 2130, Threat Assessment Policy 3 (2019), <http://www.broward.k12.fl.us/sbbcpolicies/docs/Threat%20Assessment%20Policy.pdf> [<https://perma.cc/9S6W-VY84>] (requiring threat-assessment teams to plan, implement, and monitor appropriate interventions aimed at “manag[ing] or mitigat[ing] a student’s risk for engaging in violence” that would remain in place until they find that “the student is no longer in need of support” nor “pose[s] a threat to self or others”).

33. See, e.g., Ike Swetlitz, *Who’s the Threat?*, Searchlight N.M. (Oct. 15, 2019), <https://searchlightnm.org/whos-the-threat/> [<https://perma.cc/KG2L-DK9T>] (outlining the experience of Jamari Nelson, a seven-year-old student with a disability in New Mexico who was expelled from school after being labeled a “high-level threat”).

34. Federal courts have repeatedly found that plaintiffs receiving community-based services may still be at risk of segregation or isolation when services are administered in a manner that restricts access to the community. See, e.g., *Steimel v. Wernert*, 823 F.3d 902, 910 (7th Cir. 2016) (noting that plaintiffs argued that the state policies “impermissibly rendered the plaintiffs institutionalized in their own homes, and . . . put them at serious risk of institutionalization”); *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1184 (10th Cir. 2003) (finding that the integration mandate applied when the state restricted plaintiffs’ choice of services, undermining their ability to remain in the community); *Lane v. Kitzhaber*, 841 F. Supp. 2d 1199, 1205 (D. Or. 2012) (finding that segregation in an

undermining this goal of integration.³⁵ Overprotective surveillance policies in group homes adversely impact people's ability to enjoy privacy and autonomy in their homes.³⁶ Surveillance used to police and prevent Medicaid fraud prevents recipients from freely accessing the community for fear of triggering a fraud alert and losing essential services.³⁷ Finally, surveillance policies that target people with disabilities based on ableist notions of dangerousness can result in their exclusion from school settings and their incarceration in prisons or hospitals.³⁸

To avoid these outcomes, one must ask critical questions about whether surveillance systems will actually solve the problems that drive their use, how surveillance may be experienced by people subject to it, and whether the motivations behind these policies are rooted in prejudice. Failing to ask these questions before deploying these systems in community-based settings can result in superficial, rather than meaningful, integration within the community.³⁹ Conversely, asking these questions will allow policymakers to think more critically about surveillance systems

employment setting violated the integration mandate because plaintiffs could not interact with people without disabilities while in that setting).

35. Torin Monahan, *Regulating Belonging: Surveillance, Inequality, and the Cultural Production of Abjection*, 10 *J. Cultural Econ.* 191, 192 (2017) (noting that surveillance works as a tool of regulation but also marks those subject to it as “dangerous or socially illegible”).

36. See, e.g., Natalie Chin, *Group Homes as Sex Police and the Role of the Olmstead Integration Mandate*, 42 *N.Y.U. Rev. L. & Soc. Change* 379, 382 (2018) (making the argument that the failure by group homes to support the choices of residents with I/DD to exercise sexual rights could constitute a violation of the integration mandate); Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans With Disabilities Act*, 81 *U. Colo. L. Rev.* 157, 161 (2010) (arguing that guardianship could segregate and isolate people with disabilities in a manner that violates the integration mandate).

37. See Alexandra Mateescu, *Data & Soc’y, Electronic Visit Verification: The Weight of Surveillance and the Fracturing of Care* 8 (2021), https://datasociety.net/wp-content/uploads/2021/11/EVV_REPORT_11162021.pdf [<https://perma.cc/FW8A-XABX>] (noting that due to a lack of federal policy guidance, “[s]tate-level policies and technology design encoded far more invasive features into EVV systems than were required”).

38. See, e.g., *United States v. Georgia*, 461 F. Supp. 3d 1315, 1323–25 (N.D. Ga. 2020) (finding that plaintiffs had stated an *Olmstead* claim when students with disabilities were removed from general education and placed in a separate program for students with “behavioral” issues).

39. See Liat Ben-Moshe, *The Contested Meaning of “Community” in Discourses of Deinstitutionalization and Community Living in the Field of Developmental Disability*, in *Disability and Community* 241, 260 (Allison C. Carey & Richard K. Scotch eds., 2011) [hereinafter Ben-Moshe, *Contested Meaning*] (noting that “mere[ly] clos[ing] . . . large state institutions . . . d[id] not necessarily entail a radical change in the discursive formations of developmental disability and the lived experiences of those so labeled,” resulting in mini-institutions that are now located in the community); *id.* at 251 (observing that “physical integration [of services] is only the first step to integration” and that to achieve full inclusion, people with disabilities require “associations and friendships” that “encourage community membership” among disabled people).

and how they fray community bonds, feed negative stereotypes, and segregate and isolate people with disabilities.

To that end, this Essay proceeds in five parts. Part I outlines how surveillance is intertwined with the history of incarceration of people with disabilities. Part II outlines the ADA's clear remedial mission and the integration mandate's potential to disrupt carceral systems. Part III unpacks the arguments frequently made to justify surveillance of people with disabilities and uncovers the ableism underpinning those surveillance systems. Section III.A demonstrates how group home surveillance creates settings within the community that look like the institutions of the past, within which residents were deprived of privacy, self-determination, and autonomy. Similarly, section III.B uncovers how surveillance that looks like an innocuous bureaucratic tool for recording how services are provided in the community legitimizes old and unwarranted fears about the disability con while degrading the quality of those services and risking the reinstitutionalization of people currently receiving them. Section III.C describes how surveillance of students with disabilities to prevent dangerous behavior in schools makes it easier to remove them from integrated settings and place them in psychiatric hospitals or in jail. Part IV applies the integration mandate to these systems to demonstrate how the mandate can be used to disrupt and dismantle these surveillance systems, functioning as a tool of resistance. This Essay concludes with questions that must be asked before society turns to surveillance as a response to disability.

I. SURVEILLANCE AND DISABILITY

This Part argues that surveillance has played a critical role in the history of the management of people with disabilities. It begins by exploring the discriminatory potential of surveillance as a mechanism that is used to "sort[]" people into categories of risk and worthiness.⁴⁰ It then considers how surveillance was historically used to separate people with disabilities; remove them from public spaces; and funnel them into prisons, asylums, and residential schools. It tracks how the rationale for this surveillance has changed over the centuries: from managing the poor and ensuring that they were deserving of public aid, to policing the criminality associated with disability, to treating and rehabilitating disability. It concludes that the surveillance of people with disabilities has not relented even as public policies have shifted away from institutionalization and toward integration.

40. David Lyon, Introduction to Surveillance as Social Sorting: Privacy, Risk, and Digital Discrimination 1, 1 (David Lyon ed., 2003) ("[S]urveillance today sorts people into categories assigning worth or risk, in ways that have real effects on their life-chances. Deep discrimination occurs, thus making surveillance not merely a matter of personal privacy but of social justice.").

Rather, prejudicial ideas about disability continue to drive modern surveillance policies and practices.

A. *The Discriminatory Potential of Surveillance*

“Biopower,” a term of Foucauldian provenance, refers to how authorities “rationalise the problems that the phenomena characteristic of a group of living human beings, when constituted as a population, pose to governmental practice,” such as health, sanitation, and longevity.⁴¹ Surveillance scholar Ayse Ceyhan points out that to regulate behavior, governments need to know their populations’ present and likely future behavior.⁴² Accordingly, government agencies have developed “a whole series of systems of knowledge focusing on the identification, the tracking and the surveillance of individuals considered as dangerous for the population’s health . . . and well-being.”⁴³ Government systems orient populations around a constructed idea of “normalcy”⁴⁴ whereby differences between populations are “materialised and made perceptible as pathology, while the subjects who come to bear them are rendered as defective, are disabled, and [are] signified as less than fully human.”⁴⁵ The categorization of people as “mad or sane, sick or healthy, criminal or good” exemplifies the exercise of biopower.⁴⁶

Biopower is concerned with protecting the population from bodies that are deemed risky or dangerous.⁴⁷ This perception of risk, however, is tied to discriminatory ideas about race, class, gender, sexuality, and

41. See Shelley Tremain, *The Biopolitics of Bioethics and Disability*, 5 *Bioethical Inquiry* 101, 101 (2008) [hereinafter Tremain, *Biopolitics*] (citing 1 Michel Foucault, *The History of Sexuality* 143 (Robert Hurley trans., 1978)).

42. Ayse Ceyhan, *Surveillance as Biopower*, in *Routledge Handbook of Surveillance Studies* 38, 41 (Kirstie Ball, Kevin D. Haggerty & David Lyon eds., 2012).

43. *Id.*

44. See Lennard J. Davis, *Enforcing Normalcy* 24–29 (1995) (discussing the construction of the concept of “normalcy,” tracing its roots as a statistical science, and tracking the reification of the norm as an ideal); Tremain, *Biopolitics*, supra note 41, at 102 (“[B]iopower has facilitated the emergence of regulatory mechanisms whose function is to provide forecasts, statistical estimates, and overall measures[,] . . . [which] have brought into being guidelines and recommendations that prescribe norms, adjust differentials to an equilibrium, maintain an average, and compensate for variations within the ‘general population’ . . .”); see also Torin Monahan & Rodolfo D. Torres, *Introduction to Schools Under Surveillance: Cultures of Control in Public Education* 1, 7 (Torin Monahan & Rodolfo D. Torres eds., 2010) (noting that biopower operates by “regulariz[ing]” the population).

45. Tremain, *Biopolitics*, supra note 41, at 102.

46. Shelley Tremain, *On the Government of Disability*, 27 *Soc. Theory & Prac.* 617, 619 (2001).

47. Ceyhan, supra note 42, at 41–42 (arguing that biopower is driven by ideas of risk and security, resulting in a reliance on “risk-based surveillance approaches and solutions”).

ability.⁴⁸ Surveillance scholarship has explored how surveillance acts as a sorting mechanism, defining who is in and who is out.⁴⁹ The implications of being sorted in this manner are severe and adverse for marginalized communities: Information gathered through surveillance can be used to exclude people from accessing rights, experiences, and processes.⁵⁰

A rich body of scholarship has considered how communities of color are subjected to heightened surveillance that leads to marginalization and incarceration. Surveillance and Black Studies scholar Simone Browne has written evocatively and extensively about how surveillance techniques are used to create and maintain boundaries along racial lines, a process that she refers to as “racializing surveillance.”⁵¹ Historically, slave passes, runaway notices, and laws requiring that enslaved people carry lit candles as they moved about New York City after dark are all examples of othering practices that structured social relations in a way that privileged whiteness.⁵² The legacy of this racialized surveillance persists. Professor Anita Allen has coined the term “Black Opticon” to describe the discriminatory oversurveillance of African Americans in online spaces, including tracking by police using facial recognition software.⁵³

Scholars have also written extensively about how poor people are oversurveilled. Poor pregnant women seeking Medicaid-funded prenatal services are subjected to the rigorous and unrelenting eye of the state.⁵⁴

48. See, e.g., Monahan, *supra* note 35, at 192–93 (noting that surveillance contributes to “gendered, racialized, and classed violence” and that “cultural narratives (e.g. [,] about dangerousness or unworthiness) are often key drivers for the adoption of surveillance systems that in turn reify those discriminatory categories and subject positions”).

49. *Id.* at 192.

50. See David Lyon, Kevin D. Haggerty & Kirstie Ball, *Introducing Surveillance Studies*, in *Routledge Handbook of Surveillance Studies*, *supra* note 42, at 1, 3 (“[S]urveillance of more powerful groups is often used to further their privileged access to resources, while for more marginalized groups surveillance can reinforce and exacerbate existing inequalities.”).

51. See Browne, *supra* note 15, at 50–55. These techniques included keeping records and creating rules about the management of enslaved people on plantations. *Id.* at 51–52. They also included the outsourcing of surveillance to the white public. Through newspaper advertisements and “wanted” posters, white citizens were conscripted into watching and regulating Black bodies. See *id.* at 53–55. Another technique was the use of slave passes to manage the mobility of enslaved people. *Id.* at 52–53. In other cases, surveillance was branded onto enslaved peoples’ skin—a form of biometric identification used to track their movements. See *id.* at 42.

52. See *id.* at 50–55, 78–80.

53. Anita L. Allen, *Dismantling the “Black Opticon”: Privacy, Race Equity, and Online Data-Protection Reform*, 131 *Yale L.J. Forum* 907, 910 (2022), https://www.yalelawjournal.org/pdf/F7.AllenFinalDraftWEB_6f26iyu6.pdf [<https://perma.cc/3FVL-RUH9>].

54. See Khiara M. Bridges, *The Poverty of Privacy Rights* 5 (2017) (explaining that the intrusive questioning poor pregnant women experience when seeking to access Medicaid programs in New York and California demonstrates that “[t]o be poor is to be subject to invasions of privacy that we might understand as demonstrations of the danger of government power without limit”).

Professor Khiara M. Bridges argues that to access these services, poor women are forced to answer intrusive questions about their relationships, finances, and health, suffering violations of their privacy that wealthy women do not.⁵⁵ Similarly, scholar Scott Skinner-Thompson describes how people living on the streets are subject to constant surveillance because of their unhoused status, both by police—who may forcibly remove them from public land—and “by social gaze and feelings of shame and disenfranchisement.”⁵⁶ John Gilliom’s scholarship on welfare surveillance demonstrates that surveillance is a key part of identifying, controlling, and managing poor people seeking state support.⁵⁷

Surveillance practices are also influenced by ableist ideas about disability.⁵⁸ “Ableism” refers to beliefs that reinforce the subordination of people with disabilities.⁵⁹ As Professor Michelle Nario-Redmond explains, “[t]he term ableism emerged out of the disability rights movements within the United States and Britain to serve as an analytic parallel to sexism and racism for those studying disability as social creation.”⁶⁰ “Ableism” refers to the complex web of political, cultural, economic, and social practices that subordinate people with disabilities.⁶¹ It manifests in “labeling—or pathologizing—bodies and minds as deviant, abnormal, incapable, incompetent, dependent, or impaired” and therefore undesirable and unproductive.⁶² It may also seem benevolently “inspired by charitable intentions that nevertheless allow for the justification of control, restricted rights, and dehumanizing actions.”⁶³

People with disabilities may be *disparately impacted* by surveillance practices in various contexts, from education to employment to the

55. See *id.* at 8.

56. Scott Skinner-Thompson, *Privacy at the Margins* 17, 19 (2020).

57. See John Gilliom, *Overseers of the Poor: Surveillance, Resistance, and the Limits of Privacy* 2–3 (2001) (“The politics of surveillance necessarily include the dynamics of power and domination.”).

58. Natasha Saltes, ‘Abnormal’ Bodies on the Borders of Inclusion: Biopolitics and the Paradox of Disability Surveillance, 11 *Surveillance & Soc’y* 55, 56 (2013) (“When disability surveillance is carried out in ways that pathologize and exclude people with impairments . . . to limit access to resources and/or citizenship, disability tends to be defined in terms of a functional limitation and people with impairments are seen as those with non-normative bodies that pose a ‘risk.’”).

59. See, e.g., Talila A. Lewis, *Working Definition of Ableism—January 2022 Update*, Talila A. Lewis: Blog (Jan. 1, 2022), <https://www.talilalewis.com/blog/working-definition-of-ableism-january-2022-update> [<https://perma.cc/6J6K-82LB>].

60. Michelle R. Nario-Redmond, *Ableism: The Causes and Consequences of Disability Prejudice* 5 (2020).

61. Jamelia N. Morgan, *Reflections on Representing Incarcerated People With Disabilities: Ableism in Prison Reform Litigation*, 96 *Denv. L. Rev.* 973, 980 (2019).

62. See *id.* at 981.

63. Nario-Redmond, *supra* note 60, at 10.

criminal legal system.⁶⁴ For example, employers are increasingly relying on monitoring software to track employee productivity through surveillance technology that can punish workers with disabilities, who “often require opportunities for rest, flexibility, and supportive work environments to attend to disability-related needs.”⁶⁵ This Essay’s focus is on surveillance systems that directly target people with disabilities—particularly intellectual and developmental disabilities (I/DD) and psychiatric disabilities—and mark them as *requiring* surveillance. As expounded more fully in the following section, people with disabilities have historically experienced the state’s heavy-handed and intrusive management in their lives and affairs. Surveillance mechanisms were critical to this mission of ensuring that the dangers posed by disability were, quite literally, isolated and contained.

B. *The Long History of Disability Surveillance*

1. *The Carceral Purposes of Early Surveillance Mechanisms.* — In colonial times, the need to manage disabled bodies was interwoven with the need to control and incarcerate populations that required governmental assistance, including the poor, widows, orphans, and the elderly.⁶⁶ Relief that was once “outdoor[s]” and provided to poor families in their homes was brought indoors into the poorhouses, where those accepting aid could be properly scrutinized, supervised, and ultimately deterred from seeking

64. For example, virtual proctoring systems have become increasingly popular in the wake of the COVID-19 pandemic as high schools and universities across the United States have employed these systems to replace in-person proctored exams. See Lydia X.Z. Brown, Ridhi Shetty, Matthew U. Scherer & Andrew Crawford, Ctr. for Democracy & Tech., *Ableism and Disability Discrimination in New Surveillance Technologies* 7–8 (2022), <https://cdt.org/wp-content/uploads/2022/05/2022-05-23-CDT-Ableism-and-Disability-Discrimination-in-New-Surveillance-Technologies-report-final-redu.pdf> [<https://perma.cc/664Z-WCU3>]. Students with disabilities are more likely to be “flagged as potentially suspicious” by this technology for engaging in disability-related behavior during an exam, like taking longer bathroom breaks or using dictation software. *Id.* at 8, 14 (noting that virtual proctoring systems adversely impact “students with disabilities, who already face disproportionately high rates of school discipline and surveillance”); see also Lydia X.Z. Brown, *How Automated Test Proctoring Software Discriminates Against Disabled Students*, Ctr. for Democracy & Tech. (Nov. 16, 2020), <https://cdt.org/insights/how-automated-test-proctoring-software-discriminates-against-disabled-students/> [<https://perma.cc/CY5J-CUJ2>]; Drew Harwell, *Mass School Closures in the Wake of the Coronavirus Are Driving a New Wave of Student Surveillance*, *Wash. Post* (Apr. 1, 2020), <https://www.washingtonpost.com/technology/2020/04/01/online-proctoring-college-exams-coronavirus/> (on file with the *Columbia Law Review*).

65. Brown et al., *supra* note 64, at 53.

66. See Rothman, *supra* note 13, at 4; see also Chapman et al., *supra* note 11, at 3–4 (noting that “[c]riminalization and class oppression” were “central to the earliest forms of confining disabled (and nondisabled) people” in almshouses and poorhouses, which housed the “poor, disabled, widowed, orphaned, and sick”).

public assistance.⁶⁷ From 1824 on in New York, it was mandatory for each county to have a poorhouse—a move that wove the institution into the management of the needs of people with disabilities.⁶⁸ In agricultural states like Texas, poor farms housed and worked indigent people.⁶⁹

These poorhouses were heavily regulated spaces with harsher living conditions than those occupied by the poorest of laborers.⁷⁰ A Massachusetts Legislative Committee report authored by Josiah Quincy recommended that these houses be “well regulated under the superintendent of the principal inhabitants of the vicinity; and be conducted systematically, with strictness and intelligence.”⁷¹ Indeed, “paupers” who resided in workhouses had to give up control of their personal lives and their rights as citizens.⁷² Gilliom notes that the surveillance carried out in workhouses and poorhouses was a precursor to modern welfare surveillance.⁷³ Much like modern surveillance systems that gather information to assess whether poor people are really eligible for the aid they are receiving, workhouse surveillance was intended to sort and categorize people as being part of either the “impotent poor” or the “able poor.”⁷⁴

Surveillance tools were also used to demean the poor and discourage them from seeking state assistance. Engaging in “exhaustive investigations of poor families” was one such tactic.⁷⁵ The suspicion of the poor resulted in the development of another surveillance mechanism—that of the “friendly visitor.”⁷⁶ The Charity Organization Society (COS), a New York-based charity organizer that played an important role in shaping state responses to poverty, had a mission to “coordinate, investigate, and

67. See, e.g., Rothman, *supra* note 13, at 166 (“[C]ommittees [in Massachusetts and New York] insisted that outdoor relief aggravated rather than relieved poverty by encouraging the poor to rely upon a public dole instead of their own energy.”); see also Debbie Mauldin Cottrell, *The County Poor Farm System in Texas*, 93 *Sw. Hist. Q.* 169, 171 (1989) (describing Massachusetts and New York reports that claimed that indoor care would “frighten[]” people to work and “generally discourage[] applicants for assistance”).

68. Act to Provide for the Establishment of County Poorhouses, ch. 331, 1824 N.Y. Laws 382; see also Trent, *supra* note 10, at 6 (tracing the move toward “indoor relief”).

69. See Cottrell, *supra* note 67, at 170 (discussing poor farms in predominantly agricultural states like Texas).

70. See Ben-Moshe, *Decarcerating Disability*, *supra* note 12, at 41–42 (noting that the conditions in almshouses and poorhouses were deliberately inhumane and abusive to deter the “unworthy” poor).

71. Josiah Quincy, *Report of the Committee on the Subject of Pauperism and a House of Industry in the Town of Boston* 8 (1821).

72. See Cottrell, *supra* note 67, at 172.

73. See Gilliom, *supra* note 57, at 23–24.

74. See *id.* at 23.

75. See *id.*

76. See *id.* at 24.

counsel” rather than provide material relief.⁷⁷ The COS’s main concern was to suppress idleness and beggary and relieve “worthy, self-respecting poverty.”⁷⁸ That is, the COS was primarily concerned with detecting and preventing fraud.⁷⁹ It sent a “friendly visitor” to visit each poor family.⁸⁰ While ostensibly a kind and benevolent presence, the friendly visitor was also a way of collating information, “unmask[ing] impostures of poverty or disability.”⁸¹ COS organizers advocated “systematic record-keeping, surveys and research into every ‘case.’”⁸² As disability studies and history scholar Susan Schweik puts it: “These bureaucratic records might seem like individual microcosms or microaggressions, but they were of course far more than that; they connected the system of surveillance to broader mechanisms of disciplinary power and control.”⁸³

2. *Surveillance for the Purpose of Reform and Rehabilitation.* — In the early to mid-nineteenth century, a “cult of asylum” swept across America, resulting in the development of new surveillance practices aimed at rehabilitating disability.⁸⁴ As medical service providers insisted that mental illnesses could be cured, confinement in an asylum became the first stop in the treatment of disabled people.⁸⁵ Around this time, attitudes and behaviors focused on housing “the insane, disabled, and feeble minded,” who were deemed to be festering away in workhouses.⁸⁶ Psychiatrists and medical superintendents argued that they could rehabilitate disability through properly organized institutions with rigorous reformatory curricula.⁸⁷ This resulted in the creation of schools that aimed to reform disabled individuals’ character.⁸⁸ In 1847, Massachusetts set aside funding

77. See Schweik, *supra* note 10, at 41 (internal quotation marks omitted) (quoting Michael B. Katz, *In the Shadow of the Poorhouse: A Social History of Welfare in America* 78 (1986)).

78. *Id.* (internal quotation marks omitted) (quoting Frank Dekker Watson, *The Charity Organization Movement in the United States* 188 (1922)).

79. See *id.* at 43 (noting that fraud detection was “a trademark COS enterprise in the public eye”).

80. *Id.*

81. *Id.*

82. *Id.*

83. *Id.*

84. Appleman, *supra* note 16, at 428 (internal quotation marks omitted) (quoting Rothman, *supra* note 13, at 130).

85. See *id.* at 432 (noting that in 1842, New York’s commitment statute required a minimum six-month detention in the new state asylum in Utica).

86. See *id.* at 433.

87. See Chapman et al., *supra* note 11, at 7 (“Within the walls of the institution or penitentiary, experts could create an environment that exemplified the principles of a well-ordered society and thereby (it was believed) cure inmates of insanity, deficiency, and deviancy.”).

88. See Trent, *supra* note 10, at 8 (describing the development of these schools for people with intellectual disabilities as inspired by two famous institutions established in

for an “idiot” school.⁸⁹ Connecticut, Kentucky, Ohio, and Pennsylvania quickly followed.⁹⁰

These schools and asylums were heavily regulated spaces. Their routines resembled those of the nation’s prisons and penitentiaries and brought a “bell-ringing precision” into residents’ lives.⁹¹ This drive toward discipline was also echoed in the architecture of asylums that housed people with psychiatric disabilities: “Typically, a central structure of several stories stood in the middle of the asylum grounds, and from it radiated long and straight wings [where patients lived].”⁹² This system permitted officials to watch over the patients. Social and medical historian David Rothman notes, “Each class of patients had its own particular obligations and privileges, and a hierarchy of officials watched their behavior, ready to move them from one category to another.”⁹³ The asylums exercised strict control over whom the “inmates” interacted with: They were frequently removed from their families and not permitted any visitors or correspondence during the time they spent at the asylum.⁹⁴

3. *Surveilling “Criminals” and “Degenerates”*. — Between 1790 and 1830, the nation’s population increased exponentially.⁹⁵ American legislators, newly independent and free from the shackles of British rule, developed new criminal codes that moved away from the British system of capital punishment and toward incarceration.⁹⁶ As concern about an increase in crime intensified, Americans devised new ways of rooting out and stopping deviant behavior.⁹⁷ Society turned to finding that deviancy in peoples’ biology, personal histories, and experiences.⁹⁸ Surveillance during this

Paris, Salpêtrière and Bicêtre, which were focused on treating the insane and educating those deemed “idiots”).

89. See *id.*

90. See *id.* at 10.

91. See Rothman, *supra* note 13, at 153–54 (noting that the strict regimentation of the asylums “represented both an attempt to compensate for public disorder in a particular setting and to demonstrate the correct rules of social organization”).

92. *Id.* at 153.

93. *Id.* at 154.

94. *Id.* at 151.

95. See *id.* at 57 (“In 1790, no American city had more than fifty thousand residents. By 1830, almost half a million people lived in urban centers larger than that.”).

96. See *id.* at 60–61 (observing that by 1820, states had amended their criminal laws to abolish the death sentence except as punishment for first-degree murder or other very serious crimes). Rothman notes that American society shifted away from British laws that seemed to serve the passions of the few to laws concerned with the causes of deviant behavior. See *id.* at 60. Accordingly, “[m]en intently scrutinized the life history of the criminal and methodically arranged the institution to house him.” *Id.* at 62.

97. *Id.* at 65.

98. *Id.*

time took on a moral dimension, playing a role in identifying aberrance and keeping it out of society.⁹⁹

This use of surveillance had implications for people with disabilities.¹⁰⁰ Laws began to criminalize disability and disability-related behavior, sanctioning the increased scrutiny of disabled bodies, particularly in public spaces. Across the nation, cities like San Francisco, Chicago, and New Orleans passed “ugly laws” to remove people with disabilities from the streets.¹⁰¹ These laws employed a variety of mechanisms to delegitimize disabled people’s use of public spaces. Some were wrapped up in a language of care.¹⁰² Others overtly criminalized activities that people with disabilities routinely engaged in—like public begging.¹⁰³

Social policies that targeted the purported link between disability and criminality were bolstered by the eugenics movement.¹⁰⁴ In 1851, English philosopher Herbert Spencer argued that “nature’s failures” included “those with mental, physical, or moral deficiencies.”¹⁰⁵ Eugenacists believed that moral degeneracy and criminality were inherited.¹⁰⁶ In his book *The Kallikak Family*, Henry Goddard, of the Vineland School for Feeble-Minded Girls and Boys, emphasized the need to carefully study the minds of the “feble-minded” by analyzing the trajectories of two lines of descendants from the same man—one through “a woman of his quality”

99. See *id.* at 69–70 (observing that the Jacksonians grappled with how to “eliminate crime and corruption” while also “doubt[ing] the society’s survival, fearing it might succumb to chaos”). This fear made it critical to create social organizations to police the “problem” of deviance.

100. See Liat Ben-Moshe, *Disabling Incarceration: Connecting Disability to Divergent Confinements in the USA*, 39 *Critical Socio.* 385, 389 (2011) (“The history of treatment and categorization of those labeled as feeble-minded, and later mentally retarded, is also paved with cobblestones of notions of social danger, as prominent eugenicists tried to ‘scientifically’ establish that those whom they characterized as feeble-minded had a tendency to commit violent crimes.”).

101. See Schweik, *supra* note 10, at 24–39 (describing the specific characteristics of laws enacted in each of these cities).

102. See *id.* at 64 (providing an example of Denver’s “ugly ordinance,” which “[spoke] the language of regulatory care,” even as its law on “[d]eformed persons—how cared for” was “followed immediately by ‘shall not expose himself to public view’”).

103. See *id.* at 24 (“The San Francisco ordinance begins with a general order to ‘Prohibit Street Begging’ . . .”).

104. See Appleman, *supra* note 16, at 438 (explaining a popular nineteenth-century criminology theory that linked “the criminal mind” to physical features and defects through genetic inheritance, giving “eugenicists a scientific basis for attacking and controlling crime . . . through institutionalization, incarceration . . . , and sterilization”).

105. Adam Cohen, *Imbeciles: The Supreme Court, American Eugenics, and the Sterilization of Carrie Buck* 45 (2016).

106. See *id.* at 51 (“[Eugenicists] created elaborate pedigrees showing how feeble-mindedness, drunkenness, criminality, and moral degeneracy were inherited within families. In [their] view, Mendel’s laws supported their belief that if the ‘socially defective’ were prevented from having children[,] . . . bad traits could be bred out, and good traits would proliferate.”).

and another “through a ‘feeble-minded girl.’”¹⁰⁷ Ultimately, Goddard decided that visits by trained workers to the children’s families were required to study mental defectiveness in the families as a whole. Goddard came up with the categories of “idiots,” “imbeciles,” and “morons” to describe various levels of disability.¹⁰⁸

Surveillance was deemed necessary to ensure that those classified as “imbeciles” or “feebleminded” did not marry or have children and thereby pass down their immorality and criminality. For example, eugenics laws prohibiting marriage imposed criminal penalties if people deemed to be epileptic or “imbecilic” married.¹⁰⁹ Many prominent lawmakers, however, did not believe this was sufficient because nothing prevented “defective” people from procreating without a marriage license.¹¹⁰ Accordingly, they proposed identifying and institutionalizing them during their reproductive years.¹¹¹ People with disabilities were to be watched carefully and monitored to prevent procreation. As Goddard put it:

Determine the fact of their defectiveness as early as possible, and place them in colonies under the care and management of intelligent people who understand the problem . . . Train them, make them happy; make them as useful as possible, but above all, bring them up with good habits and keep them from ever marrying or becoming parents.¹¹²

The Eugenics Record Office, a research institute that became the center of the eugenics movement in America, was established in 1910.¹¹³ Its focus was on the collection of eugenics information. Office trainees were taught to investigate communities, families, and individuals.¹¹⁴ As journalist Adam Cohen notes, “[t]he trainees, who were overwhelmingly young women[,] . . . were deployed to mental hospitals, poorhouses, and

107. See *id.* at 52–53 (quoting Henry Goddard, *The Kallikak Family* 50, 69 (1912)) (“The line from Kallikak’s wife, Goddard found, included generations of doctors, judges, and other successful men. The line from the ‘feeble-minded girl’ was rife with prostitutes, criminals, and epileptics.”).

108. See *id.* at 52 (internal quotation marks omitted) (quoting Henry Goddard, *The Kallikak Family* 11, 102, 104 (1912)).

109. See *id.* at 63 (internal quotation marks omitted) (quoting 1895 Conn. Pub. Acts 677) (“Connecticut, the first state to act, adopted an 1895 law barring ‘epileptic, imbecile, or feeble-minded’ individuals from marrying if the woman was under forty-five. The penalty was up to three years in prison [F]orty-one states would [follow] by the mid-1930s.” (quoting 1895 Conn. Pub. Acts 677)).

110. See *id.*

111. See *id.* at 63–64 (noting that eugenicists like Goddard and Dr. Walter E. Fernald of Massachusetts “began to rally around a tactic” of segregation and colonization: “identify[ing] the feebleminded and other people who should not have children[] and plac[ing] them in state institutions during their reproductive years”).

112. *Id.* at 64 (internal quotation marks omitted) (quoting Henry H. Goddard, *Sterilization and Segregation* 4 (1913)).

113. *Id.* at 114–15.

114. *Id.* at 115.

other institutions across the country,” including “Ellis Island, where they were instructed on how to identify feeble-minded people trying to enter the country.”¹¹⁵ The office then used this carefully gathered data in trait-heritability studies and projects tracking certain qualities, like criminality, through family generations.¹¹⁶ The Eugenics Record Office also provided individualized data to couples “considering marrying but uncertain of the eugenic implications.”¹¹⁷ By the 1920s, this office began influencing the U.S. government, beginning with proposals for forced sterilization laws, which became the impetus for immigration laws that limited the number and characteristics of immigrants in the 1920s and beyond.¹¹⁸ Poor people with disabilities, particularly “feeble-minded” women, were subject to near-constant surveillance as law and medicine colluded to confine them in facilities where they could be sterilized.¹¹⁹

The “science” of eugenics began to lose favor only in the 1960s, when popular attitudes toward the treatment of marginalized groups began to change.¹²⁰ Up until that time, however, the institutionalization of people with disabilities continued in full force. In the 1940s and 1950s, many physicians recommended institutionalization as a way to provide specialized care to people with significant needs.¹²¹ Middle-class people saw the institutionalization of children with disabilities as necessary for the well-being of the family.¹²² The prevailing belief was that people with intellectual disabilities were perpetual children, requiring oversight in therapeutic, institutionalized settings.¹²³

115. *Id.*

116. *See id.* at 115–16.

117. *Id.* at 116.

118. *See id.* at 116–35 (describing how Harry Laughlin ascended in rank within the Eugenics Record Office, proposed several sterilization laws, and turned to immigration law as the solution for eradicating “defective” people—a decision that ultimately resulted in the passage of the Immigration Act of 1924).

119. *See id.* at 22–23. The experience of Emma Buck illustrates this point. Emma was the mother of Carrie Buck, the woman at the heart of the notorious Supreme Court decision in *Buck v. Bell*. In that case, the Court ruled that Virginia’s statute mandating involuntary sexual sterilization of people with disabilities did not violate the Due Process and Equal Protection Clauses of the Fourteenth Amendment. *Buck v. Bell*, 274 U.S. 200, 207 (1927). Emma Buck was arrested on the grounds of prostitution—a vague charge that was applied to a wide range of conduct, including vagrancy. Cohen, *supra* note 105, at 22. Judge Charles D. Shackelford, of the Charlottesville, Virginia, domestic relations court, adjudged Emma as being feeble-minded, and she was committed to the Colony for Epileptics and Feeble-Minded. *Id.* She was given an intelligence test when she arrived and was diagnosed as being a “Moron.” *Id.* at 23. She would remain incarcerated for the rest of her life. *Id.*

120. *See* Cohen, *supra* note 105, at 319 (noting that from 1965 to 1979, at least fifteen states repealed laws permitting involuntary sterilization).

121. *See* Trent, *supra* note 10, at 228.

122. *See id.* at 229.

123. *See id.*; *see also* Ben-Moshe, *Decarcerating Disability*, *supra* note 12, at 193–94 (noting that parents opposing the closure of institutions would “often raise questions like ‘what will happen to my child?’ even though the child in question is often someone in his

4. *Surveillance in the Age of Integration.* — By the 1960s, cracks were beginning to appear in the logic of institutionalization. Thomas Szasz’s book *The Myth of Mental Illness* was published in 1961, casting doubt on psychiatry as a profession and condemning its role in subjecting people diagnosed with mental illness to coercive state practices.¹²⁴ Psychologists like Wolf Wolfensberger promoted the notion of “normalization”—the idea that people with intellectual disabilities should and could live in the community as valuable members of society.¹²⁵ Media exposés demonstrated the horror of living in asylums and centers for the intellectually and developmentally disabled.¹²⁶ In 1961, John F. Kennedy formed the President’s Panel on Mental Retardation, which advocated for additional supports and services within the community for those diagnosed with intellectual disabilities.¹²⁷ At the same time, federal Medicaid funding became available to move people out of institutions.¹²⁸ Financial factors, including the expense of upgrading run-down facilities, also prompted the end of institutionalization.¹²⁹ Further, as institutionalization became less popular, institutions “lost one of their major labor forces: the institutionalized.”¹³⁰

While the deinstitutionalization movement was very successful in depopulating large institutions, it was less effective in changing social

or her fifties or older,” evoking “tropes of some disabled people as innocent and eternal children”).

124. See Thomas S. Szasz, *The Myth of Mental Illness* 296 (1961) (arguing that the definition of psychiatry “as a medical specialty concerned with . . . mental illness” is “worthless and misleading” because “[m]ental illness is a myth” and “[p]sychiatrists are not concerned with mental illnesses and their treatments”).

125. See Wolfensberger, *supra* note 25, at 27–28.

126. Ben-Moshe, *Decarcerating Disability*, *supra* note 12, at 46–53 (detailing the numerous exposés that played a role in changing public perceptions toward institutionalization, including Geraldo Rivera’s exposé of Willowbrook, an institution on Staten Island that housed thousands of people with various disabilities).

127. See David L. Bazelon & Elizabeth M. Boggs, *The President’s Panel on Mental Retardation: Report of the Task Force on Law 30 (1963)*, <https://mn.gov/mnddc/parallels2/pdf/60s/63/63-ROT-PPMR.pdf> [<https://perma.cc/6HZZ-FQU8>] (“To the maximum feasible extent, the status of the [institutionalized] mentally retarded patient should be reviewed by the institutional authorities and his ability to return to society reassessed by them on a periodic basis.”).

128. Trent, *supra* note 10, at 249 (“By 1976, most states were using Medicaid funding to plan for the deinstitutionalization of incarcerated retarded adults.”). In 1981, Congress added section 1915(c) to the Social Security Act, giving states the option to develop home- and community-based services to provide supports and services to people with disabilities within the community, rather than in institutions. See Omnibus Budget Reconciliation Act of 1981, Pub. L. No. 97-35, secs. 2175–2176, 95 Stat. 357, 809–13 (codified as amended at 42 U.S.C. § 1396n (2018)).

129. See Ben-Moshe, *Decarcerating Disability*, *supra* note 12, at 57.

130. *Id.* at 59.

prejudices against people with disabilities.¹³¹ In 1967, close to 200,000 people lived in large public institutions.¹³² By 2012, that number had dropped to 22,099 residents.¹³³ As institutions were downsized, however, community-based residential settings never wholly abandoned the strictures of the institution, including the need to oversee and control group home residents.¹³⁴ Wolfensberger emphasized that “both positive imagery and competency-enhancing measures . . . can diminish the negativity of a negative role perception.”¹³⁵ Group home service providers subverted the meaning of normalization as they translated it into policy by developing a range of disciplinary techniques, including “cultivating bodily regimens in relation to hygiene, conduct, sexuality, and so on in order to resemble peer like behavior.”¹³⁶ Consequently, this meant deploying “different techniques of surveillance of the resident and their actions and the constant monitoring and recording of their compliance.”¹³⁷

Deinstitutionalization also did not erase perceptions of people with disabilities as “risky” or dangerous. Deinstitutionalizing asylums and psychiatric hospitals came about after growing social critiques of conditions within these facilities as well as a growing concern about psychiatry as an “agent of social control.”¹³⁸ By the end of the 1970s, all states had restrictions on civil commitment based on whether one posed a danger to oneself or to others.¹³⁹ Ironically, this framing of psychiatric disability reinforced a public and legal discourse linking mental illness with dangerousness and criminality.¹⁴⁰ This association gave rise to new forms of surveillance and control.¹⁴¹ Professor Liat Ben-Moshe notes that the courts were tasked with deciding who could be hospitalized, which “embedded psy powers in the law.”¹⁴² The focus shifted from “involuntary hospitalization based on psych diagnosis to one based on psychiatrists’ and

131. See Ben-Moshe, *Contested Meaning*, supra note 39, at 243 (“[T]he shift from custodial care and institutionalization to deinstitutionalization and community living should not be . . . seen as the rise and fall of one epoch to be replaced by the other . . . because the effects of the former still linger on in the latter.”).

132. See Trent, supra note 10, at 266.

133. See *id.*

134. See Ben-Moshe, *Decarcerating Disability*, supra note 12, at 108 (noting the reach of the therapeutic state’s control over those who live in group homes and other institutions).

135. See Wolf Wolfensberger, *A Brief Introduction to Social Role Valorization: High-Order Concept for Addressing the Plight of Societally Devalued People, and for Structuring Human Services* 94 (3d ed. 1998). Wolfensberger further explains that these principles of positive imagery and competency enhancement “are equally applicable to . . . decisions . . . outside of formal, organized human services.” *Id.* at 1.

136. Ben-Moshe, *Decarcerating Disability*, supra note 12, at 77.

137. *Id.*

138. *Id.* at 88.

139. *Id.* at 99–100.

140. *Id.* at 100.

141. *Id.* at 108.

142. See *id.* at 99.

courts' opinions of dangerousness, which was racial[ized], gendered, and intertwined with sexuality."¹⁴³ As a result, "psychiatric coercion[] lay everywhere"—although they were no longer institutionalized, people with psychiatric disabilities were "still under the surveillance of the therapeutic State."¹⁴⁴

There continues to be an appetite to surveil those deemed disabled. While a growing movement of advocates has sought to claim disability as an affirmative and positive identity,¹⁴⁵ public discourse has tended to treat disability identity as lacking and resource-intensive. Jasmine Harris, Elizabeth Emens, and Doron Dorfman have pointed out how a cost narrative continues to permeate public discourse around disability, such that expenditures on accommodations and public benefits continue to be viewed with suspicion.¹⁴⁶ Scholars like Jamelia Morgan have written extensively about how disability-related behaviors continue to be managed through the criminalization of those behaviors.¹⁴⁷ Current statistics are sobering: As of a 2015 DOJ report documenting national disability rates among incarcerated people from 2011 to 2012, around 32% of people incarcerated in prisons and 40% of those in jails have at least one disability; 20% of prisoners and 31% of jail inmates report having a cognitive disability.¹⁴⁸

This has led disability advocates and scholars to ask the difficult question whether true community integration has really been achieved. Ben-Moshe proposes two visions of community integration.¹⁴⁹ One idea is that of community as negation—the presumption that the work is done

143. *Id.* at 100.

144. *Id.* at 108.

145. See, e.g., Katie Eyer, *Claiming Disability*, 101 *B.U. L. Rev.* 547, 553 (2021) (calling for people to embrace disability identity as a way to disrupt disability stigma).

146. Dorfman, *supra* note 30, at 1054 ("[W]ho would not want to park closer to the entrance, take the dog to venues that usually prohibit pets, receive more time on exams, or skip the lines . . . ? Those 'small disability perks' can . . . [be] behind people's suspicions that others fake disabilities to enjoy . . . perks or 'special rights.'"); Elizabeth F. Emens, Kaaryn S. Gustafson & Jasmine E. Harris, *The Disability Cost Narrative: A Roundtable Discussion*, 170 *U. Pa. L. Rev.* 1951, 1951, 1957 (2022) (arguing that the question of cost permeates disability rights discussions).

147. See Jamelia Morgan, *Disability's Fourth Amendment*, 122 *Colum. L. Rev.* 489, 510 (2022) ("Disability policing reinforces stereotypes that associate disability with criminality, specifically those that construct disabled people as suspicious, deviant, risky, dangerous, or threatening."); Jamelia N. Morgan, *Rethinking Disorderly Conduct*, 109 *Calif. L. Rev.* 1637, 1642 (2021) (arguing that disorderly conduct laws enforce discriminatory norms that deny people with disabilities access to public spaces and criminalize disability-related "non-conforming" behavior).

148. Jennifer Bronson, Laura M. Maruschak & Marcus Berzofsky, DOJ, NCJ 249151, *Disabilities Among Prison and Jail Inmates, 2011–12*, at 3 (2015), <https://bjs.ojp.gov/content/pub/pdf/dpji1112.pdf> [<https://perma.cc/3EH6-PKNC>] (reporting that cognitive disabilities are four times more prevalent in persons incarcerated in prison and six-and-a-half times more prevalent among persons incarcerated in jails).

149. See Ben-Moshe, *Contested Meaning*, *supra* note 39, at 244–52.

once services are provided outside the walls of the institution.¹⁵⁰ “Community,” here, simply means “that which is not the institution.”¹⁵¹ The richer and more nuanced idea of community integration emphasizes the importance of ensuring that people with disabilities develop meaningful relationships within the community and retain autonomy and control over their lives.¹⁵² The concept of “community-based services” is about not just the location of services but also “an epistemic shift in regard to the hierarchical system of care.”¹⁵³

As the next Part of this Essay demonstrates, the integration mandate—as codified in Section 504 of the Rehabilitation Act and in the ADA and interpreted by the Supreme Court in *Olmstead*—embraces the latter vision of community.¹⁵⁴ Accordingly, it is necessary and appropriate to ask critical questions about the utility of policies that promote surveillance, with its potential to isolate based on perceptions of risk, and those policies’ impact on the goal of community integration of people with disabilities. The integration mandate provides a legal framework to challenge surveillance policies that isolate people with disabilities or threaten them with institutionalization.

II. SURVEILLANCE AND THE INTEGRATION MANDATE

Part II has three goals. First, it outlines the codification of integration in Section 504 of the Rehabilitation Act and in the ADA as a key prescriptive remedy for discrimination. Second, it examines the Supreme Court’s holding in *Olmstead v. L.C. ex rel. Zimring* that the unjustified isolation of people with disabilities constitutes a violation of the integration mandate—a decision that was enthusiastically embraced by the executive and judicial branches. Finally, Part II demonstrates how *Olmstead* jurisprudence now recognizes that people with disabilities can be isolated and segregated even when they are outside the walls of an institution and residing in the community.¹⁵⁵ *Olmstead* jurisprudence adopts a vision of community that is expansive and geared toward protecting the autonomy, privacy, and self-determination of people with disabilities.¹⁵⁶ This has been bolstered by guidance issued by the Department of Justice on the scope of the integration mandate.¹⁵⁷ The integration mandate thus provides a

150. See *id.* at 244, 249.

151. *Id.* at 244.

152. *Id.* at 249–51 (“Community seems more about support and acceptance, and therefore about personal and interpersonal characteristics, rather than size or place.”).

153. *Id.* at 257.

154. See *infra* section II.B.

155. See *infra* section II.B.

156. See *infra* section II.C.

157. See *infra* section II.C.

means to interrogate the use of ableist surveillance practices that threaten to isolate or segregate people with disabilities within the community.

A. *Legislative Measures Mandating Integration*

The integration mandate was first codified in Section 504 of the Rehabilitation Act of 1973—the precursor to the ADA.¹⁵⁸ It provides that “[n]o otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.”¹⁵⁹ In 1976, President Gerald R. Ford issued an executive order instructing the Department of Health, Education, and Welfare (HEW) to issue regulations implementing Section 504 that clarified whom the law protected and what discriminatory acts it prohibited.¹⁶⁰ In 1978, HEW issued Section 504 regulations that required recipients of federal funds to “administer programs and activities in the most integrated setting appropriate to the needs of qualified handicapped persons.”¹⁶¹ The preamble to these regulations provided that “separate” treatment of people with disabilities was justified only “where necessary to ensure equal opportunity and truly effective benefits and services.”¹⁶² Section 504 makes clear that federal agencies and recipients of federal funding have to make reasonable modifications to their policies to avoid discrimination and promote integration.¹⁶³

While Section 504 applied to entities that received federal funding, people with disabilities continued to face isolation and segregation, even within the community. Senator Paul Simon commented that despite the enactment of laws like the Rehabilitation Act, a “sizable part of our population remain[ed] substantially hidden . . . in institutions[,] . . . in nursing homes[,] . . . [and] in the homes of their families.”¹⁶⁴ In 1988, Congress introduced federal legislation that formed the foundation of the ADA.¹⁶⁵ The ADA is founded on Congress’s explicit recognition that

158. The text of the ADA provides that it is based on the “remedies, procedures, and rights” of Section 504. See 42 U.S.C. § 12133 (2018) (“The remedies, procedures, and rights set forth in section [504 of the Rehabilitation Act] shall be the remedies, procedures, and rights this subchapter provides to any person alleging discrimination on the basis of disability in violation of section 12132 of this title.”).

159. 29 U.S.C. § 794(a) (2018).

160. Exec. Order No. 11,914, 3 C.F.R. § 117 (1977).

161. Implementation of Executive Order 11,914, Nondiscrimination on the Basis of Handicap in Federally Assisted Programs, 43 Fed. Reg. 2132, 2138 (Jan. 13, 1978) (codified at 45 C.F.R. § 85.21(d)).

162. *Id.* at 2134.

163. 29 U.S.C. § 794(a).

164. 134 Cong. Rec. 9384 (1988) (statement of Sen. Simon).

165. H.R. 4498, 100th Cong. (1988); S. 2345, 100th Cong. (1988).

people with disabilities have historically been isolated and segregated and that this continued to be “a serious and pervasive social problem” at the time of enactment.¹⁶⁶ Accordingly, the ADA was clear that “[a] public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”¹⁶⁷ In so stating, the ADA extended to state entities the obligation to prevent discrimination against people with disabilities.¹⁶⁸

When it was passed, the ADA was perceived to be groundbreaking legislation, unusual in the clarity of its “remedial mission” to shift social norms and integrate people with disabilities into society.¹⁶⁹ Congressional debates demonstrate the clear link made between segregation and discrimination: “To be segregated is to be misunderstood, even feared. . . . [O]nly by breaking down barriers between people can we dispel the negative attitudes and myths that are the main currency of oppression.”¹⁷⁰ This framing clarifies that the purpose behind integration was more profound than simply changing the location of services from institutions to the community—it required the removal of *all* barriers that prevented people with disabilities from truly becoming part of the community, including the persistent prejudices around disability.

B. *The Impact of Olmstead*

The ADA’s integration mandate was strengthened by the Supreme Court’s decision in *Olmstead v. L.C. ex rel. Zimring*.¹⁷¹ The plaintiffs in this case were two institutionalized women, Lois Curtis (L.C.) and Elaine Wilson (E.W.), who were dually diagnosed with intellectual and developmental disabilities and psychiatric disabilities.¹⁷² They argued that once their treating physicians deemed them capable of receiving treatment within the community, their continued institutionalization in the state psychiatric facility violated the integration mandate of Title II of the ADA.¹⁷³ In finding for the plaintiffs, the Supreme Court held that

166. See 42 U.S.C. § 12101(a)(2) (2018).

167. 28 C.F.R. § 35.130(d) (2023).

168. 42 U.S.C. § 12101(b)(1); 28 C.F.R. § 35.130(d).

169. See Jasmine E. Harris, *The Aesthetics of Disability*, 119 *Colum. L. Rev.* 895, 903 (2019) (emphasis omitted) (“[T]he ADA is the only antidiscrimination statute with such a clear normative orientation and *remedial* mission.”).

170. *Id.* at 922 (alterations in original) (internal quotation marks omitted) (quoting 136 *Cong. Rec.* 11,430 (1990) (statement of Rep. Collins)).

171. 527 U.S. 581 (1999).

172. See *id.* at 593 (“Respondents L.C. and E.W. are mentally retarded women; L.C. has also been diagnosed with schizophrenia, and E.W. with a personality disorder. Both women have a history of treatment in institutional settings.”).

173. See *id.* at 594 (“L.C. alleged that the State’s failure to place her in a community-based program, once her treating professionals determined that such placement was appropriate, violated, *inter alia*, Title II of the ADA. . . . E.W. intervened in the action, stating an identical claim.”).

the “unjustified isolation” of people with intellectual disabilities could constitute discrimination under Title II of the ADA.¹⁷⁴ The Supreme Court also recognized the profoundly isolating and stigmatizing impact of institutionalization:

First, 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. . . . Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.¹⁷⁵

Accordingly, the Court held that the State was obligated to ensure that people with disabilities were given reasonable accommodations so that they did not need to “relinquish participation in community life” to access necessary medical services.¹⁷⁶

The Court was careful, however, to place limits on the state’s obligations. First, the Court held that the state’s medical professionals should agree that community-based treatment was appropriate for the individual.¹⁷⁷ In other words, the Court was careful to soften the requirement that people with mental disabilities be placed in the community if professionals deemed it inappropriate.¹⁷⁸ A second element was that the disabled person needed to agree to community placement.¹⁷⁹ The Court’s framing of community placement as a reasonable accommodation meant that it incorporated language from Title II regulations stating that a person could not be forced to accept a reasonable accommodation.¹⁸⁰

174. See *id.* at 597.

175. *Id.* at 600–01.

176. *Id.* at 601.

177. This has not proven to be a significant hurdle to community integration. Lower courts have interpreted *Olmstead* to permit plaintiffs to rely on their own experts to demonstrate that they can be served in a community-based setting. See, e.g., *Disability Advoc., Inc. v. Paterson*, 653 F. Supp. 2d 184, 258–59 (E.D.N.Y. 2009), vacated on other grounds sub nom. *Disability Advoc., Inc. v. N.Y. Coal. for Quality Assisted Living, Inc.*, 675 F.3d 149 (2d Cir. 2012); *Joseph S. v. Hogan*, 561 F. Supp. 2d 280, 291 (E.D.N.Y. 2008).

178. See *Olmstead*, 527 U.S. at 607 (“Title II of the ADA[] [requires] States . . . to provide community-based treatment . . . when the State’s treatment professionals determine that such placement is appropriate, the affected persons [don’t] oppose such treatment, and the placement can be reasonably accommodated, [considering] resources available to the State and the needs of others with mental disabilities.”).

179. See *id.*

180. See *id.* at 602–03 (“Nothing in this part shall be construed to require an individual with a disability to accept an accommodation . . . which such individual chooses not to accept.” (alteration in original) (internal quotation marks omitted) (quoting 28 C.F.R. § 35.130(e)(1) (1998))).

Third, the Supreme Court expressed some sympathy for the State of Georgia's argument that it had inadequate funding to place the plaintiffs in community settings.¹⁸¹ Accordingly, the Court imposed a generous fundamental-alteration limitation, permitting the state to meet its obligations under the integration mandate if it "were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated."¹⁸² In so doing, it placed an "exceptionally high burden on plaintiffs seeking services in a more integrated setting."¹⁸³ Finally, in a footnote, the Court also held that the ADA does not require states to provide a certain standard of care or level of benefits.¹⁸⁴ Its holding was a conservative one: States did not have to provide new services but, for the services they *did* provide, could not discriminate against people with disabilities.¹⁸⁵

Despite these limitations, *Olmstead* marked a watershed in the integration movement. The decision's impact was surprising, not just because of the curial recognition that unjustified isolation constituted discrimination but also because of how wholeheartedly the executive branch embraced it.¹⁸⁶ Disability law scholar Robert Dinerstein notes that while the case had been brought on behalf of two individuals, the Supreme Court treated *Olmstead* as if it were a class action suit, opining broadly on the rights of people with disabilities.¹⁸⁷ The Court's decision was then embraced by the Clinton Administration in support of its policies.¹⁸⁸ Secretary of Health and Human Services Donna Shalala extolled the decision and stated that it embraced the goal of "a nation that integrates people with disabilities into the social mainstream, promotes equality of opportunity, and maximizes individual choice."¹⁸⁹ In 2001, President George W. Bush issued

181. See *id.* at 597 ("In evaluating a State's fundamental-alteration defense, the [court] must consider, in view of the resources available to the State, . . . the cost of providing community-based care to the litigants, . . . the range of services the State provides others with mental disabilities, and [its] obligation to . . . [offer] those services equitably.").

182. *Id.* at 605–06 (plurality opinion).

183. Salzman, *supra* note 36, at 191.

184. See *Olmstead*, 527 U.S. at 603 n.14.

185. See *id.*

186. Robert Dinerstein, *The Olmstead Imperative: The Right to Live in the Community and Beyond*, 4 *Inclusion* 16, 18 (2016).

187. *Id.* But see *United States v. Mississippi*, 82 F.4th 387, 395–98 (5th Cir. 2023) (finding that *Olmstead* claims based on individualized determinations of discrimination could not support generalized determinations of the risk of institutionalization for a whole class of people).

188. Dinerstein, *supra* note 186, at 18.

189. *Id.* (internal quotation marks omitted) (quoting *Enforcing the Olmstead Decision*, Ctr. for an Accessible Soc'y, http://www.accessiblesociety.org/topics/persasst/Olmstead_shalala.htm [<https://perma.cc/3FRM-8NLW>] (last visited Jan. 4, 2024)) (describing and excerpting a speech by Donna Shalala, the then-HHS Secretary).

Executive Order No. 13217, “Community-Based Alternatives for Individuals with Disabilities,” which placed on the federal government the responsibility to create community-based alternatives for individuals with disabilities.¹⁹⁰ Under the Obama Administration, the DOJ brought statewide investigations leading to letters of findings and consent decrees on behalf of people with disabilities across the country.¹⁹¹ As Dinerstein writes, the “Executive Branch’s embrace of *Olmstead* was critical in making sure that the decision stood for more than providing community-based services to two individuals.”¹⁹²

C. *The Expansive Vision of the Integration Mandate*

Courts have also played an important role in ensuring that *Olmstead* is enforced. Emphasizing the ADA’s expansive purpose, courts have rejected states’ attempts to narrow the reach of the mandate. For instance, courts have rejected the argument that a person may be eligible for community-based services only when the state’s experts declare them capable of benefiting from a more integrated setting.¹⁹³ Courts have also rejected arguments that to state an *Olmstead* claim, plaintiffs must already be institutionalized like the plaintiffs in *Olmstead*.¹⁹⁴

190. *Id.* at 19.

191. *Id.*; see also *Olmstead: Community Integration for Everyone*, DOJ, C.R. Div., <https://archive.ada.gov/olmstead/index.html> [<https://perma.cc/9TUB-B5NN>] (last visited Nov. 4, 2023). Dinerstein notes that the DOJ brought statewide investigations leading to letters of findings and consent decrees on behalf of people with I/DD and psychiatric disability institutionalized in Delaware, Georgia, Mississippi, Nebraska, New Hampshire, Puerto Rico, and Virginia, extending the application of *Olmstead* to “all of a state’s institutions,” including nursing homes and adult care homes. Dinerstein, *supra* note 186, at 19.

192. Dinerstein, *supra* note 186, at 19.

193. See, e.g., *Day v. District of Columbia*, 894 F. Supp. 2d 1, 23 (D.D.C. 2012) (stating that “[s]ince *Olmstead*, lower courts have universally rejected the absolutist interpretation” that only the State could determine whether community-based services were appropriate for the plaintiff); *Disability Advoc., Inc. v. Paterson*, 653 F. Supp. 2d 184, 258–59 (E.D.N.Y. 2009) (stating that requiring a determination by professionals contracted by the State would “eviscerate the integration mandate” and permit the State “virtually unreviewable discretion” over the suitability of placement in the community), vacated on other grounds *sub nom.* *Disability Advoc., Inc. v. N.Y. Coal. for Quality Assisted Living, Inc.*, 675 F.3d 149 (2d Cir. 2012).

194. See, e.g., *Waskul v. Washtenaw Cnty. Cmty. Mental Health*, 979 F.3d 426, 461 (6th Cir. 2020) (recognizing a “serious risk of institutionalization” claim as a violation of the integration mandate); *Steimel v. Wernert*, 823 F.3d 902, 914 (7th Cir. 2016) (holding 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”); *Davis v. Shah*, 821 F.3d 231, 264 (2d Cir. 2016) (recognizing a violation of the integration mandate when New York’s restrictions on orthopedic footwear and compression socks put the plaintiffs at risk of institutionalization); *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1181 (10th Cir. 2003) (stating that “nothing in the plain language of the regulations . . . limits protection to persons who are currently institutionalized” and that the ADA’s protections “would be meaningless if plaintiffs were required to segregate

Perhaps most striking, however, is courts' endorsement of the application of the integration mandate to settings beyond institutions. Indeed, *Olmstead* jurisprudence reflects an emphasis on averting "the risk of segregation and isolation *within the community*."¹⁹⁵ DOJ guidance has aided courts in taking this approach by expanding upon the characteristics of an integrated setting versus a segregated one:

Integrated settings are located in mainstream society; offer access to community activities and opportunities at times, frequencies and with persons of an individual's choosing; afford individuals choice in their daily life activities; and, provide individuals with disabilities the opportunity to interact with non-disabled persons to the fullest extent possible. . . . By contrast, segregated settings often have qualities of an institutional nature. Segregated settings include, but are not limited to: (1) congregate settings populated exclusively or primarily with individuals with disabilities; (2) congregate settings characterized by regimentation in daily activities, lack of privacy or autonomy, policies limiting visitors, or limits on individuals' ability to engage freely in community activities and to manage their own activities of daily living; or (3) settings that provide for daytime activities primarily with other individuals with disabilities.¹⁹⁶

Notably, this guidance looks beyond the services' specific setting to whether the services promote values like privacy, autonomy, choice, and the ability to develop meaningful relationships with those without disabilities in the community. This has meant, as the Seventh Circuit noted in *Steimel v. Wernert*, that while *Olmstead* "dealt only with the problem of unjustified institutional segregation[,] . . . [i]ts rationale . . . reaches more broadly."¹⁹⁷

Accordingly, courts have held that segregating individuals with disabilities in employment settings like sheltered workshops violates the integration mandate.¹⁹⁸ School systems that create separate programs that

themselves by entering an institution before they could challenge an allegedly discriminatory law or policy"). The Fifth Circuit is a notable exception in departing from this well-established precedent. See *United States v. Mississippi*, 82 F.4th 387, 392 (5th Cir. 2023) (holding that "the ADA does not define discrimination in terms of a prospective risk to qualified disabled individuals").

195. Chin, *supra* note 36, at 389 (pointing to DOJ guidance and collecting cases in which courts have applied an expanded definition of the integration mandate as applying outside the confines of institutional walls).

196. 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.*, DOJ (June 22, 2021), http://www.ada.gov/olmstead/q&a_olmstead.htm [<https://perma.cc/6L5K-ZBQT>] [hereinafter DOJ *Olmstead* Statement].

197. 823 F.3d at 910.

198. See, e.g., *Ball ex rel. Burba v. Kasich*, 244 F. Supp. 3d 662, 679 (S.D. Ohio 2017) ("[F]ederal law has since clarified that the integration mandate that applies to residential

isolate students with disabilities also violate the integration mandate.¹⁹⁹ In some cases, even isolation in one's own home can violate the integration mandate.²⁰⁰ As the court noted in *Steimel*, the Supreme Court's goal was to prevent the "evils" of unjustified isolation in an institution, namely: (1) pernicious assumptions about the capability or worthiness of institutionalized people with disabilities to participate in community life and (2) the loss of opportunities to engage in everyday life activities, develop social relationships, attain economic independence, and participate in cultural enrichment.²⁰¹ The *Steimel* court argued that those "evils" could "exist in some settings outside of an institution."²⁰² Indeed, "isolation in [the] home may often be worse than confinement to an institution on [virtually] every . . . measure of 'life activities' that *Olmstead* recognized."²⁰³

This expansive interpretation of the integration mandate has contributed to disability advocates' efforts to apply *Olmstead* to policies that restrict or isolate people with disabilities. For instance, disability law scholar Natalie Chin argues that group homes violate the integration mandate when they adopt "overprotective and punitive sexuality policies" that sexually isolate people with disabilities.²⁰⁴ Disability law scholar Leslie Salzman argues that the integration mandate could provide a way to challenge restrictive guardianship statutes that prevent people with disabilities from making "self-defining personal decisions" and deprive them of autonomy and opportunities to learn and develop their own decisionmaking abilities.²⁰⁵

The remainder of this Essay argues that the integration mandate can also be applied to policies that permit or mandate surveillance of people with disabilities. Part III provides three examples of such surveillance and

services applies to employment and day programs as well."); *Guggenberger v. Minnesota*, 198 F. Supp. 3d 973, 1026–27 (D. Minn. 2016) (interpreting the integration mandate as applying across a wide array of settings); *Jensen v. Minn. Dep't of Hum. Servs.*, 138 F. Supp. 3d 1068, 1072–73 (D. Minn. 2015) (approving the state's court-ordered amended "*Olmstead* Plan" aimed at making supported employment services for people with developmental disabilities more integrated); *Lane v. Kitzhaber*, 841 F. Supp. 2d 1199, 1205 (D. Or. 2012) (finding an expansive definition of the integration mandate appropriate given "the broad language and remedial purposes of the ADA, the corresponding lack of any limiting language in either the ADA or the integration mandate itself, and the lack of any case law restricting the reach of the integration mandate" (footnote omitted)).

199. See, e.g., *United States v. Georgia*, 461 F. Supp. 3d 1315, 1324–25 (N.D. Ga. 2020) (declining to dismiss proceedings, on the basis that the United States had sufficiently alleged that Georgia's educational program violated the integration mandate).

200. *Guggenberger*, 198 F. Supp. 3d at 1029 (holding that lack of service provision to disabled persons living in their own homes could plausibly contribute to "isolation and segregation" by preventing those persons from fully participating in the community).

201. See *Steimel*, 823 F.3d at 910.

202. See *id.*

203. *Id.* at 911 (quoting *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 601 (1999)).

204. Chin, *supra* note 36, at 431.

205. See Salzman, *supra* note 36, at 170.

demonstrates how ableist ideas of disability are translated into surveillance policies that are carceral in nature, depriving the people subject to them of privacy and autonomy, physically restricting their ability to access the community, and increasing their risk of institutionalization. Part IV then demonstrates how the integration mandate and *Olmstead* jurisprudence can be used to address and dismantle ableist surveillance practices.

III. ABLEIST SURVEILLANCE SYSTEMS

This Part argues that the carceral logic that once justified the institutionalization of people with disabilities continues to permeate modern surveillance policies. It tracks three examples of policies mandating the surveillance of people with disabilities in community-based settings: electronic monitoring devices in group homes, the use of Electronic Verification Systems in private residences, and threat-assessment processes in public schools. In each of these settings, surveillance is deployed with laudable goals, namely, protecting vulnerable people with disabilities from abuse and neglect, preventing the fraudulent use of limited Medicaid funds, and preventing acts of mass violence in schools. Turning to surveillance to achieve these goals, however, results in coercive social control and further marginalizes and isolates people with disabilities.

A. *Carceral Ableism and Surveillance in Group Homes*

On August 28, 2017, William Cray, a thirty-three-year-old man with I/DD living in a group home in Somers Point, New Jersey, was found dead on the floor of his bedroom closet.²⁰⁶ An autopsy concluded that Cray had died of natural causes. In the months before his death, however, his mother, Martha Cray, had raised her concerns about unexplained bruises and injuries on his body with the operators of the state-licensed group home.²⁰⁷ Although state agencies investigated these prior injuries, they always found the claims to be unsubstantiated.²⁰⁸ Since her son's death, Martha Cray has pushed for additional oversight of group home residents, including the installation of electronic monitoring devices in group homes.²⁰⁹

206. Susan K. Livio, *Her Disabled Son Died Alone in a Group Home Closet. Now N.J. May Require Group Homes to Install Cameras.*, NJ.com (Dec. 14, 2020), <https://www.nj.com/politics/2020/12/her-disabled-son-died-alone-in-a-group-home-closet-now-nj-may-require-group-homes-to-install-cameras.html> [<https://perma.cc/5M9L-TM26>].

207. *Id.*

208. *Id.*

209. Dana DeFilippo, *Advocates Demand Cameras in Homes for Developmentally Disabled Adults to Reduce Abuse*, N.J. Monitor (Dec. 5, 2022), <https://newjerseymonitor.com/2022/12/05/advocates-demand-cameras-in-homes-for-developmentally-disabled-adults-to-reduce-abuse/> [<https://perma.cc/78EA-XZZ5>].

People with disabilities, particularly intellectual and developmental disabilities, are vulnerable to abuse and neglect.²¹⁰ Such abuse can take place in spaces inaccessible to members of the public, like group homes.²¹¹ For states to receive federal Medicaid funding under the Home and Community-Based Services (HCBS) waiver,²¹² group home service providers must comply with rules developed by Centers for Medicare and Medicaid Services (CMS), a federal agency that administers the Medicaid program, and with state regulations aimed at preventing abuse and neglect.²¹³ Each state must give CMS specific information about the safeguards it has put in place to prevent abuse and neglect, including whether it operates a critical-event- or incident-reporting system.²¹⁴ States must provide specific information about how group homes will report and

210. See, e.g., Joseph Shapiro, *The Sexual Assault Epidemic No One Talks About*, NPR (Jan. 8, 2018), <https://www.npr.org/2018/01/08/570224090/the-sexual-assault-epidemic-no-one-talks-about> [<https://perma.cc/PJN8-E52E>] (“[Unpublished DOJ data] show that people with intellectual disabilities . . . are the victims of sexual assaults at rates more than seven times those for people without disabilities. It’s one of the highest rates of sexual assault of any group in America, and it’s hardly talked about at all.”). A 2013 study by the Spectrum Institute Disability and Abuse Project found that 70% of the 7,289 respondents who took the Institute’s national survey reported experiencing some form of abuse or neglect. See Nora J. Baladerian, Thomas F. Coleman & Jim Stream, *Spectrum Inst. Disability & Abuse Project, Abuse of People With Disabilities: Victims and Their Families Speak Out 1, 3* (2013), <https://tomcoleman.us/publications/2013-survey-report.pdf> [<https://perma.cc/9B6B-YQSH>].

211. See Michael J. Berens & Patricia Callahan, *In Illinois Group Homes, Adults With Disabilities Suffer in Secret*, *Chi. Trib.* (Nov. 21, 2016), <https://www.chicagotribune.com/investigations/ct-group-home-investigations-cila-met-20161117.htmlstory.html> (on file with the *Columbia Law Review*) (“The Tribune found at least 42 deaths linked to abuse or neglect in group homes or their day programs over the last seven years.”); Benjamin Weiser & Danny Hakim, *Residents Cowered While Workers at a Group Home Smacked and Pushed Them*, *N.Y. Times* (June 9, 2019), <https://www.nytimes.com/2019/06/09/nyregion/new-york-group-home-abuse.html> (on file with the *Columbia Law Review*) (reporting that group home employees found to have committed abuse-related offenses at group homes were frequently “put back on the job”).

212. 42 U.S.C. § 1396n(c) (2018). The HCBS waiver program permits a state to provide home and community-based services to make it possible for people to live within the community rather than in an institution. Home & Community-Based Services 1915(c), <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html> [<https://perma.cc/T49Y-23ET>] (last visited Nov. 4, 2023). States like Arizona that provide community-based services under section 1115 of the Social Security Act (SSA), a provision that permits states to be exempt from certain provisions of the SSA, must also comply with CMS rules pertaining to the reporting of incidents of abuse and neglect. 42 U.S.C. § 1315.

213. 42 C.F.R. § 441.302 (2022).

214. See HHS Off. of Inspector Gen., *Admin. for Cmty. Living & HHS Off. for C.R., Joint Report: Ensuring Beneficiary Health and Safety in Group Homes Through State Implementation of Comprehensive Compliance Oversight 5* (2018), <https://www.oig.hhs.gov/reports-and-publications/featured-topics/group-homes/group-homes-joint-report.pdf> [<https://perma.cc/52KG-G935>] [hereinafter HHS, *Joint Report: Group Homes*].

address critical incidents of abuse and neglect and must establish an investigation process.²¹⁵ Critical incidents that require a major level of review include deaths, physical and sexual assaults, unplanned hospitalizations, and serious injuries.²¹⁶ Despite these reporting requirements, group homes and community-based providers frequently fall short of their obligations to report critical incidents to be investigated.²¹⁷

To address public concern about the protection of vulnerable people, some states have introduced legislation that permits the installation of electronic monitoring devices (EMDs), like “granny cams,” in group homes.²¹⁸ Bills to this effect were proposed in New Jersey²¹⁹ (Mr. Cray’s state of residence) and Massachusetts.²²⁰ These bills’ proponents see EMDs as a simple way to ensure a certain level of care in group homes—a form of consumer empowerment.²²¹

Arizona is one state that has actually enacted legislation permitting group home service providers to install EMDs in group home common areas.²²² State Senator Nancy Barto, sponsor of Arizona’s bill, touted the legislation’s benefits: “By allowing video monitoring systems within [group homes], we will be able to give families peace of mind, accountability, [and] transparency, and potentially stop life-threatening conduct in its tracks.”²²³

215. See *id.*

216. *Id.* at 6 (“Critical incidents requiring a major level of review generally include deaths, physical and sexual assaults, suicide attempts, unplanned hospitalizations, near drowning, missing persons, and serious injuries. Critical incidents requiring a minor level of review generally include suspected verbal or emotional abuse, theft, and property damage.”).

217. See *id.* at 7 (providing information on reporting failures in Connecticut, Maine, and Massachusetts as well as examples of unreported critical incidents).

218. See Karen Levy, Lauren Kilgour & Clara Berridge, *Regulating Privacy in Public/Private Space: The Case of Nursing Home Monitoring Laws*, 26 *Elder L.J.* 323, 335 (2019) (noting that Illinois, Louisiana, New Mexico, Texas, Utah, and Washington have laws and regulations permitting the installation of EMDs in nursing facilities).

219. See Billy Cray’s Law, Gen. Assemb. 4013, 219th Leg., 2020–2021 Sess. (N.J. 2020).

220. See An Act Relative to Ensuring the Safety of Residents of Facilities Under the Authority of the Department of Mental Health and the Department of Developmental Services, H.R. 158, 191st Gen. Ct., Reg. Sess. (Mass. 2019).

221. See, e.g., Billy Cray’s Law, Gen. Assemb. 5676, 220th Leg., 2022–2023 Sess. § 2(d) (N.J. 2023) (“The use of video surveillance in group homes . . . will enable consenting residents and their authorized representatives to more proactively and effectively review and ensure the propriety of care that is being provided to such residents . . .”).

222. Ariz. Rev. Stat. Ann. § 36-568 (2023).

223. Press Release, Ariz. State Senate Republican Caucus, Sen. Barto Strengthens Transparency and Oversight Inside Group Homes for Arizona’s Most Vulnerable (May 24, 2022), <https://www.azsenaterepublicans.com/post/sen-barto-strengthens-transparency-and-oversight-inside-group-homes-for-arizona-s-most-vulnerable> [https://perma.cc/3EK7-NC9N] [hereinafter Ariz. Senate Republican Caucus Press Release] (internal quotation marks omitted) (quoting Sen. Barto).

The legislation outlines two ways in which EMDs may be introduced in an Arizona group home setting. First, a service provider that operates a group home, referred to in the legislation as a “qualified vendor,”²²⁴ may install, oversee, and monitor EMDs, defined as video surveillance cameras and audio devices,²²⁵ in a group home’s common areas “unless any client or the client’s responsible person objects to the installation of the electronic monitoring devices.”²²⁶ These devices may be installed in virtually any common space, including kitchens, living areas, employment spaces, and day program facilities.²²⁷ The regulations give the service provider broad latitude to determine which personnel may access the recordings and under what circumstances and to train staff on the need to comply with HIPAA and maintain confidentiality.²²⁸ Alternatively, a group home resident or their “responsible person” must be allowed to install and pay for EMDs if they wish to do so.²²⁹ These devices may be installed in residents’ bedrooms.²³⁰ The qualified vendor may not turn EMDs off, move them, cover them, or otherwise obscure their ability to have “full view of the area chosen by the Responsible Person.”²³¹

As Senator Barto’s comments indicate, this kind of surveillance is intended to protect vulnerable group home residents by “potentially stopping life-threatening conduct in its tracks.”²³² As disability and feminist scholars have noted, however, being cast as vulnerable is a double-edged sword.²³³ It can trigger a host of “‘toxic associations’” that position

224. Ariz. Rev. Stat. Ann. § 36-551(41).

225. *Id.* § 36-568(A), (F).

226. *Id.* § 36-568(A). “Responsible person,” for an adult resident of a group home, is defined as “the guardian of an adult with a developmental disability or an adult with a developmental disability who is a client or an applicant for whom no guardian has been appointed.” *Id.* § 36-551(40). If a guardian has been appointed, they have the power to consent or withdraw consent to the installation of EMDs. See *id.* § 36-568(A).

227. See *id.* § 36-568(A); see also Div. of Dev. Disabilities, Dep’t of Econ. Sec., Provider Manual, Chapter 42: Electronic Monitoring in Program Sites 1 (2023), https://des.az.gov/sites/default/files/media/DDD_Provider_Manual_Chapter_42_Electronic_Monitoring_in_Program_Sites.pdf [<https://perma.cc/2P9X-E4EV>] [hereinafter Ariz. Dep’t of Econ. Sec., Electronic Monitoring] (defining “common area” as “a room, including a hallway that is designed for use by multiple individuals, including residents”).

228. See Ariz. Rev. Stat. Ann. § 36-568(C)(4)–(8) (requiring facility directors to “adopt rules regarding the use of electronic monitoring” in relation to the discussed categories); see also Ariz. Dep’t of Econ. Sec., Electronic Monitoring, *supra* note 227, at 6 (“[The] Qualified Vendor shall . . . [s]pecify in policy how Electronic Monitoring Device recordings, regardless of format, will be secured to protect the confidentiality of residents . . .”).

229. Ariz. Rev. Stat. Ann. § 36-568(B).

230. Ariz. Dep’t of Econ. Sec., Electronic Monitoring, *supra* note 227, at 9.

231. *Id.*

232. Ariz. State Senate Republican Caucus Press Release, *supra* note 223.

233. See, e.g., Shelley Bielefeld, Cashless Welfare Transfers for ‘Vulnerable’ Welfare Recipients: Law, Ethics and Vulnerability, 26 *Feminist Legal Stud.* 1, 2 (2018) (“The phrase ‘vulnerability’ is increasingly used across a range of law and policy areas, . . . yet there is

those characterized as vulnerable as being “immature, weak, helpless, passive, and ‘unusually open to manipulation and exploitation,’” turning those individuals into “‘stigmatized subjects.’”²³⁴ Given the negative associations with vulnerability—immaturity, weakness, passivity, and exploitability—“the more vulnerable a disabled person is believed to be, the less likely it is that others will treat the choices [they] make[] or opinions [they] hold[] as worthy of respect.”²³⁵ The notion of vulnerability can thus be used in a manner that both socially and politically marginalizes people with disabilities. Professor Liat Ben-Moshe uses the term “carceral ableism” to describe protective measures like these that are undertaken to protect people with disabilities but result in further marginalization and isolation.²³⁶

The dynamic of marginalizing group home residents’ opinions and perspectives in the name of protection can be seen at play within this piece of legislation, particularly in how it treats consent.²³⁷ Arizona’s EMD statute simply does not do enough to ensure that group home residents’ opinions are sufficiently solicited and protected.²³⁸ The statute hinges on consent—that is, a person or their “responsible person,” who may be a legal guardian, can either choose to or refuse to consent to the installation of EMDs.²³⁹ But consent is a complex issue, especially for people with significant disabilities. Some people with disabilities may not understand the implications of consenting to these measures or be able to effectively communicate their consent or lack thereof. Others may feel pressure to agree to surveillance from their “responsible people” or other residents.²⁴⁰

concern about how this term can result in disempowerment for those to whom it is applied.”).

234. *Id.* at 4 (internal quotation marks omitted) (first quoting Jackie Leach Scully, Disability and Vulnerability: On Bodies, Dependence, and Power, *in* Vulnerability: New Essays in Ethics and Feminist Philosophy 204, 210, 219 (Catriona Mackenzie, Wendy Rogers & Susan Dodds eds., 2014); then quoting Martha Albertson Fineman, The Vulnerable Subject: Anchoring Equality in the Human Condition, 20 *Yale J.L. & Feminism* 1, 8 (2008)).

235. Jackie Leach Scully, Disability and Vulnerability: On Bodies, Dependence, and Power, *in* Vulnerability: New Essays in Ethics and Feminist Philosophy 204, 209–210 (Catriona Mackenzie, Wendy Rogers & Susan Dodds eds., 2014).

236. See Ben-Moshe, Decarcerating Disability, *supra* note 12, at 17.

237. Senator Barto’s comments make clear that the purpose of the legislation is to grant families, not group home residents themselves, “peace of mind.” See *Ariz. State Senate Republican Caucus Press Release*, *supra* note 223.

238. Sociologist Karen Levy and her coauthors observe that in the context of nursing facilities, some states include measures that require court intervention before installing EMDs. See Levy et al., *supra* note 218, at 350 (discussing Washington State’s requirement that a representative may consent on a resident’s behalf only after receiving authorization from a court order). Arizona’s legislation does not require that additional oversight.

239. See *Ariz. Rev. Stat. Ann.* § 36-568(A) (2023) (“A service provider . . . may install [EMDs] . . . unless any client or the client’s responsible person objects to the installation of the electronic monitoring devices.”).

240. Written Testimony on Bill A4013 (Billy Cray’s Law) from Gwen Orlowski, Exec. Dir., Disability Rights N.J., to N.J. Assembly Hum. Servs. Comm. (Dec. 10, 2020),

The statute offers no protections to ensure that the person has provided informed consent free from coercion or pressure.²⁴¹ And those with guardians may disagree with the decision made by their “responsible [people]” but have their wishes overridden.²⁴² The legislation and its accompanying rules do not clarify whose view will prevail if the person disagrees with their “responsible person.”²⁴³ This creates the potential for new vulnerabilities that the statute does not account for—namely, the risk that the responsible person could dismiss the person’s privacy preferences, coerce them into agreement, or use the information collected by EMDs in abusive ways.²⁴⁴

Further, designating populations as “vulnerable” can facilitate the enactment of measures that undermine the autonomy, rights, and self-determination of people cast as requiring those additional protections.²⁴⁵ Group homes are part of the continuum of community-based placements and services for people with I/DD and psychiatric disabilities.²⁴⁶ They play a critical role in filling a gap in housing for people with severe disabilities who may struggle to find appropriate community-based

<https://disabilityrightsnj.org/wp-content/uploads/12102020-Assembly-Testimony-A4013-Billy-Crays-Law.pdf> [<https://perma.cc/N3C2-SKS3>] [hereinafter DRNJ Testimony]. The then-Executive Director of Disability Rights New Jersey, Gwen Orlowski, raised this concern with respect to Billy Cray’s Law, arguing that the “consent structure” contemplated by the law—namely, the requirement that consent to the installation of EMD is unanimous among residents—“creates a hostile environment” whereby the individual may be subject to “coercion from providers and housemates to accept EMDs if the majority requests them.” *Id.*

241. Ariz. Rev. Stat. Ann. § 36-568.

242. The definition of “responsible person” is extremely unclear. See *id.* § 36-551 (40) (defining “[r]esponsible person” as “the parent or guardian of a minor with a developmental disability, the guardian of an adult with a developmental disability or an adult with a developmental disability who is a client or an applicant for whom no guardian has been appointed”). One interpretation of the provision is that the term applies to “the guardian of an adult with a developmental disability” or “[the guardian of] an adult with a developmental disability who is a client” or an applicant for whom no guardian has been appointed. See *id.* In this case, the guardian’s view prevails unless no guardian has been appointed. An alternate interpretation is that “responsible person” refers to both the “guardian of an adult with a developmental disability” and the adult with a developmental disability who is a “client,” defined by the statute as a recipient of services. See *id.* § 36-551 (14). If this interpretation is correct, a group home resident with a guardian may be able to argue that they are their own “responsible person.” Even if this is the case, the legislation appears to presume that the person and their guardian will share the same opinion and does not clarify whose view will prevail if disagreement arises.

243. *Id.* § 36-551 (40).

244. Levy et al., *supra* note 218, at 362 (noting that laws that fail to address the potential for conflict in decisions about camera use exacerbate the risk of abuse by family members who install cameras in nursing facilities).

245. See Scully, *supra* note 235, at 209–10.

246. See HHS, Joint Report: Group Homes, *supra* note 214, at 1.

accommodation.²⁴⁷ Although group homes may be staffed for twenty-four hours per day, they are meant to “provide many individuals with greater independence, the choice to live in the community, and access to other opportunities.”²⁴⁸ Permitting surveillance systems to be installed in group homes profoundly compromises group home residents’ ability to make autonomous and independent decisions about whom they interact with and how they do so. As disability scholars Anita Ho, Tim Stainton, and Anita Silvers write:

Surveillance by its very nature can give others access to an individual’s inner space, and the idea of being targeted may stimulate self-consciousness. People may feel demeaned when their seclusion or personal space is penetrated by uninvited spectators’ eyes, and their development as persons may thereby be stultified. This experience of being violated may cast a chilling pall over the target subject’s capacity to trust and become a deterrent to intimacy. . . . And it may have a chilling effect on the person’s feeling free to form moral, political, and religious beliefs and to associate with others who embrace similar values and views.²⁴⁹

Arizona’s EMD legislation prevents people from deciding even when and where they can be *seen*.²⁵⁰ This constant monitoring, although intended to be protective, could be experienced as a “debilitating restriction”²⁵¹ on the lives and relationships of group home residents.²⁵²

A troubling element of carceral protectionism is the potential of protective measures to result in further harm to the very people they are

247. See *id.* (“[C]ommunity-based settings, such as group homes, provide many individuals with greater independence, the choice to live in the community, and access to other opportunities.”).

248. *Id.*

249. Anita Ho, Anita Silvers & Tim Stainton, Continuous Surveillance of Persons With Disabilities: Conflicts and Compatibilities of Personal and Public Goods, 45 *J. Soc. Phil.* 348, 355 (2014) (footnote omitted).

250. See *supra* notes 224–231 and accompanying text.

251. George Yancy, Institutions Often Treat Disability and Mental Health Not With Care but Violence, *Truthout* (June 15, 2023), <https://truthout.org/articles/institutions-often-treat-disability-and-mental-health-not-with-care-but-violence/> [<https://perma.cc/2S34-QD7V>].

252. Christina Quinn, The Group Home Surveillance Camera Debate, *GBH* (July 23, 2012), <https://www.wgbh.org/news/politics/2012-07-23/the-group-home-surveillance-camera-debate> [<https://perma.cc/254E-Q88N>] (last updated Feb. 11, 2016) (“[I]magine the entire first floor of your home with a camera in every room: the living room, dining room, hallway and kitchen. Essentially the entire first floor of the house would resemble the set of the TV show ‘Big Brother.’”); see also *DRNJ Testimony*, *supra* note 240 (“EMDs that monitor the individual’s movements and activities in living quarters violate the privacy of the individual. . . . [I]magine being under constant surveillance while in your kitchen or living room attending to everyday activities. . . . [C]urrent CMS rules prohibit EMDs regardless of resident consent.”).

meant to protect.²⁵³ In this case, surveillance in group homes may be turned onto people within the group home who engage in disability-related behaviors to exclude or punish them. The information gathered could, for instance, be used as justification to exclude people who exhibit “inappropriate” behaviors. Indeed, proposed legislation in New Jersey explicitly permits “family members to promptly identify and respond to wrongdoing that may be committed by caregivers, guardians, staff, and *other persons* at the home.”²⁵⁴ Arizona’s legislation does not restrict how surveillance footage may be used, particularly when EMDs are installed by family members. Accordingly, there is a real risk that surveilled group home residents will be penalized for engaging in disability-related behavior. At its most extreme, pharmaceutical or physical restraints could be used to manage the “risky” behavior of people with disabilities.²⁵⁵

B. *Surveillance and “Dis Inc.”*

The political economy framework provides a helpful way to understand the surveillance of people with disabilities who receive public benefits. As disability scholars Marta Russell and Ravi Malhotra wrote, disabled bodies form a “central contradiction of capitalism.”²⁵⁶ On the one hand, policymakers perceive people with disabilities as a drain on resources.²⁵⁷ When states need to tighten their belts, governments narrow the definition of “disability” and cut social programs.²⁵⁸ Under this construction of disability, they justify surveillance of the disabled to control how and to whom resources are allocated.²⁵⁹ Conversely, disability also *supports* the economy. Scholars and activists like Angela Davis and Ruth Gilmore Wilson have expounded on the notion of the prison–industrial complex.²⁶⁰ Corporations associated with this “punishment industry”

253. See Krystle Shore, Targeting Vulnerability With Electronic Location Monitoring: Paternalistic Surveillance and the Distortion of Risk as a Mode of Carceral Expansion, 29 *Critical Criminology* 75, 81 (2021) (arguing that protective surveillance practices “often retain[] coercive elements and may ultimately contribute to a strengthening of state power through processes of carceral expansion”).

254. Gen. Assemb. 5676, 220th Leg., 2022–2023 Sess. § 2(b) (N.J. 2023) (emphasis added).

255. See Ho et al., *supra* note 249, at 359–60 (noting that “the promised institutional benefit of security that continuous surveillance might bring must be assessed against the potential for the targets of scrutiny being harmed by institutional responses”).

256. Marta Russell & Ravi Malhotra, Capitalism and the Disability Rights Movement, *in* *Capitalism and Disability: Selected Writings by Marta Russell* 9, 9 (Keith Rosenthal ed., 2019).

257. See *id.* at 10 (discussing how disabled people were excluded from the workplace because they could not add to their employer’s net profits).

258. *Id.* at 11.

259. Ben-Moshe, Decarcerating Disability, *supra* note 12, at 11–13.

260. See Angela Y. Davis, Are Prisons Obsolete? 12, 14 (2003) (“Because of the extent to which prison building and operation began to attract vast amounts of capital—from the construction industry to food and health care provision—in a way that recalled the

reap profits and acquire a stake in continuing and preserving these incarceration sites.²⁶¹ In the same way, the interaction of “disability incarcerated” and “Disability Incorporated,” or “Dis Inc.,” a term coined by Ben-Moshe, commodifies disability and funds the carceral sites and practices that are developed to “support” the disabled, including prisons, hospitals, and nursing homes—creating a disability–industrial complex.²⁶² The disabled body is commodified so that, as Russell and Malhotra observe, “social policies get created or rejected according to their market value.”²⁶³ In other words, public and private interests may collude to shape and benefit from these policies.

These conflicting narratives about disability can be observed in federal legislation that requires states to adopt EVV systems to monitor disabled peoples’ use of Medicaid funds. In December 2016, Congress signed the 21st Century Cures Act (Cures Act) into law.²⁶⁴ The legislation’s purpose was manifold: to develop an accelerated way for the FDA to approve prescription drugs and medical devices, to fund various biomedical research programs, and to equip states to fight the opioid crisis.²⁶⁵ The Cures Act also included a spate of Medicare and Medicaid reforms, including section 12006(a), which mandates that states implement EVV systems to track all Medicaid-funded home healthcare services and personal care systems.²⁶⁶ The requirement to implement EVV has been called “the biggest federal public health initiative since the Affordable Care Act,” affecting millions of people receiving community-based personal care services and hundreds of thousands of workers.²⁶⁷

Medicaid is jointly financed by the federal government and the states.²⁶⁸ While Medicaid funding for long-term care and support was historically directed toward institutional settings like nursing homes, this

emergence of the military industrial complex, we began to refer to a ‘prison industrial complex.’” (quoting Mike Davis, *Hell Factories in the Field: A Prison-Industrial Complex*, *Nation*, Feb. 20, 1995, at 260)).

261. See *id.* at 16.

262. See Ben-Moshe, *Decarcerating Disability*, *supra* note 12, at 11–14 (arguing that the rise of the prison–industrial complex coincided with the deinstitutionalization of mental health).

263. Russell & Malhotra, *supra* note 256, at 11.

264. See 21st Century Cures Act, Pub. L. No. 114-255, 130 Stat. 1033 (2016) (codified as amended in scattered titles of the U.S.C.).

265. Press Release, White House, Statement by the Press Secretary on H.R. 34 (Dec. 13, 2016), <https://obamawhitehouse.archives.gov/the-press-office/2016/12/13/statement-press-secretary-hr-34> [<https://perma.cc/23J7-W6ZV>].

266. See 21st Century Cures Act sec. 12006(a), 130 Stat. at 1275.

267. Agency Workforce Mgmt., *EVV Rules Across the USA 1*, <https://mitcagen.cies.com/wp-content/uploads/2021/02/EVV-Rules-Across-the-USA-eBook.pdf> [<https://perma.cc/JH9G-3NLZ>] (last visited Oct. 4, 2023).

268. See Elizabeth Williams, Robin Rudowitz & Alice Burns, *Medicaid Financing: The Basics*, KFF (Apr. 13, 2023), <https://www.kff.org/medicaid/issue-brief/medicaid-financing-the-basics/> [<https://perma.cc/9R6Z-7BK5>].

trend has changed over the past decade.²⁶⁹ The majority of Medicaid spending has shifted to home and community-based services, including personal care services (PCS).²⁷⁰ PCS are critical to providing community-based care to people of all ages who, because of disability, require assistance with performing activities of daily living, including bathing, dressing, toileting, and grocery shopping.²⁷¹

In a 2017 statement submitted to the House of Representatives Subcommittee on Oversight and Investigations, the U.S. Government Accountability Office (GAO) reported that different systems employed by states across various programs resulted in inconsistent reporting from states, making it difficult to identify potential fraud and abuse.²⁷² The GAO concluded that “[p]ersonal care services are at high risk for improper payments[,] and beneficiaries may be vulnerable and at risk of unintentional harm.”²⁷³ To address this problem, the GAO recommended that CMS take steps to “harmonize and achieve a more consistent application of program requirements.”²⁷⁴

To increase federal oversight of PCS programs operated by states, section 12006(e) of the Cures Act, which added section 1903(l) to the Social Security Act, mandates that each visit made by a Medicaid-funded home healthcare aide or PCS provider to assist a consumer with a disability be tracked through an EVV system.²⁷⁵ Specifically, states must implement EVV systems that capture the following pieces of information: (1) the type of service performed, (2) the individual receiving the service, (3) the date of the service, (4) the location of service delivery, (5) the individual providing the service, and (6) the time the service begins and ends.²⁷⁶ Guidance from CMS describes EVV as “a critical component of states’ fiscal integrity processes and oversight.”²⁷⁷ In short, payment for the services is contingent on the accurate recording of these services. If states fail to implement an EVV system, they risk losing millions of dollars in Medicaid funding.²⁷⁸

269. See Combating Waste, Fraud, and Abuse in Medicaid’s Personal Care Services Program: Hearing Before the Subcomm. on Oversight & Investigations of the H. Comm. on Energy & Com., 115th Cong. 30 (2017) (prepared statement of Katherine M. Iritani, Dir., Health Care, Gov’t Accountability Off.).

270. See *id.*

271. See *id.* at 30–31.

272. See *id.* at 48.

273. *Id.* at 51.

274. *Id.* at 45.

275. See 42 U.S.C. § 1396b(l) (2018).

276. See *id.* § 1396b(l)(5).

277. Ctrs. for Medicare & Medicaid Servs., 1915(c) Home and Community-Based Waiver Application Job Aid 2 (2022), <https://www.medicaid.gov/medicaid/home-community-based-services/downloads/documenting-ewv.pdf> [<https://perma.cc/W2DD-6ZNQ>].

278. 42 U.S.C. § 1396b(l)(1).

Despite the significant stakes, neither the Cures Act nor CMS guidance have clearly explained how EVV systems should be implemented.²⁷⁹ As a result, states have wide latitude to determine how they will gather this information.²⁸⁰ Because EVV's legislative goal is to address fraud, several states have adopted EVV systems that have broad capabilities to capture and monitor all consumer and provider activities.²⁸¹ Some states have implemented EVV systems that use global positioning systems (GPS) to track service providers' locations.²⁸² Another method used to gather the information required by the Cures Act involves the use of biometric voice-authentication systems that require the worker or consumer to log in and out by calling from a cellular or landline device.²⁸³

Legislation mandating the use of EVV systems is a striking manifestation of the narratives of fraud and the disability con that have always haunted benefits payments to people with disabilities.²⁸⁴ The rhetoric used to promote EVV is that of rampant PCS fraud.²⁸⁵ And yet there is little evidence of this rampant fraud.²⁸⁶ In states like California, with the largest

279. Section 12006(c)(2) of the Cures Act provides that “[n]othing in the amendment made by this section shall be construed to require the use of a particular or uniform electronic visit verification system . . . by all agencies or entities that provide personal care services or home health care under a State Plan” or waiver under the SSA. 21st Century Cures Act, Pub. L. No. 114-255, sec. 12006(c)(2), 130 Stat. 1033, 1278 (2016).

280. See Mateescu, *supra* note 37, at 8 (noting that due to a lack of federal policy guidance, “[s]tate-level policies and technology design encoded far more invasive features into EVV systems than were required”).

281. See *id.* at 15–16.

282. See, e.g., Jacob Metcalf, *When Verification Is Also Surveillance*, Data & Soc’y: Points (Feb. 27, 2018), <https://medium.com/datasociety-points/when-verification-is-also-surveillance-21edb6c12cc9> [<https://perma.cc/5L6T-MPNY>] (analyzing Ohio’s implementation of EVV that sends users a device produced by data services company Sandata with cameras and microphones, which uses voice verification to confirm logged work and GPS to track service providers’ locations).

283. See *id.*

284. See Marta Russell, *Targeting Disability*, *Monthly Rev.* (Apr. 1, 2005), <https://monthlyreview.org/2005/04/01/targeting-disability/> [<https://perma.cc/65QM-BQ8J>] (“Over the years, hard-right critics of SSDI have deemed it rife with fraud. Congresspersons have spoken of the dilemma of disability ‘dependency’ and accused the program’s growth of being out of control.”).

285. See Ctr. for Medicaid & CHIP Servs., *Ctrs. for Medicare & Medicaid Servs., Leveraging Electronic Visit Verification (EVV) to Enhance Quality Monitoring and Oversight in 1915(c) Waiver Programs 17* (2020), <https://www.medicaid.gov/sites/default/files/2020-02/evv-enhance-quality.pdf> [<https://perma.cc/3BNK-GT5V>] (“EVV requirements were included in the Cures Act in response to long-standing fraud, waste, and abuse (FWA) concerns for Medicaid PCS and HHCS.” (emphasis omitted)).

286. *Electronic Visit Verification (EVV) Task Force Statement of Principles and Goals*, Nat’l Council on Indep. Living (Oct. 15, 2018), <https://www.ncil.org/wp-content/uploads/2018/10/10-15-18-EVV-Principles-and-Goals.pdf> [<https://perma.cc/DJX7-XHKQ>] [hereinafter *Task Force Statement of Principles and Goals*]. Disability groups like the National Council on Independent Living have argued that the legislation builds on a “[n]egative stereotype[] that individuals with disabilities who rely on benefits programs are malingerers.” *Id.*

direct care workforce, disability advocacy groups like the National Council on Independent Living note that the PCS fraud rate was extremely low—just 0.04% in 2014.²⁸⁷

The EVV policy is also an example of a policy driven by both public and private interests. As noted by scholars like Ben-Moshe and Russell, Dis Inc. and institutionalization go hand in hand.²⁸⁸ The adoption of EVV has contributed to the creation of a robust surveillance technology industry. While the state has traditionally been the key player in carrying out surveillance activities, private companies are playing a bigger role in marketing and developing surveillance tools.²⁸⁹ In this case, companies that develop EVV systems lobbied for EVV to be included within the Cures Act.²⁹⁰ One of these companies, Sandata Technologies, has contracted to be the state provider of EVV services for Arizona, Colorado, Connecticut, Hawaii, Idaho, Illinois, Indiana, Maine, Missouri, North Carolina, Ohio, Pennsylvania, Rhode Island, Tennessee, Vermont, Wisconsin, and the District of Columbia.²⁹¹ Surveilling the disabled is clearly a lucrative business, and these entities have every incentive to continue this surveillance.²⁹²

PCS surveillance has isolated and segregated people with disabilities in their own homes. GPS tracking and “geofencing”²⁹³ discourage people

287. Mateescu, *supra* note 37, at 16. When Medicaid fraud is identified, institutional rather than individual actors tend to be the perpetrators behind the high-profile cases. *Id.* Rather than focusing on institutional accountability and liability, however, the Cures Act places the onus on individual workers and their clients. See *id.*

288. See Ben-Moshe, *Decarcerating Disability*, *supra* note 12, at 11–13; Russell & Malhotra, *supra* note 256, at 11.

289. See Virginia Eubanks & Alexandra Mateescu, ‘We Don’t Deserve This’: New App Places US Caregivers Under Digital Surveillance, *The Guardian* (July 28, 2021), <https://www.theguardian.com/us-news/2021/jul/28/digital-surveillance-caregivers-artificial-intelligence> [<https://perma.cc/XL8T-FLTR>] (discussing an increase in implementation of EVV, catalyzed in part by technology companies and lawmakers’ contentions that EVV would improve home care by increasing efficiency and reducing abuse).

290. See Kendra Scalia, *Electronic Visit Verification (EVV) Is Here*, Disability Visibility Project (Mar. 24, 2019), <https://disabilityvisibilityproject.com/2019/03/24/electronic-visit-verification-evt-is-here/> [<https://perma.cc/2BLE-E39V>] (“[V]endors have done a decent job controlling much of the conversation . . . [arguing] that consumers and employers commit fraud on such a regular basis that only the most intrusive EVV systems will protect a state.”).

291. See Taylor Mallory Holland, *What Are the EVV Compliance Rules in Your State?*, Insights (July 19, 2021), <https://insights.samsung.com/2021/07/19/what-are-the-evt-compliance-rules-in-your-state-4/> [<https://perma.cc/767N-SW6R>].

292. See Scalia, *supra* note 290 (“[EVV vendors] are uniquely positioned to make billions of dollars selling their EVV products to states.”).

293. See Jane Lawrence, *Applied Self-Direction, Electronic Visit Verification (EVV): A Blueprint for Self-Direction 9* (2018), <https://www.appliedselfdirection.com/sites/default/files/EVV%20Blueprint%20for%20Self-Direction.pdf> [<https://perma.cc/4VYZ-35Y7>] (defining geofencing as “a virtual geographic boundary, defined by a global positioning system (GPS) or other technology, that enables software to trigger a response when a mobile device enters or leaves a particular area”).

and their aides from leaving their homes because of the risk that those entries will be flagged as fraudulent.²⁹⁴ For people who self-direct their services—that is, make their own decisions about whom to hire and what services they receive—EVV systems undermine the flexibility of self-direction by introducing rigid rules about when and where services must be provided.²⁹⁵ Punitive EVV systems unduly burden a workforce that is essential to the mission of ensuring that people can reside within the community rather than in institutions. Missed clock-ins or technical glitches can result in shifts being rejected or flagged for noncompliance, resulting in workers being inadequately paid for their time.²⁹⁶ The diminution of this workforce magnifies the threat of institutionalization of those who depend on that care to remain in the community.²⁹⁷

Attempts to roll back the scope of EVV systems to limit their intrusiveness have been met with resistance. In 2019, Disability Rights California and other advocates, collaborating with the California Department of Social Services, developed an EVV solution that expanded on the existing electronic timesheet system and permitted home care workers to manually enter the general location—“home” or “community”—where they provided services.²⁹⁸ CMS refused to approve the use of this less-invasive system on the basis that “such a system would not be sufficient for electronically verifying the six data elements” required by the Cures Act.²⁹⁹ Legislative attempts to limit the use of invasive surveillance technologies like GPS and biometric verification in EVV systems have also stalled.³⁰⁰ By December 2021, forty states had

294. See Eubanks & Mateescu, *supra* note 289 (“The EVV app incorporates GPS to verify a home care worker’s location and a feature called ‘geofencing’. It establishes a maximum distance around a client’s home inside which a care worker is allowed to clock in or out without getting flagged as noncompliant.”).

295. See *id.* (relating the problems EVV poses to people who self-direct their care).

296. See *id.* (“[One home care worker] downloaded the state’s EVV app . . . and began to use it. But it was frequently glitchy. Her 13-26 April timesheet was denied for ‘insufficient funds,’ which made no sense to [her client] . . . She was out \$900 for two weeks’ work.”).

297. See *id.* (noting the “freedom and stability” one home care worker provides her client).

298. See Mateescu, *supra* note 37, at 14; DRC Position on Electronic Visit Verification (EVV), Disability Rts. Cal. (Dec. 12, 2020), <https://www.disabilityrightsca.org/legislation/drc-position-on-electronic-visit-verification-evt> [<https://perma.cc/N243-DRJZ>] (last updated Feb. 2023).

299. Ctrs. for Medicare & Medicaid Servs., CMCS Informational Bulletin: Additional EVV Guidance 3 (2019), <https://www.medicaid.gov/sites/default/files/Federal-Policy-Guidance/Downloads/cib080819-2.pdf> [<https://perma.cc/7C4U-5AWN>].

300. See Cures 2.0 Act, H.R. 6000, 117th Cong. § 409 (2021) (“Section 1903(l)(5)(A) of the Social Security Act (42 U.S.C. 1396b(l)(5)(A)) is amended by inserting ‘(without the use of geographic tracking or biometrics)’ after ‘electronically verified.’”); H.R. 6000 (117th): Cures 2.0 Act, GovTrack, <https://www.govtrack.us/congress/bills/117/hr6000> [<https://perma.cc/4H25-DKF8>] (last visited Oct. 4, 2023) (indicating that the Cures 2.0 Act never received a vote).

implemented EVV systems, and all used GPS in some form.³⁰¹ Many states were also using biometric identification in their systems.³⁰² State agencies voiced concerns that “[t]he [surveillance-limiting] changes proposed [in a federal bill to modify the Cures Act] would further increase overall costs to the state and federal governments.”³⁰³ That revision has stalled, meaning that EVV in its current form is here to stay for the foreseeable future.

C. *Carceral Humanism, Surveillance, and “Dangerous” Behavior*

In the wake of school shooting incidents, school administrators, lawmakers, and impacted communities across the country have pushed for intense surveillance of students to promote school safety.³⁰⁴ Some states, like Florida, have introduced legislation mandating the creation and implementation of surveillance systems to identify any “threats” that may be present in schools. This legislation was spurred by the killing of seventeen people at Marjory Stoneman Douglas High School by a former student.³⁰⁵ The Marjory Stoneman Douglas Public Safety Commission (“the Commission”),³⁰⁶ which was established in the months after the shooting,³⁰⁷ concluded that there had been warning signs that had not

301. See Letter from Martha A. Roherty, Exec. Dir., Advancing States, Mary P. Sowers, Exec. Dir., Nat’l Ass’n of State Dirs. of Developmental Disabilities Servs. & Matt Salo, Exec. Dir., Nat’l Ass’n of Medicaid Dirs., to Reps. Diana DeGette & Fred Upton (Dec. 31, 2021), https://medicaiddirectors.org/wp-content/uploads/2022/02/State-Associations-Request-Removal-of-EVV-GPS-Ban-from-21st-Century-Cures-Act_pdf.pdf [<https://perma.cc/P3AA-XVCT>] [hereinafter State Associations Letter].

302. See *id.* (referencing “[s]tates using certain biometric features, such as fingerprint or voice verification”).

303. *Id.*

304. See, e.g., Shawna Reid & Jamie Braun, Fla. Dep’t of Educ., Florida Schools Safety Portal & Safety Monitoring 4 (2019), <http://www.fdle.state.fl.us/MSDHS/Meetings/2019/August/August-15-200pm-Florida-Schools-Safety-Presentation.aspx> [<https://perma.cc/7ZCK-U73E>] (describing social media monitoring of Florida students).

305. Jon Schuppe, Florida Governor Signs ‘School Safety’ Bill That Could Arm Teachers, NBC News (Mar. 9, 2018), <https://www.nbcnews.com/news/us-news/florida-governor-signs-school-safety-bill-could-arm-teachers-n855311> [<https://perma.cc/E6SS-WCEZ>].

306. Located within the Florida Department of Law Enforcement, the Commission was formed to analyze the shootings that have occurred across Florida and recommend system improvements. Marjory Stoneman Douglas High School Public Safety Commission, Fla. Dep’t of L. Enf’t, <https://www.fdle.state.fl.us/MSDHS/Home.aspx> [<https://perma.cc/J5LK-WTN2>] (last visited Oct. 4, 2023).

307. Marjory Stoneman Douglas High Sch. Pub. Safety Comm’n, Initial Report Submitted to the Governor, Speaker of the House of Representatives and Senate President 7 (2019), <http://www.fdle.state.fl.us/MSDHS/CommissionReport.pdf> [<https://perma.cc/2DDH-WETH>] [hereinafter Commission Report] (noting that the Commission was a key component of the Marjory Stoneman Douglas High School Public Safety Act that was signed into law on March 9, 2018—one month after the shooting at Marjory Stoneman Douglas High School).

been reported to law enforcement until the shooting had occurred.³⁰⁸ It concluded that “people need to report more of what they see and hear.”³⁰⁹ The Florida legislature passed the Marjory Stoneman Douglas High School Public Safety Act on February 14, 2018, with the purpose of “comprehensively address[ing] the crisis of gun violence,” including gun violence on campuses, through “enhanced coordination between education and law enforcement entities at the state and local level.”³¹⁰

Under this Act, Florida public schools must create and implement systems that subject students, particularly students with disabilities, to near-constant surveillance. Schools must create “threat assessment teams” (TATs) composed of teachers, mental health professionals, and law enforcement officers.³¹¹ These teams’ purpose is to identify “threats,” broadly defined to include “an expression of intent to harm someone that may be spoken, written, gestured, or communicated in some other forms, such as text message or email.”³¹² They may be “explicit or implied, directed at the intended target or communicated to a third party.”³¹³ To facilitate the reporting of threats, the Florida legislature has created and funded a statewide mobile suspicious activity reporting tool called FortifyFL.³¹⁴ Anyone may download the app and anonymously submit a

308. See Marjory Stoneman Douglas High Sch. Pub. Safety Comm’n, Unreported Information Showing Nikolas Cruz’s Troubling Behavior 3 (2018), https://schoolshooters.info/sites/default/files/Unreported%20Information%20Showing%20Nikolas_Cruz_Troubling_Behavior.pdf [<https://perma.cc/27D7-R53M>] (“We have identified at least 30 people who had knowledge of troubling behavior Cruz exhibited prior to the MSDHS shooting that was not reported or it was reported but not acted upon.” (emphasis omitted)).

309. *Id.* at 4.

310. See Marjory Stoneman Douglas High School Public Safety Act, ch. 2018-3, § 2, 2018 Fla. Laws 6, 10.

311. Fla. Dep’t of Educ., Form BTAP-2022, Model Behavioral Threat Assessment: Policies and Best Practices for K–12 Schools 7 (2022), <https://www.fldoe.org/core/fileparse.php/18612/urlt/threat-assessment-model-policies.pdf> [<https://perma.cc/6NM5-JYLJ>] [hereinafter Model Behavioral Threat Assessment].

312. Form CSTAG-2022, Threat Assessment and Response Protocol: Comprehensive School Threat Assessment Guidelines, Fla. Dep’t of Educ. (June 2022), <https://www.fldoe.org/core/fileparse.php/18612/urlt/FLStandSWBehavAssess.pdf> [<https://perma.cc/QJ4N-2MLW>] [hereinafter Comprehensive School Threat Assessment Guidelines].

313. *Id.*

314. See Fla. Stat. Ann. § 943.082 (West 2023) (“In collaboration with the Department of Legal Affairs, the [Department of Law Enforcement] shall competitively procure a mobile suspicious activity reporting tool that allows students and the community to relay information anonymously concerning unsafe, potentially harmful, dangerous, violent, or criminal activities, or the threat of these activities”); How It Works, FortifyFL, <https://getfortifyfl.com/#howitworks> [<https://perma.cc/SK6L-JS2F>] (last visited Nov. 4, 2023). The app was named by students from Marjory Stoneman Douglas High School, and its rollout was coordinated by the Florida Office of the Attorney General, Department of Education, and Department of Law Enforcement. Press Release, Fla. Dep’t of Educ., Florida Launches Suspicious Activity Reporting App for Students (Oct. 8, 2018),

tip, which is then reported automatically to school officials, local law enforcement, and state-level officials.³¹⁵ Florida lawmakers have also introduced a statewide database that “combine[s] individuals’ educational, criminal justice, and social service records with their social media data, then share[s] it all with law enforcement.”³¹⁶ Features of the Social Media Monitoring Tool include real-time monitoring and geofencing as well as automatic notifications at the state, district, and school levels.³¹⁷

Once the TAT identifies a student as having made a threat, the team assesses the “threat” using a standardized statewide behavioral-assessment instrument³¹⁸ and categorizes the threat as either transient³¹⁹ or substantive.³²⁰ Depending on how the threat is categorized, the TAT has broad authority to take a multitude of actions. If conduct is deemed a serious or very serious substantive threat, TATs may refer the student to mental health or counseling services or report them to law enforcement.³²¹ They may also suspend students or require them to comply with certain readmission conditions to come back to school.³²² The Act authorizes broad disclosure of information to other agencies—including law enforcement agencies, the Department of Children and Families, and the Agency for Persons with Disabilities—about the student deemed to be experiencing or at risk of an “emotional disturbance or a mental illness.”³²³ All these agencies must “communicate, collaborate, and coordinate efforts to serve such students.”³²⁴

These processes specifically target students with disabilities. The Commission specifically recommended that students with individualized education programs (IEPs) and “severe behavioral issues” be referred to

<https://www.fldoe.org/newsroom/latest-news/florida-launches-suspicious-activity-reporting-app-for-students.stml> [<https://perma.cc/S5EJ-S47Q>].

315. See *How It Works*, supra note 314.

316. Benjamin Herold, *Schools Are Deploying Massive Digital Surveillance Systems. The Results Are Alarming*, *Educ. Wk.* (May 30, 2019), <https://www.edweek.org/technology/schools-are-deploying-massive-digital-surveillance-systems-the-results-are-alarming/2019/05> (on file with the *Columbia Law Review*).

317. See Reid & Braun, supra note 304, at 2.

318. Fla. Stat. Ann. § 1001.212(12) (West 2023).

319. See *Model Behavioral Threat Assessment*, supra note 311, at 7 (characterizing “transient threats” as those that involve “[no] sustained intent to harm” and that “can be resolved with an apology, retraction or explanation by the person who made the threat”).

320. See *id.* (describing “substantive threats” as all nontransient threats, “serious substantive threats” as threats to “hit, fight or beat up another person,” and “very serious substantive threats” as threats to “kill, rape or cause serious injury with a weapon”).

321. See *id.* at 17.

322. See *id.* at 18.

323. Marjory Stoneman Douglas High School Public Safety Act, ch. 2018-3, § 24, 2018 Fla. Laws 6, 43 (codified at Fla. Stat. Ann. § 1006.07(7)(g)).

324. *Id.*

and evaluated by the TAT.³²⁵ Florida's behavioral-threat-assessment instrument specifies the factors that may require TAT intervention. These include a history of serious depression or mental illness, qualification for special education services due to emotional or behavioral disturbance, and use of prescribed psychotropic medication.³²⁶ When they initially register for school, students must disclose if they have been referred to mental health services and, in some school districts such as Miami-Dade, enumerate "each and every service."³²⁷

These punitive surveillance processes are an example of "carceral humanism," a term coined by scholar and activist James Kilgore to refer to the "repackaging" of punishment as care.³²⁸ Kilgore identifies two ways in which the "repackaging" of mass incarceration manifests.³²⁹ The first is "carceral humanism," which manifests by positioning elements of the carceral state—corrections authorities, jails, and prisons—as social service providers.³³⁰ Threat-assessment processes are not meant to be punitive. Law enforcement, however, is a necessary presence on Florida TATs.³³¹ Law enforcement officers are heavily involved in gathering data about a student, assisting the team with accessing criminal justice information, and making decisions about the risk posed by the individual.³³² Law enforcement is thus positioned as an important part of a process that aims to take ostensibly therapeutic measures and funnel services to students regarded as threats. Kilgore notes that the second way mass incarceration repackaging manifests is through "non-alternative alternative[s] to incarceration," which often employ processes that may be well-intentioned but involve "heavy monitoring of a person's behavior."³³³ In this case, TATs may monitor students indefinitely. Florida Department of Education guidance provides, "Many cases should be kept open and subject to periodic review until the student is no longer attending that school."³³⁴

325. Commission Report, *supra* note 307, at 294.

326. See Comprehensive School Threat Assessment Guidelines, *supra* note 312.

327. Diane Rado, *Stigmatizing Kids? New Law Forces Families to Disclose Student's Mental Health Treatment*, Fla. Phoenix (July 11, 2018), <https://floridaphoenix.com/2018/07/11/stigmatizing-kids-new-law-forces-families-to-disclose-students-mental-health-treatment/> [<https://perma.cc/JP9K-2B49>] (internal quotation marks omitted) (quoting the Miami-Dade County school registration form used at the time of the article's publication).

328. See Kilgore, *supra* note 31.

329. See *id.*

330. See *id.*

331. Fla. Stat. Ann. § 1006.07(7)(b) (West 2023).

332. See Model Behavioral Threat Assessment, *supra* note 311, at 10 ("Having an active, sworn law enforcement officer on the threat assessment team is essential because an officer has unique access to law enforcement databases and resources that inform the threat assessment process.").

333. See Kilgore, *supra* note 31.

334. Model Behavioral Threat Assessment, *supra* note 311, at 18.

This dynamic of punishment and ostensibly “therapeutic” interventions adversely affects students with disabilities, who are disciplined by threat-assessment processes at a disproportionate rate. Dewey Cornell, the developer of the Threat Assessment Risk model used in Virginia and adopted by Florida, observed that students with disabilities were 3.9 times more likely to be referred for a threat-assessment test than their nondisabled peers.³³⁵ Further, the responses to the threats are typically punitive, regardless of whether the threat is transient or substantive. While school teams classified approximately two-thirds of threats as “low risk” or “transient,” the schools reported administering disciplinary action in 71% of those cases.³³⁶ Subject to heavy behavioral monitoring, students may be forced to comply with treatment and limitations on association and movement.³³⁷ If they are unable or fail to comply, they may face suspension, civil commitment, incarceration in prisons and jails, or referral to immigration authorities or child protective services.³³⁸ In sum, students with disabilities face the risk of being typecast as dangerous and thus excluded from school and incarcerated.

IV. APPLYING *OLMSTEAD* TO ABLEIST SURVEILLANCE SYSTEMS

This Part analyzes each of the examples of surveillance discussed above through the lens of the integration mandate. The purpose of this analysis is twofold: (1) to draw attention to the isolating impact of ableist surveillance practices on people with disabilities and (2) to demonstrate how the mandate can be used to disrupt and dismantle these systems of surveillance, functioning as a tool of resistance.

To that end, to make out a prima facie claim of discrimination under Title II of the ADA, one must establish that (1) the plaintiff is a “qualified individual” with a “disability” within the meaning of the ADA, (2) the defendant is a public entity or a recipient of federal funding, and (3) the surveillance system deployed by the public entity constitutes disability-based discrimination.³³⁹ A further consideration is whether placement can be reasonably accommodated by the state or whether it constitutes a

335. See Dewey Cornell & Jennifer Maeng, Student Threat Assessment as a Safe and Supportive Prevention Strategy: Final Technical Report 24 (2020), <https://www.ojp.gov/pdffiles1/nij/grants/255102.pdf> [<https://perma.cc/XF43-VRL4>].

336. See *id.* at 17.

337. See *id.*

338. See *id.*; see also Nat’l Disabilities Rts. Network, K-12 Threat Assessment Processes: Civil Rights Impacts 3–4 (2022), <https://www.ndrn.org/wp-content/uploads/2022/02/K-12-Threat-Assessment-Processes-Civil-Rights-Impacts-1.pdf> [<https://perma.cc/KG4P-KAH6>].

339. See, e.g., *Dean v. Univ. at Buffalo Sch. of Med. & Biomedical Scis.*, 804 F.3d 178, 187 (2d Cir. 2015) (citing *Powell v. Nat’l Bd. of Med. Exam’rs*, 364 F.3d 79, 85 (2d Cir. 2004)).

“fundamental alteration” of the public entity’s programs, services, and activities.³⁴⁰

A. *Overprotective Rules in Group Homes*

1. *Group Home Residents: “Qualified Individuals With Disabilities”*. — To bring a claim that Arizona’s EMD legislation violates the integration mandate,³⁴¹ a plaintiff must demonstrate that they are a person with a “disability”;³⁴² that is, that they have “a physical or mental impairment that substantially limits one or more major life activities.”³⁴³ This definition is meant to be broadly construed. In response to a series of Supreme Court decisions³⁴⁴ that narrowly construed the definition of “disability,” Congress

340. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 603 (1999) (plurality opinion). In addition to this requirement, the *Olmstead* plurality held that it was necessary to demonstrate that community-based services were appropriate for the person. See *id.* at 607 (majority opinion). Courts routinely permit plaintiffs to rely on determinations from their own medical service providers that they would be able to benefit from services in the community. See, e.g., *United States v. Georgia*, 461 F. Supp. 3d 1315, 1323 (N.D. Ga. 2020); *Joseph S. v. Hogan*, 561 F. Supp. 2d 280, 291 (E.D.N.Y. 2008); *Frederick L. v. Dep’t of Pub. Welfare*, 157 F. Supp. 2d 509, 540 (E.D. Pa. 2001). Further, the affected people must not oppose movement into the community. *Olmstead*, 527 U.S. at 607. The analysis undertaken in this Part presumes that any plaintiffs in a suit are qualified to receive services in a more integrated setting and that they do not oppose integrated services or settings.

341. Title II of the ADA and Section 504 of the Rehabilitation Act contain language that is nearly identical in nature. Title II provides that “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.” 42 U.S.C. § 12132 (2018). Section 504 provides that “[n]o otherwise qualified individual with a disability . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.” 29 U.S.C. § 794(a) (2018). It is worth noting, however, that under Section 504 the discrimination must be “solely by reason of . . . disability.” 29 U.S.C. § 794(a); see also 28 C.F.R. § 41.51 (2023). In the context of the integration mandate, courts have found it unnecessary to analyze the “solely by reason of . . . disability” standard when the plaintiff is “alleging a violation of the integration mandate because the discrimination—undue isolation—stems from a failure to satisfy an affirmative duty, regardless of discriminatory intent.” See *Guggenberger v. Minnesota*, 198 F. Supp. 3d 973, 1032 (D. Minn. 2016).

342. 42 U.S.C. § 12131(2).

343. *Id.* § 12102(1)(A). The meaning of “disability” is meant to be read broadly: Consistent with the ADA Amendments Act’s purpose of reinstating a broad scope of protection under the ADA, the definition of “disability” in this part shall be construed broadly in favor of expansive coverage to the maximum extent permitted by the terms of the ADA. The primary object of attention in cases brought under the ADA should be whether entities covered under the ADA have complied with their obligations and whether discrimination has occurred, not whether the individual meets the definition of “disability.”

28 C.F.R. § 35.101(b).

344. See *Toyota Motor Mfg., Ky., Inc. v. Williams*, 534 U.S. 184, 198 (2002) (holding that to be “substantially limited,” a person must be “prevent[ed] or severely restrict[ed]”

passed the ADA Amendments Act (ADAAA) in 2008.³⁴⁵ Congress was clear that “the new law direct[ed] the courts toward a broader meaning and application of the ADA’s definition of disability.”³⁴⁶

Accordingly, an impairment will qualify as a disability protected by the ADA if it “substantially limits” a major life activity “as compared to most people in the general population.”³⁴⁷ “Major life activity” is defined as including a wide range of activities, like “caring for oneself[,] . . . sleeping, walking, standing, lifting, . . . learning, reading, concentrating, thinking, communicating, and working.”³⁴⁸ It also includes major bodily functions, including “functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions.”³⁴⁹ An impairment need only substantially limit one life activity to be considered a disability.³⁵⁰ Episodic disabilities also fall within the definition of “disability” when the impairment “would substantially limit a major life activity when active.”³⁵¹ “Substantially limits” is not meant to be a demanding standard—the regulations specify that the impairment “need [not] prevent, or significantly or severely restrict, the individual from performing a major life activity in order to be considered substantially limiting.”³⁵²

To qualify for group home services, individuals must have an I/DD diagnosis.³⁵³ I/DD refers to conditions “that are usually present at birth and that uniquely affect the trajectory of [an] individual’s physical, intellectual, and/or emotional development.”³⁵⁴ An I/DD diagnosis is based

from doing daily activities and that this impairment must be “permanent or long term”); *Albertson’s, Inc. v. Kirkingburg*, 527 U.S. 555, 565–66 (1999) (holding that “mitigating measures must be taken into account in judging whether an individual possesses a disability” and that determination of disability must be made on an individual basis); *Murphy v. United Parcel Serv., Inc.*, 527 U.S. 516, 525 (1999) (holding that to be regarded as disabled, a person’s impairment must “substantially limit” their ability to perform “major life activities”); *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 487 (1999) (finding that the ADA does not cover people whose impairments can be corrected). All of these cases were superseded by the ADA Amendments Act of 2008 (ADAAA), Pub. L. No. 110-325, 122 Stat. 3553 (codified in scattered sections of 29 and 42 U.S.C.).

345. See ADA Amendments Act § 2, 122 Stat. at 3553–54 (explicitly rejecting a narrow reading of disability espoused by the Supreme Court).

346. 154 Cong. Rec. 22232 (2008) (statement of Sen. Reid).

347. 28 C.F.R. § 35.108(d)(1)(v) (2023).

348. 42 U.S.C. § 12102(2)(A).

349. *Id.* § 12102(2)(B).

350. *Id.* § 12102(4)(C).

351. *Id.* § 12102(4)(D).

352. 28 C.F.R. § 35.108(d)(1)(v).

353. See AHCCCS Housing Programs, *Ariz. Health Care Cost Containment Sys.*, <https://www.azahcccs.gov/housing> [<https://perma.cc/9D2N-84UG>] (last visited Jan. 4, 2024).

354. About Intellectual and Developmental Disabilities (IDDs), Eunice Kennedy Shriver Nat’l Inst. Child Health & Hum. Dev., <https://www.nichd.nih.gov/health/topics/idds/conditioninfo> [<https://perma.cc/SF6B-HBGW>] (last updated Nov. 9, 2021).

on a finding of “significant limitations in both intellectual functioning and adaptive behavior.”³⁵⁵ This means that a person with I/DD may have significant limitations in learning, reasoning and problem solving. Alternatively, “limitations in adaptive behavior” may mean that the person has difficulty with learning and exercising skills that people perform in their everyday lives. This includes language and literacy, interpersonal skills, and practical skills like toileting, dressing, and feeding oneself.³⁵⁶ Some people may have co-occurring mental illnesses, or psychiatric disabilities, which are defined as conditions that affect a person’s “emotion, thinking or behavior (or a combination of these).”³⁵⁷ They include a wide range of conditions, including bipolar disorder, depression, eating disorders, schizoaffective disorders, and schizophrenia.³⁵⁸

I/DD can affect interpersonal skills, the ability to perform activities of daily living, and skills like language and literacy.³⁵⁹ Psychiatric disabilities can also profoundly impact day-to-day living, including the ability to relate to or interact with others, bringing these conditions within the definition of “disability.”³⁶⁰ Using an interpretation of “substantially limits” that comports with the ADA’s broad remedial purpose, a plaintiff with I/DD or a psychiatric disability will likely be able to demonstrate that their disability substantially limits one or more major life activities like learning, communicating, or caring for oneself.³⁶¹

To be “qualified” under the ADA, an individual must show that they “meet[] the essential eligibility requirements for the receipt of services or the participation in programs or activities” provided by a public entity or

355. Defining Criteria for Intellectual Disability, Am. Ass’n on Intell. & Developmental Disabilities, <https://www.aaid.org/intellectual-disability/definition> [<https://perma.cc/4LGG-HLJ6>] (last visited Oct. 4, 2023).

356. *Id.*

357. See What Is Mental Illness?, Am. Psychiatric Ass’n, <https://www.psychiatry.org/patients-families/what-is-mental-illness> [<https://perma.cc/VUR4-C4XK>] (last updated Nov. 2022).

358. See *id.*

359. Defining Criteria for Intellectual Disability, *supra* note 355; see also *Adams v. Crestwood Med. Ctr.*, 504 F. Supp. 3d 1263, 1291 (N.D. Ala. 2020) (stating that “[w]ithout ongoing support,” people with intellectual and developmental disabilities will have “limit[ed] functioning in one or more activities of daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work, and community” (internal quotation marks omitted) (quoting Am. Psychiatric Ass’n, *Diagnostic and Statistical Manual of Mental Disorders* 33 (5th ed. 2013))); *Clark v. California*, 739 F. Supp. 2d 1168, 1185 (N.D. Cal. 2010) (finding that intellectual and developmental disabilities impact peoples’ ability to engage in major life activities, including communication, socialization, and self-care).

360. See *Joseph S. v. Hogan*, 561 F. Supp. 2d 280, 293 (E.D.N.Y. 2008) (finding that plaintiffs had demonstrated that mentally ill people warehoused in nursing facilities were “disabled” within the meaning of the ADA).

361. See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 605 (1999) (plurality opinion). For instance, both plaintiffs in *Olmstead* fell into this category. See *supra* note 172 and accompanying text.

a recipient of federal funds, with or without “reasonable modifications to rules, policies, or practices, the removal of . . . communication . . . barriers, . . . or the provision of auxiliary aids and services.”³⁶² Assessing this will depend on the nature of the program or service and involves a fact-based inquiry about whether the plaintiff meets the public entity’s eligibility criteria.³⁶³ Courts have typically interpreted this requirement as imposing only a low bar on plaintiffs.³⁶⁴

To qualify under Arizona’s EMD legislation, a person must demonstrate that they are “a bona fide resident of the state of Arizona” and “a person with a developmental disability.”³⁶⁵ Applicants must also need services provided in an institution like a nursing facility or intermediate care facility³⁶⁶ and be Medicaid-eligible.³⁶⁷ Demonstrating that people who already reside in Arizona group homes are qualified will not be difficult because they have already been found to be eligible for community-based services.³⁶⁸

362. 42 U.S.C. § 12131(2) (2018). The ADA provides that “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.” *Id.* § 121312; see also 28 C.F.R. § 41.32(b) (2023) (defining a “qualified handicapped person” as any disabled person who fulfills the “essential eligibility requirements” for a given service). The Rehabilitation Act uses similar language to prohibit discrimination by recipients of federal funds. See 29 U.S.C. § 794(a) (2018); see also *supra* note 341.

363. See, e.g., *Castellano v. City of New York*, 946 F. Supp. 249, 254 (S.D.N.Y. 1996) (“[Q]uestions of the reasonableness of an accommodation or the essentialness of an eligibility requirement generally need a fact-specific inquiry . . .”).

364. See, e.g., *PGA Tour, Inc. v. Martin*, 532 U.S. 661, 675 (2001) (interpreting the ADA as a “broad mandate”). A plaintiff need not meet all the formal legal eligibility requirements of a program to prove that they are “qualified.” See *Mary Jo C. v. N.Y. State & Loc. Ret. Sys.*, 707 F.3d 144, 156–57 (2d Cir. 2013). Rather, the question is whether the person meets all “essential” requirements. *Id.* A court will consider whether “[w]aiving an essential eligibility standard would constitute a fundamental alteration in the nature of the . . . program.” *Pottgen v. Mo. State High Sch. Activities Ass’n*, 40 F.3d 926, 930 (8th Cir. 1994). Nor must the plaintiffs demonstrate that other placements in the community could not fully meet their needs. See, e.g., *Williams v. Wasserman*, 164 F. Supp. 2d 591, 630 (D. Md. 2001) (finding that “qualified individuals with disabilities” like plaintiffs did not need to show that existing community placements did not fully meet their needs (internal quotation marks omitted) (quoting 28 C.F.R. § 35.130(d) (2001))).

365. *Ariz. Rev. Stat. Ann.* § 36-559 (2023). The statute defines “developmental disability” as “a severe, chronic disability” that “[i]s attributable to a cognitive disability, cerebral palsy, epilepsy, Down syndrome or autism,” “[i]s manifested before the age of eighteen,” and “[i]s likely to continue indefinitely.” *Id.* § 36-551(20). It defines “cognitive disability” as “a condition that involves subaverage general intellectual functioning[] [and] exists concurrently with deficits in adaptive behavior manifested before the age of eighteen.” *Id.* § 36-551(15).

366. *Id.* § 36-2936(A).

367. *Id.* § 36-2901.07(A).

368. See *id.* § 36-551(25)(a) (defining a “group home” as “a community residential setting for . . . persons with developmental disabilities”).

2. *Allocating Responsibility Under Federal Disability Law.* — The next question is whether the activity, service, or benefit is being provided by an entity covered by either Title II of the ADA or Section 504 of the Rehabilitation Act. Group home services in Arizona are provided by third-party service providers licensed by the Arizona Department of Health Services.³⁶⁹ As such, the services they provide may not qualify as being provided by a “public entity,” defined under Title II of the ADA as “any State or local government” or “any department, agency, special purpose district, or other instrumentality of a State or States or local government.”³⁷⁰

Group home service providers do, however, receive federal financial aid and rely on Medicaid funding to administer their programs and activities.³⁷¹ Section 504 of the Rehabilitation Act is worded virtually identically to the ADA³⁷² but applies to programs that receive “[f]ederal financial assistance.”³⁷³ Section 504 of the Rehabilitation Act thus serves as

369. *Id.* §§ 36-591(A), -132(A)(21); see also *Contracted Group Homes*, Ariz. Dep’t of Econ. Sec., <https://www.azahcccs.gov/shared/Downloads/HCBS/Appendix/12AppendixLGroupHomeFactSheet.pdf> [<https://perma.cc/EVE5-72XL>] (last visited Jan. 4, 2024).

370. 42 U.S.C. § 12131(1)(A)–(B) (2018). The regulations are clear that “[t]he programs or activities of entities that are licensed or certified by a public entity are not” covered by Title II. 28 C.F.R. § 35.130(b)(6) (2023); see also *Noel v. N.Y.C. Taxi & Limousine Comm’n*, 687 F.3d 63, 70 (2d Cir. 2012) (“[E]ven if private industry . . . fails to provide meaningful access for persons with disabilities, a licensing entity . . . is not therefore in violation of Title II(A), unless the private industry practice results from the licensing requirements.”).

371. See Peter Valencia, *Arizona Targets Phony Group Homes, Accused of Defrauding Millions From Medicaid System*, Ariz.’s Fam. (May 16, 2023), <https://www.azfamily.com/2023/05/16/arizona-targets-phony-group-homes-accused-defrauding-millions-medicaid-system/> [<https://perma.cc/U648-QD7F>] (reporting that fraudsters exploited group home providers’ receipt of Medicaid funding). Arizona Home and Community Based Services (HCBS), including group homes, are subsidized by Medicaid funds from the Arizona Health Care Cost Containment System (AHCCCS), a statewide managed-care program established under a Section 1115 Research and Demonstration Waiver. Ariz. Health Care Cost Containment Sys., *Arizona’s Section 1115 Waiver Demonstration Annual Report 3–4* (2022), <https://azahcccs.gov/Resources/Downloads/FY2022AnnualReportCMS.pdf> [<https://perma.cc/E997-JVH3>].

372. See *Henrietta D. v. Bloomberg*, 331 F.3d 261, 272 (2d Cir. 2003) (holding that while there are subtle differences between Title II of the ADA and Section 504, “unless one of those subtle distinctions is pertinent to a particular case, we treat claims under the two statutes identically”); see also 28 C.F.R. § 41.51(b)(3)(i) (stating that a “recipient may not . . . utilize criteria or methods of administration[] . . . [t]hat have the effect of subjecting qualified handicapped persons to discrimination on the basis of handicap”); *id.* § 41.51(d) (“Recipients shall administer programs and activities in the most integrated setting appropriate to the needs of qualified handicapped persons.”).

373. 29 U.S.C. § 794(b)(3)(A) (2018). Under Section 504, a “program or activity” includes “an entire corporation, partnership, or other private organization . . . which is principally engaged in the business of providing education, health care, housing,” or “social services.” *Id.*

a mechanism to challenge discriminatory conduct by group homes not operated by state or local governments.³⁷⁴

Arguably, however, that violation of the integration mandate arises from criteria set out by the state itself. Arizona group home service providers are, after all, bound by (1) statutes governing the operation of group homes and (2) the regulations issued by the director of the Department of Economic Security.³⁷⁵ A public entity might violate the ADA's integration mandate when, "through its planning, service system design, funding choices or service implementation practices, [it] promotes or relies upon the segregation of individuals with disabilities in private facilities or programs."³⁷⁶ States have been found to have violated the integration mandate when they have developed statutory and regulatory frameworks that have resulted in the segregation of people with disabilities.³⁷⁷ Accordingly, the State could be held liable for restrictive measures taken by private entities.

3. *The Overly Restrictive Impact of Electronic Monitoring Devices.* — The use of EMDs prevents group home residents from accessing services in the "most integrated setting" appropriate to their needs. Specifically, as expounded further below, the use of EMDs profoundly and adversely impacts residents' privacy. This has flow-on effects that hurt group home residents' ability to have meaningful and intimate relationships with family members, staff, and nondisabled community members.

374. Courts have held that Medicaid reimbursements qualify as "[f]ederal financial assistance." See, e.g., *Wagner ex rel. Wagner v. Fair Acres Geriatric Ctr.*, 49 F.3d 1002, 1010 (3d Cir. 1995) ("The legislative history of section 504 indicates that Congress clearly contemplated that section 504 would apply to nursing homes that receive federal funding."); *Mitchell ex rel. Mitchell v. Cmty. Mental Health of Cent. Mich.*, 243 F. Supp. 3d 822, 842 (E.D. Mich. 2017) (concluding that the plaintiffs had viable Rehabilitation Act claims because Medicaid reimbursements are a form of federal financial assistance).

375. *Ariz. Rev. Stat. Ann.* §§ 36-568(C), -551(20) (2023).

376. DOJ *Olmstead* Statement, *supra* note 196; see also 28 C.F.R. § 35.130(b)(1) (prohibiting a public entity from discriminating "directly or through contractual, licensing, or other arrangements, on the basis of disability"); *id.* § 35.130(b)(3) (prohibiting a public entity from "directly or through contractual or other arrangements[] utiliz[ing] criteria or methods of administration" that "have the effect of . . . discriminat[ing] on the basis of disability").

377. See, e.g., *Conn. Off. of Prot. & Advoc. for Persons With Disabilities v. Connecticut*, 706 F. Supp. 2d 266, 277 (D. Conn. 2010) (holding that Connecticut could not avoid its legal obligations even though "its consumers resided in privately-run facilities" and that "the actions of the state that led to a denial of integrated settings could serve as the basis for an ADA claim"); see also *Disability Advocs., Inc. v. Paterson*, 598 F. Supp. 2d 289, 317–18 (E.D.N.Y. 2009) ("The statutory and regulatory framework governing the administration, funding, and oversight of New York's mental health services . . . involves 'administration' on the part of [state-government defendants]."), vacated on other grounds *sub nom.* *Disability Advocs., Inc. v. N.Y. Coal. for Quality Assisted Living, Inc.*, 675 F.3d 149 (2d Cir. 2012).

Privacy is one of the key differences between integrated and nonintegrated settings.³⁷⁸ The Home and Community Based Services (HCBS) Settings Rule, issued by CMS in 2014, was drafted due to concerns that group homes were imposing restrictions on residents that were reminiscent of institutional settings, isolating and segregating people with disabilities from the broader community.³⁷⁹ To correct this trajectory, the HCBS Settings Rule emphasizes that community-based settings must ensure a person's right to "privacy, dignity, respect, and freedom from coercion and restraint."³⁸⁰ DOJ guidance also provides that to be integrated, settings must do more than merely assure that disabled people can interact with people without disabilities. Rather, residents must be able to enjoy "those aspects of life that all persons enjoy, including privacy, autonomy, the ability to exercise choice and opportunities to engage in activities alongside others in the community."³⁸¹ By contrast, segregated settings "often have the qualities of an institutional nature," including "congregate settings characterized by regimentation in daily activities" and "lack of privacy or autonomy."³⁸²

Both the DOJ guidance and the HCBS Settings Rule specifically identify residents' privacy as something to be protected to the maximum extent possible. Infringements on privacy should be permitted only when necessary to meet a person's individually assessed needs.³⁸³ Arizona's legislation, however, risks creating spaces in which people are completely deprived of privacy. The legislation permits EMDs to be used and installed in any room, "designed for use by multiple individuals, including residents."³⁸⁴ Beyond this constraint, the statute and its implementing regulations can be widely interpreted to include all communal living and working spaces. These privacy violations are exacerbated when a resident's

378. HCBS Settings Rule, 79 Fed. Reg. 2948, 3012 (Jan. 16, 2014) ("We are including language in the final rule that focuses on the critical role of person-centered planning and addresses fundamental protections regarding freedom, dignity, control, daily routines, privacy and community integration."); see also 42 C.F.R. § 441.301(c)(4) (2022).

379. ACLU, *The Home and Community Based Services Setting Rule Frequently Asked Questions 1* (2018), https://www.aclu.org/wp-content/uploads/legal-documents/aclu_faq_-_hcbs_settings_rule-final_1-10-18.pdf [<https://perma.cc/7X2U-NTN6>] (noting that the HCBS Settings Rule is a "complement to the [ADA]" developed to address "concerns that many states and providers were using federal dollars dedicated to community-based supports to pay for [institutional] disability services" and to remedy this situation by "articulating . . . minimum requirements for HCBS funding").

380. *Id.* at 2.

381. Chin, *supra* note 36, at 428; see DOJ *Olmstead* Statement, *supra* note 196.

382. DOJ *Olmstead* Statement, *supra* note 196.

383. HCBS Settings Rule, 79 Fed. Reg. at 2966 ("[A] person's ability to receive services identified in the person-centered service plan should not be infringed upon . . . [A]ny setting not adhering to the regulatory requirements will not be considered home and community-based. The supports necessary to achieve an individual's goals must be reflected in the person-centered service plan [per] [42 C.F.R.] § 441.725(b)(5).").

384. Ariz. Dep't of Econ. Sec., *Electronic Monitoring*, *supra* note 227, at 1.

responsible person requests and pays for the monitoring device to be installed in the resident's bedroom.³⁸⁵ Accordingly, residents will have limited opportunity to avoid monitoring devices, even in extremely private spaces like bedrooms.

Other than the infringement on privacy, the use of EMDs could also have a chilling effect on relationships between residents in the group home and between residents and staff. The use of EMDs in group homes could erode relationships between direct-service providers and the people in the house. They may inhibit nonabusive behaviors that are an essential part of developing intimate relationships but could be perceived as being problematic, like having sensitive conversations with staff members.³⁸⁶ Workers subject to monitoring in nursing home facilities report being worried how "being made to work on camera would communicate mistrust, have a chilling effect on care relationships, and contribute to the problem of low-quality jobs and poor retention."³⁸⁷ Other disability scholars have argued that EMDs will permit staff to use the cameras to monitor people and forgo personal contact.³⁸⁸

The social model of disability encapsulated by the ADA and Section 504 requires specified entities to adjust their policies to create "access and opportunity" for people with disabilities.³⁸⁹ Overprotective policies that prevent human connection and intimacy for people with disabilities fall foul of this requirement.³⁹⁰ The lack of privacy caused by EMDs, particularly in bedrooms, can affect group home residents' ability to engage in intimate and sexual relationships. Further, the lack of privacy may also deter group home residents from having guests or visitors.³⁹¹

In *Olmstead*, the Supreme Court deferred to Title II regulations issued by the Attorney General that "define[] 'the most integrated setting appropriate to the needs of qualified individuals with disabilities' to mean 'a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.'"³⁹² Courts have repeatedly found that isolating people with disabilities in settings where they cannot have meaningful interactions with nondisabled people violates the

385. *Id.* at 4.

386. See Levy et al., *supra* note 218, at 356 ("Because visitors are likely to be only occasionally present within resident rooms, they may have less familiarity with monitoring regimes than other parties (workers, roommates, or residents)—and have less ability to consent to or place conditions upon being monitored while in the room.").

387. *Id.* at 334.

388. See Ho et al., *supra* note 249, at 359.

389. Chin, *supra* note 36, at 407.

390. *Id.*

391. Levy et al., *supra* note 218, at 356 (noting the potential for this kind of isolation in nursing facilities with EMDs).

392. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 592 (1999) (quoting 28 C.F.R. pt. 35, app. A (1998)).

integration mandate.³⁹³ So, for instance, in *Lane v. Kitzhaber*, a federal district court in Oregon found that plaintiffs had stated a sufficient claim under the integration mandate because the sheltered workshops at issue, which afforded limited opportunities for people with disabilities to interact with other workers, did not permit interaction with nondisabled people to the fullest extent possible.³⁹⁴ In *Guggenberger v. Minnesota*, a federal district court in Minnesota found that plaintiffs had adequately pled that they were suffering from unjustified isolation.³⁹⁵ In making this determination, the court considered how plaintiffs experienced “disconnectedness from the community” and could not interact with “peers with disabilities and without disabilities.”³⁹⁶ The social isolation that EMDs would cause group home residents with disabilities is precisely the kind of situation the integration mandate seeks to prevent.

4. *Less Restrictive Safety Measures.* — This Essay argues that states should consider modifications that bolster the oversight and accountability of group homes but would not fundamentally alter the state’s services. Once it is established that a state has engaged in a form of disability-based discrimination by isolating group home residents using EMD, the next step is to consider whether any proposed modification is reasonable or would fundamentally alter the nature of the state’s programs or activities.³⁹⁷ These measures include increasing the pressure on service providers to report on incidents of abuse and neglect,³⁹⁸ mandating the prompt and thorough investigation of these incidents,³⁹⁹ increasing state

393. See, e.g., *Joseph S. v. Hogan*, 561 F. Supp. 2d 280, 292 (E.D.N.Y. 2008) (finding that the restrictive nature of nursing facilities, including restrictions on movement and limited access to the community, prevented nursing home residents from interacting with “nondisabled persons to the fullest extent possible” (internal quotation marks omitted) (quoting 35 C.F.R. pt. 35, app. A at 450)).

394. 841 F. Supp. 2d 1199, 1206 (D. Or. 2012).

395. See 198 F. Supp. 3d 973, 1029 (D. Minn. 2016).

396. *Id.*

397. See 28 C.F.R. § 35.130(b)(7) (2023) (describing public entities’ obligations to make reasonable modifications to avoid disability-based discrimination).

398. See HHS, Joint Report: Group Homes, *supra* note 214, app. A at A-iii (recommending that service providers “ensure that all incidents are reported as soon as possible after discovery”). These recommendations are drawn from model practices in a Joint Report issued by three HHS divisions: the HHS Office of Inspector General, the Administration for Community Living, and the HHS Office for Civil Rights. The report includes four compliance oversight components: “1. reliable incident management and investigation processes; 2. audit protocols that ensure compliance with reporting, review, and response requirements; 3. effective mortality reviews of unexpected deaths; and 4. quality assurance mechanisms that ensure the delivery and fiscal integrity of appropriate community-based services.” *Id.* at 13–14. Together, these components “help ensure that beneficiary health, safety, and civil rights are adequately protected, that provider and service agencies operate under appropriate accountability mechanisms, and that public services are delivered consistent with funding expectations and commitments.” *Id.* at 14.

399. *Id.* app. A at A-viii to A-ix (recommending that most investigations be completed within thirty days and that investigations review (1) surrounding circumstances;

oversight of group home services,⁴⁰⁰ and ensuring that group home residents receive individualized services to prevent the risk of abuse and revictimization.⁴⁰¹

There are significant problems with Arizona's abuse and neglect investigation and oversight processes.⁴⁰² In 2019, Governor Douglas A. Ducey issued Arizona Executive Order 2019-03, calling for relevant state agencies to convene the Abuse and Neglect Prevention Taskforce, a working group to recommend measures to protect and improve care for people with disabilities.⁴⁰³ The Task Force recommended that state agencies develop policies pertaining to "preventing abuse, neglect, and exploitation, reporting incidents, conducting investigations, and ensuring incident stabilization and recovery."⁴⁰⁴ In 2022, Arizona Health Care Cost Containment System (AHCCCS), one of the state agencies with the authority to conduct abuse and neglect investigations on behalf of people with disabilities, had only made partial progress toward creating these protocols.⁴⁰⁵

In 2023, an audit of the Arizona Department of Economic Security's Adult Protective Services (APS), another agency responsible for protecting

(2) interviews with witnesses to the incident, family, and the provider agency; and (3) any reports from the State protection and advocacy agency pertaining to group home incident investigations).

400. *Id.* app. A at A-x to A-xi (recommending that the state conduct a "trend analysis of incidents," "identify the specific incident types that would benefit from a systemic intervention," and "ensure ongoing monitoring of the implementation of accepted recommended corrective actions"); see also *id.* app. B at B-i to B-xiii (outlining guidelines for states to carry out regular incident management audits to ensure compliance with incident reporting and timely completion of investigations by group home service providers).

401. *Id.* app. D at D-viii (emphasizing the need for "[p]erson-centered quality reviews" to ensure that the individual was provided with services "in the amount, frequency, duration, and scope required").

402. See, e.g., Amy Silverman, *Unsafe Abuse and Neglect of Arizona's Most Vulnerable Can Happen Anywhere*, KJZZ (Dec. 2, 2022), <https://kjzz.org/content/1827172/unsafe-abuse-and-neglect-arizonas-most-vulnerable-can-happen-anywhere> [<https://perma.cc/W6NF-PBUF>] (noting that Arizona's Division of Developmental Disabilities received over 10,000 incident reports in 2019 and 2020, many of which were never resolved).

403. *Ariz. Health Care Cost Containment Sys., Report of the Abuse & Neglect Prevention Task Force to Governor Douglas A. Ducey 4, 7* (2019), <https://www.azahcccs.gov/AHCCCS/Downloads/AbuseAndNeglectPreventionTaskForceReport2019.pdf> [<https://perma.cc/EM8C-HEKQ>].

404. *Id.* at 8.

405. Univ. of Ariz. Sonoran Ctr. for Excellence in Disabilities, *Implementation and Impact of Arizona's Abuse & Neglect Prevention Task Force Recommendations 13, 26* (2022), https://www.azahcccs.gov/AHCCCS/Downloads/AbuseAndNeglectPrevention_TF_Recommendations-SonoranUCEDD.pdf [<https://perma.cc/XJU3-GXWQ>] (noting that AHCCCS had made limited progress in identifying, tracking, and analyzing incidents, which would "require significant structural and systems change across Arizona agencies," though progress toward "boost[ing] accountability of vendors and services for the protection of vulnerable individuals" had been achieved).

“vulnerable adults” in the state,⁴⁰⁶ revealed that problems with investigation and monitoring processes persisted.⁴⁰⁷ Investigations carried out by APS resulted in substantiation⁴⁰⁸ less than one percent of the time—a rate “far lower than the national average.”⁴⁰⁹ Stakeholders raised concerns about the quality of investigations carried out,⁴¹⁰ and the report noted that the investigative timeframe was longer than the national average.⁴¹¹ The audit report concluded that the system lacked an adequate mechanism to track incidents of abuse and neglect.⁴¹² It recommended that the state develop protocols for providing case management services to ensure that vulnerable adults received the support and services they required to prevent revictimization.⁴¹³

Overhauling Arizona’s processes could be framed not as a fundamental alteration of the state’s services but as part and parcel of its obligations to secure federal Medicaid funding.⁴¹⁴ To receive Medicaid funds, states must provide “satisfactory assurances” to CMS that they have engaged in the “necessary safeguards” to “protect the health and welfare of the beneficiaries” of services under any waiver.⁴¹⁵ As part of annual reporting requirements, CMS requires that states develop systems to “prevent, detect, and remediate critical incidents,”⁴¹⁶ or incidents that are likely to cause harm to beneficiaries, and define standards for service

406. Ariz. Rev. Stat. Ann. § 46-451 (2023) (defining a “vulnerable adult” as an individual “who is eighteen years of age or older and who is unable to protect himself from abuse, neglect or exploitation by others because of a physical or mental impairment” or whom a court has deemed an “incapacitated person”); see also *id.* § 14-5101 (defining “incapacitated person” as someone “impaired by reason of mental illness, mental deficiency, mental disorder, physical illness or disability, chronic use of drugs, chronic intoxication or other cause, except minority, to the extent that he lacks sufficient understanding or capacity to make or communicate responsible decisions concerning his person”).

407. LeCroy & Milligan Assocs., Inc., *Examining the Delivery of Services to Vulnerable Adults in the Arizona Adult Protective Services System* 3 (2023), https://www.azauditor.gov/sites/default/files/23-114_Report.pdf [<https://perma.cc/4LN9-44B2>] (finding that Arizona’s APS system lacked a “strategic direction” for “ensuring vulnerable adults are protected from abuse, neglect, and exploitation and receive the services they need” and that it lacked a case management process for evaluating its efficacy).

408. *Id.* at 8, 50 (“Substantiated decisions indicate the APS investigation found supporting evidence that the alleged allegations of abuse, neglect, or maltreatment occurred and result in the perpetrator being placed on the Arizona APS Registry.”).

409. *Id.* at 7.

410. *Id.* at 52.

411. *Id.* at 8.

412. *Id.* at 34 (“This review found that the DES APS data system is not set up to track and measure service outcomes for vulnerable adults. . . . Service outcome information is critical to identifying ways to improve the delivery of services.”).

413. *Id.* at 31–32.

414. See 42 C.F.R. § 441.302(a) (2022) (listing requirements that Medicaid beneficiaries must meet).

415. *Id.* § 441.302.

416. *Id.* § 438.330(b)(5)(ii).

providers to meet to protect the welfare of enrollees in any home and community-based services.⁴¹⁷ While states have broad discretion to design these systems, they must report on the processes they have in place to “[i]dentify[] and respond[] to alleged instances of abuse, neglect and exploitation” and “[i]nstitut[e] appropriate safeguards concerning practices that may cause harm to the participant or restrict participant rights.”⁴¹⁸ Creating robust investigative and case-monitoring processes is therefore already part of the state’s responsibilities.

B. *Electronic Visit Verification (EVV) Subjects: “Qualified Individuals With Disabilities”*

This section of the Essay analyzes the EVV system used in Arkansas, which is perhaps one of the country’s most burdensome.⁴¹⁹ Arkansas is one of a handful of states that has incorporated geofencing, GPS tracking, and biometric identification as part of its EVV system.⁴²⁰

1. *People Subject to EVV: “Qualified Individuals With Disabilities”*. — To qualify for protection under the ADA, people subject to EVV requirements will need to demonstrate that they have an impairment that “substantially limits one or more major life activities.”⁴²¹ PCS recipients may have a range of disabilities—from physical disabilities to intellectual and developmental disabilities—that impact their independence and ability to perform their activities of daily living.⁴²² They may require assistance with performing

417. Id. § 441.730(a).

418. Ctrs. for Medicare & Medicaid Servs., Application for a § 1915(c) Home and Community-Based Waiver: Instructions, Technical Guide and Review Criteria 8 (2019), https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf [<https://perma.cc/J2SX-QC24>].

419. See, e.g., Eubanks & Mateescu, *supra* note 289 (finding that Arkansas’s system—which did not include self-directed clients or live-in caregivers in pilot testing—to be burdensome, difficult to use, and unduly punitive).

420. See Ariana Aboulafla & Henry Claypool, *The Vast Surveillance Network that Traps Thousands of Disabled Medicaid Recipients*, Slate (July 26, 2023), <https://slate.com/technology/2023/07/ada-anniversary-disability-electronic-visit-verification.html> [<https://perma.cc/48CA-A7FK>] (“[O]ther outlets have reported on disabled people who have been forced to share photographs and biometric data with third-party apps if they want to continue receiving government support to pay for their in-home care.”); EVV Frequently Asked Questions for Providers, Ark. Dep’t of Hum. Servs., <https://humanservices.arkansas.gov/divisions-shared-services/medical-services/evv-info/evv-provider-faq/> [<https://perma.cc/9Z29-GN2G>] (last visited Oct. 4, 2023) (“[W]hen the caregiver clocks in/out outside of the geo fence (more than 1/8 of a mile) from the client’s residence, the system will flag the clock in/out location as out of geo-fence critical exception.”).

421. 42 U.S.C. § 12102(1) (2018) (defining “disability” for purposes of ADA coverage).

422. CMS defines “personal care services” as “a range of human assistance provided to persons with disabilities and chronic conditions”—a broad category of service recipients with various disabilities. See Ctrs. for Medicare & Medicaid Servs., *Preventing Medicaid Improper Payments for Personal Care Services 4* (2017), <https://www.cms.gov/medicare-medicaid-coordination/fraud-prevention/medicaid-integrity-education/downloads/pcs->

those activities, including “eating, bathing, dressing, ambulation, and transfers from one position to another.”⁴²³ They may also require assistance with “instrumental activities of daily living”—tasks that assist people with living independently, including “meal preparation, hygiene, light housework, and shopping for food and clothing.”⁴²⁴ These are all activities that are necessary for caring for oneself—a specifically delineated “major life activity” under the ADA. ⁴²⁵

Personal care services are provided to Medicaid recipients to “help them . . . stay in their own homes and communities rather than live in institutional settings, such as nursing facilities.”⁴²⁶ In other words, recipients have disabilities significant enough that they may be institutionalized if they do not receive these services. Plaintiffs requiring PCS will likely qualify as having impairments that substantially limit a major life activity.

To qualify for PCS in Arkansas, people must meet eligibility requirements for different state-developed programs depending on age and disability.⁴²⁷ Plaintiffs impacted by EVV systems would have already been assessed as being eligible for PCS under each of these programs.

prevent-improperpayment-booklet.pdf [https://perma.cc/8MVZ-3SLZ] [hereinafter CMS, Preventing Improper Payments].

423. Id.

424. Id.

425. See 42 U.S.C. § 12102(2)(A) (“[M]ajor life activities include, but are not limited to, *caring for oneself*, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.” (emphasis added)).

426. CMS, Preventing Improper Payments, supra note 422, at 3; see also Adams & Katz, supra note 1, at 63–64.

427. For an applicant to qualify for Medicaid-funded PCS in Arkansas, a doctor must find it necessary for the person to be served in their home, as long as that residence is not a nursing facility or intermediate care facility. See Arkansas Medicaid Personal Care: Eligibility and Benefits, Paying for Senior Care, <https://www.payingforseniorcare.com/arkansas/medicaid-waivers/personal-care> [https://perma.cc/Z73Q-6EJK] (last updated Jan. 4, 2023). People seeking these services must also meet certain financial requirements, including income and asset limits. Id. Personal care services for people with I/DD are available under the Community and Employment Support (CES) Waiver. CES Waiver, Ark. Dep’t of Hum. Servs., <https://humanservices.arkansas.gov/divisions-shared-services/developmental-disabilities-services/ces-waiver/> [https://perma.cc/6CPZ-MRXC] (last visited Jan. 5, 2024). To qualify for waiver services, applicants must show that they have a diagnosis of I/DD that is expected to continue indefinitely and that they meet level-of-care requirements demonstrating substantial support needs in at least three of the following categories: “self-care, understanding and use of language, learning, mobility, self-direction, or ability to live independently.” Id. Attendant care services, which include in-home assistance with Activities of Daily Living (ADL) (activities like bathing, toileting, and eating) and Instrumental Activities of Daily Living (IADL) (more complex activities like managing finances and medication), for people with physical disabilities aged twenty-one and above are provided under the AR Choices program. AR Choices in Home Care, Favor Home Care, <https://www.favorcare.com/archoices-home-care> [https://perma.cc/Y8JC-NSD4] (last visited Oct. 4, 2023); Activities of Daily Living Checklist and Assessments,

2. *EVV Systems Offered by a “Public Entity”*. — Personal care services are programs provided by a public entity within the meaning of the ADA and the Rehabilitation Act.⁴²⁸ The Supreme Court has unequivocally determined that Title II covers all programs, services, and activities of governmental entities “without any exception.”⁴²⁹

Arkansas uses an open vendor EVV model whereby the state selects an EVV vendor that provides services to agencies with no cost.⁴³⁰ The vendor chosen by the state, Fiserv, offers a system called AuthentiCare, which involves a mobile application and an Interactive Voice Response system to record caregiver visits to clients and report on service provision in real time.⁴³¹ Given that the state directly funds the use of the AuthentiCare

Paying for Senior Care, <https://www.payingforseniorcare.com/activities-of-daily-living> [<https://perma.cc/9VQB-4345>] (last updated Apr. 20, 2021). To qualify for this program, the applicant must be assessed as requiring a “nursing home level of care and require a minimum of one of the services offered through AR Choices,” which includes home modifications, adult day care, respite care, and assistance with ADLs or IADLs. AR Choices in Homecare Medicaid Waiver (Arkansas), Paying for Senior Care, <https://www.payingforseniorcare.com/arkansas/medicaid-waivers/choices-homecare> [<https://perma.cc/9DWZ-5M2M>] (last updated Jan. 8, 2023). They must also satisfy certain income and asset limits. *Id.*

428. The ADA prohibits disability-based discrimination in “services, programs, [and] activities of . . . public entit[ies].” 42 U.S.C. § 12132. The Rehabilitation Act prohibits such discrimination in “any program or activity receiving Federal financial assistance” and broadly defines “program or activity” to include “all of the operations of” a qualifying local government. 29 U.S.C. § 794(a),(b) (2018).

429. *Pa. Dep’t of Corr. v. Yeskey*, 524 U.S. 206, 209–10 (1998) (emphasis omitted) (noting that the ADA covers all state activities, including the administration of state prisons, and includes “services” provided involuntarily to prisoners and pretrial detainees); see also *Haberle v. Troxell*, 885 F.3d 170, 184 (3d Cir. 2018) (Greenaway, J., concurring) (“Section 504 of the Rehabilitation Act defines ‘program or activity’ to mean ‘all of the operations’ of an entity . . . and . . . [t]he statutory definition of “[p]rogram or activity” in Section 504 indicates that the terms were intended to be *all-encompassing*.” (first and second quotations quoting 29 U.S.C. § 794(b); third quotation quoting *Yeskey v. Pa. Dep’t of Corr.*, 118 F.3d 168, 170 (3d Cir. 1997))).

430. Electronic Visit Verification (EVV) Information, Ark. Dep’t of Hum. Servs., <https://humanservices.arkansas.gov/divisions-shared-services/medical-services/evv-info/> [<https://perma.cc/9U8D-G6KK>] (last visited Jan. 19, 2024). Not all states use the “open” model to provide EVV services. Other models include the Provider Choice Model (in which the providers select and self-fund EVV implementation), the Managed Care Organization Choice Model (in which managed care organizations select and self-fund their EVV vendor solution), the State Mandated In-House Model (in which the state develops, operates, and manages its own EVV system), and the State Mandated External Vendor Model (in which states contract with a single EVV vendor to implement a single solution). Jen Burnett & Camille Dobson, *Medicaid in a Time of Change: Electronic Visit Verification 12–15* (2018), <https://www.healthmanagement.com/wp-content/uploads/EVV-Webinar-HMAIS-05-24-18.pptx> (on file with the *Columbia Law Review*).

431. See *EVV Frequently Asked Questions for Providers*, *supra* note 420 (discussing the features and requirements for Arkansas’s preferred EVV solution, Fiserv’s AuthentiCare).

system and has specified how the system must operate, the system will likely be deemed a “service, program, or activity” provided by a public entity.⁴³²

Arkansas also permits third-party service providers to choose their own vendor as long as they comply with the state’s requirements.⁴³³ As with AuthentiCare, any EVV system chosen by a vendor must permit checking in and out using Interactive Voice Response landlines and set the geofence at one-eighth mile.⁴³⁴ In *Disability Advocates, Inc. v. Paterson*, the State of New York argued that no state “service, program, or activity” could be identified when the adult homes were privately operated and the state’s only involvement was in licensing those facilities.⁴³⁵ The court correctly observed that the plaintiffs were challenging the state’s “choice to plan and administer its mental health services in a manner that results in thousands of individuals with mental illness living and receiving services in allegedly segregated settings.”⁴³⁶ In the context of EVV in Arkansas, the state has set out the regulatory framework that service providers must comply with. Accordingly, even though third-party service providers may use their own vendors, the plaintiffs would be challenging the state’s plan in administering and providing EVV services.

3. *Arkansas’s EVV System Isolates and Segregates.* — Federal courts have recognized that segregation and isolation that results from the way home and community-based services are provided can violate the integration mandate. In *Steimel v. Wernert*, the plaintiffs alleged that their move from one waiver to another “dramatically curtailed” their ability to participate in the community by drastically cutting their number of hours of community time per week.⁴³⁷ The Seventh Circuit recognized that “[i]solation in a home can just as ‘severely diminish[] the everyday life activities’ of people with disabilities”⁴³⁸ and held that state policies that segregate people within their homes violate the integration mandate.⁴³⁹

432. See, e.g., *Frame v. City of Arlington*, 657 F.3d 215, 227 (5th Cir. 2011) (arguing that programs and activities of a public entity include all of its “operations,” defined as “the whole process of planning for and operating a business or other organized unit” (internal quotation marks omitted) (quoting *Operations*, Webster’s Third New International Dictionary (1993))). Arkansas’s choice of EVV system could arguably be part of the process of planning and operating that goes into administering Medicaid-subsidized PCS.

433. See EVV Frequently Asked Questions for Providers, *supra* note 420 (“You can choose to use a different EVV vendor, but at your expense. If you do this, it is critical that your chosen vendor integrates with the State’s vendor, Fiserv. . . . Your vendor will be required to send the EVV data the State needs to verify visits and validate[] claims.”).

434. See *id.*

435. 598 F. Supp. 2d 289, 293, 313 (E.D.N.Y. 2009) (internal quotation marks omitted) (quoting 28 C.F.R. § 35.130(b)(7) (2009)), vacated on other grounds *sub nom.* *Disability Advocates, Inc. v. N.Y. Coal. for Quality Assisted Living, Inc.*, 675 F.3d 149 (2d Cir. 2012).

436. *Id.* at 318.

437. 823 F.3d 902, 908 (7th Cir. 2016).

438. See *id.* at 910–11 (second alteration in original) (quoting *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 602 (1999)).

439. See *id.* at 910–14.

Similarly, in *Guggenberger*, the plaintiffs resided in their own homes rather than in institutions.⁴⁴⁰ But the court found that they were not “living, working, and receiving services” in the most integrated setting because the state’s administration of the waiver services program kept them from participating fully within the community.⁴⁴¹ The court held that failing to provide supports and services to increase the plaintiffs’ ability to participate in community life violated the integration mandate.⁴⁴²

The isolation experienced by people subject to Arkansas’s EVV system is analogous to the experience of the plaintiffs in both *Steimel* and *Guggenberger*. Arkansas’s use of geofencing and GPS isolates people within their own homes, violating the integration mandate. Although EVV systems must be “minimally burdensome,” users find them extremely disruptive to services.⁴⁴³ Significantly, EVV systems “create[] an atmosphere of ambient criminalization.”⁴⁴⁴ States’ use of geofencing as part of their EVV systems exacerbates this feeling. If a caregiver clocks in or out outside of the geofence from the client’s residence, the system flags it as an “‘unauthorized location’ error.”⁴⁴⁵ The PCS provider must then explain why the worker was outside of the allowed geofence zone.⁴⁴⁶ As a result, many users report feeling imprisoned in their homes, worried about having their movements flagged as fraudulent.⁴⁴⁷ This is borne out by a survey of home care recipients conducted by the National Council on Independent Living across thirty-six states in 2020, which found that “[o]ne-third of respondents stay at home more often than prior to EVV use, due to fear that geofencing limitations will flag a visit as fraud or cause delay in or loss of provider wages.”⁴⁴⁸

440. *Guggenberger v. Minnesota*, 198 F. Supp. 3d 973, 987 (D. Minn. 2016).

441. *Id.* at 1029–30.

442. *Id.* at 1029.

443. Mateescu, *supra* note 37, at 2 (internal quotation marks omitted) (quoting Ctrs. for Medicare & Medicaid Servs., CMCS Informational Bulletin: Electronic Visit Verification 2 (2018), <https://www.medicaid.gov/federal-policy-guidance/downloads/cib051618.pdf> [<https://perma.cc/9JJL-UHG8>]).

444. *Id.* at 39.

445. *Id.* at 41 (quoting Eubanks & Mateescu, *supra* note 289).

446. *Id.*

447. DREDF Opposes Electronic Visit Verification (EVV) When It Threatens Disabled People’s Civil and Privacy Rights and Impedes Personal Choice, Autonomy, and Community Participation, Disability Rts. & Educ. Def. Fund (Mar. 2018), <https://dredf.org/2018/03/07/dredf-statement-on-electronic-visit-verification/> [<https://perma.cc/9YD4-7PMM>] (“EVV typically requires workers to check in from the homes of clients, yet consumer directed attendant programs allow services to be delivered anywhere they are needed This conflict creates the potential for an atmosphere of ‘house arrest’”).

448. Call to Action: The Need for Federal Protections in Electronic Visit Verification, Nat’l Council on Indep. Living, <https://securservercdn.net/198.71.233.129/bzd.3bc.myftpupload.com/wp-content/uploads/2020/08/8-2-20-CALL-TO-ACTION.pdf> [<https://perma.cc/P4S8-FLW7>] (last visited Oct. 6, 2023); see also Mateescu, *supra* note 37, at 39 (arguing that “GPS tracking and geofencing features pressure service recipients and their

Further, federal courts have found that the integration mandate has been violated when the administration of waiver services results in “current or future gaps in services,” putting plaintiffs at “risk of institutionalization.”⁴⁴⁹ In *Waskul v. Washtenaw County Community Mental Health*, the State of Michigan had amended the methodology it used to determine the amount that people could pay home or community-based care staff.⁴⁵⁰ Because of the change in methodology, the plaintiffs could not afford providers and so had to “pay for supports and services themselves [or] hire family members at below-market rates.”⁴⁵¹ As a result, they alleged that their conditions deteriorated, placing them at risk of institutionalization.⁴⁵² The Sixth Circuit held that the plaintiffs stated a claim for an integration mandate violation by showing that they were at serious risk of institutionalization because they could not sustain care within the community.⁴⁵³

Along those lines, EVV systems violate the integration mandate by making it unsustainable for people to participate in community-based services. First, EVV systems are costly. Their costs are borne predominantly by poorly paid workers and the people they serve.⁴⁵⁴ The requirement to adopt EVV systems presumes that personal care workers can readily access an active data plan, a functioning home internet connection, and an installed landline for workers to call in and out.⁴⁵⁵ Disabled people and their staff report that the costs of paying for EVV services can “mean the difference between having enough to eat or going hungry at the end of the month.”⁴⁵⁶

Second, EVV systems are punitive and threaten a workforce that is necessary to keep people with disabilities living in the community. Glitches in the system can mean that care providers may not be paid for their work due to inaccuracy in recording hours and services.⁴⁵⁷ The pay is frequently notoriously low, and lost wages and delayed paychecks have significant consequences for a population that struggles to buy groceries or pay rent.⁴⁵⁸ Some users report having to supplement workers’ salaries from their own limited funds to ensure that their personal care providers can

workers to re-orient their lives—including their movements, living arrangements, and routines—to conform with compliance rules”).

449. See, e.g., *Steimel v. Wernert*, 823 F.3d 902, 917 (7th Cir. 2016) (finding that such gaps can violate the integration mandate).

450. 979 F.3d 426, 438 (6th Cir. 2020).

451. *Id.* at 439.

452. *Id.*

453. *Id.* at 465–66.

454. Mateescu, *supra* note 37, at 39.

455. *Id.* at 49.

456. Task Force Statement of Principles and Goals, *supra* note 286, at 3 (emphasis omitted).

457. Mateescu, *supra* note 37, at 36.

458. Eubanks & Mateescu, *supra* note 289.

continue to work with them.⁴⁵⁹ Across the nation, there is a severe and profound shortage of qualified personal care service providers.⁴⁶⁰ This is especially true in states like Arkansas.⁴⁶¹ As this workforce diminishes, people may find it difficult to access home-based services, ultimately resulting in hospitalization or institutionalization in long-term care facilities.⁴⁶² Without these services, people who require home health aide assistance risk being institutionalized—a cognizable claim under the integration mandate.

4. *Using Less Intrusive EVV Surveillance Systems: Not a Fundamental Alteration.* — While states must make reasonable modifications to their policies, they may refuse to fundamentally alter programs or services.⁴⁶³ Arkansas’s EVV system has cost the state \$5.7 million,⁴⁶⁴ and dismantling it may also be a costly enterprise.⁴⁶⁵ The Supreme Court in *Olmstead* recognized that states’ budgetary constraints are relevant and can be considered as part of the overall fundamental alteration calculus.⁴⁶⁶ Accordingly, the state may argue that overhauling EVV systems to remove their more invasive aspects would fundamentally alter the nature of the service, program, or activity being offered.⁴⁶⁷

The state cannot, however, simply rely on the argument that amending EVV systems to make them less intrusive would cost too much.⁴⁶⁸ To succeed on such a claim, the state would have to demonstrate that, under the allocation of available resources, immediate relief for the plaintiffs is inequitable.⁴⁶⁹ States must adduce evidence about the fiscal impact

459. *Id.*

460. *Id.*

461. *Id.*

462. Mateescu, *supra* note 37, at 13.

463. See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 604 (1999) (plurality opinion) (“[T]he fundamental-alteration component of the reasonable-modification regulation 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 . . . persons with mental disabilities.”).

464. Eubanks & Mateescu, *supra* note 289.

465. See, e.g., State Associations Letter, *supra* note 301 (“We also note that repealing GPS would significantly increase the costs of implementing EVV. The changes proposed would further increase overall costs to the state and federal governments.”).

466. See *Olmstead*, 527 U.S. at 603 (plurality opinion).

467. See 28 C.F.R. § 35.130(b)(1)(vii) (2023) (“A public entity, in providing any aid, benefit, or service, may not . . . limit a qualified individual with a disability in the enjoyment of any right, privilege, advantage, or opportunity enjoyed by others receiving the aid, benefit, or service.”).

468. See *Messier v. Southbury Training Sch.*, No. 3:94-CV-1706(EBB), 1999 WL 20910, at *11 (D. Conn. Jan. 5, 1999) (“Inadequate funding ordinarily will not excuse noncompliance with the ADA or Section 504.”).

469. See *Olmstead*, 527 U.S. at 597 (noting that determining the viability of a fundamental alteration defense requires balancing various factors, including “the cost of providing community-based care[,] . . . the range of services the State provides others with

of amending their policies, including “unsuccessful attempts at fund procurement, evidence that [the state has] responsibly spent its budgetary allocations, . . . or the potential diminution of services for institutionalized persons.”⁴⁷⁰ They must also demonstrate a genuine commitment to bringing the EVV system into compliance with the integration mandate.⁴⁷¹

Courts have also recognized that states create their own administrative systems and cannot avoid the integration mandate by binding their hands in their own red tape.⁴⁷² In *Steimel*, the Seventh Circuit rejected Indiana’s argument that the methodology and criteria it was using to allocate waiver services were “‘necessary for the provision’ of the relevant services.”⁴⁷³ Arkansas has decided to implement a more restrictive EVV system than required by CMS. CMS has declared that GPS and geofencing, some of the most intrusive aspects of Arkansas’s EVV systems, are not necessary to meet federal requirements.⁴⁷⁴ A less restrictive EVV system would still permit the state to collect the information required by the Cures Act and would not fundamentally alter the state’s programs, services, or activities.⁴⁷⁵

mental disabilities, and the State’s obligation to mete out those services equitably”); *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1182–83 (10th Cir. 2003) (“[T]he fact that [a state] has a fiscal problem, by itself, does not lead to an automatic conclusion that [the provision of prescription benefits] will result in a fundamental alteration.”); *Townsend v. Quasim*, 328 F.3d 511, 520 (9th Cir. 2003) (finding that budgetary considerations are insufficient to establish a fundamental alteration defense and that the state had to prove that the asserted “extra costs would, in fact, compel cutbacks in services to other recipients”).

470. See *Pa. Prot. & Advoc., Inc. v. Pa. Dep’t of Pub. Welfare*, 402 F.3d 374, 383 (3d Cir. 2005) (“The presence of these additional factors . . . is required in order to credit an agency’s fundamental alteration defense.”); *Haddad v. Arnold*, 784 F. Supp. 2d 1284, 1304 (M.D. Fla. 2010) (“Beyond conclusory statements . . . Defendants have not shown how Plaintiff’s cost analysis is flawed, how much an expansion of their provider network would cost, or why an individual must enter a nursing home facility for a certain period of time before Defendants realize any savings.”).

471. *Haddad*, 784 F. Supp. 2d at 1305 (finding that the State had failed to show that it had a “comprehensive, effectively working plan,” which it would need to show as a prerequisite to mounting a fundamental alteration defense).

472. See, e.g., *Steimel v. Wernert*, 823 F.3d 902, 918 (7th Cir. 2016) (“Our decision today does not require the state of Indiana to adopt any particular solution to make its waiver program compliant with the integration mandate. . . . But the state cannot avoid the integration mandate by painting itself into a corner and then lamenting the view.”).

473. See *id.* at 916 (quoting 28 C.F.R. § 35.130(b)(8) (2016)).

474. See *Ctrs. for Medicare & Medicaid Servs., Frequently Asked Questions: Section 12006 of the 21st Century Cures Act 5*, <https://www.medicaid.gov/sites/default/files/federal-policy-guidance/downloads/faq051618.pdf> [<https://perma.cc/GB7Z-AFKH>] (last visited Oct. 5, 2023) (“CMS also notes that there is no requirement to use global positioning services (GPS), but it is one approach for implementation of the EVV requirements.”).

475. *Steimel*, 823 F.3d at 916.

C. *Surveillance that Segregates Students With Disabilities*

1. *The ADA, Students With Disabilities, and Threat-Assessment Processes.* — A claim that threat-assessment processes violate the integration mandate must demonstrate that public schools are public entities within the meaning of the ADA and that students with disabilities are “qualified individuals with disabilities.”⁴⁷⁶ These are relatively straightforward inquiries. A robust body of law provides that public schools are public entities and that the provision of a public education falls within the definition of “services, programs, or activities” provided by a public entity.⁴⁷⁷ The students particularly targeted by threat-assessment systems—namely, students who are receiving special education services under an IEP or have received and continue to receive mental health services—could easily demonstrate that they are qualified students with disabilities.⁴⁷⁸

2. *The Isolating and Segregating Effects of Threat-Assessment Processes.* — Courts have held that school districts have violated the integration mandate when they have excluded or removed students with disabilities from school-provided activities and programs. In *J.S., III ex rel. J.S., Jr. v. Houston County Board of Education*, the Eleventh Circuit held that persistently removing a student with a disability from his classroom because he was deemed “disruptive” violated the integration mandate and the Supreme Court’s ruling in *Olmstead*.⁴⁷⁹ The court held that the frequent exclusion and isolation from the classroom “implicat[e] those further, intangible consequences of discrimination contemplated in *Olmstead*,” including “stigmatization and deprivation of opportunities for enriching interaction with fellow students.”⁴⁸⁰ In *K.M. ex rel. D.G. v. Hyde Park Central School District*, the Southern District of New York found that a student’s being forced to eat lunch by himself could violate the integration mandate.⁴⁸¹ The court determined that this “needlessly relinquish[ed] participation in community life” and that “[e]ating lunch with other students could be considered an integral part of the public school experience, one in which D.G. would be entitled to participate if a reasonable accommodation for his disability would make it possible.”⁴⁸²

476. See 42 U.S.C. § 12131 (2018).

477. See, e.g., *Tennessee v. Lane*, 541 U.S. 509, 517, 525 (2004) (listing public education as one of the sites of discrimination that Title II was seeking to address); *K.M. ex rel. Bright v. Tustin Unified Sch. Dist.*, 725 F.3d 1088, 1097 (9th Cir. 2013) (“There is . . . no question that public schools are among the public entities governed by Title II.”).

478. See, e.g., *United States v. Georgia*, 461 F. Supp. 3d 1315, 1328 (N.D. Ga. 2020) (finding that students with behavior-related disabilities funneled into the Georgia Network for Educational and Therapeutic Support Program were protected by the Title II of the ADA).

479. 877 F.3d 979, 983, 985–89 (11th Cir. 2017).

480. *Id.* at 987.

481. 381 F. Supp. 2d 343, 360 (S.D.N.Y. 2005).

482. *Id.*

Threat-assessment procedures give schools an informal way to remove students engaging in supposedly “problematic” disability-related behavior from school.⁴⁸³ Practically speaking, once a school identifies a student as a substantive threat, the school can prevent the student from accessing the school campus altogether or participating in school activities.⁴⁸⁴ In at least one state, schools can decide to remove a student without consulting anyone familiar with their disability-related needs.⁴⁸⁵ Further, students face high barriers to reentering the school setting.⁴⁸⁶ Reentry protocols after assessment as a threat are unclear, and students can miss significant amounts of school.⁴⁸⁷ Threat-assessment processes can, therefore, result in students being excluded from school settings and provided with an

483. Ctr. for C.R. Remedies at the C.R. Project, Ctr. for Disability Rts., Council of Parent Att’ys and Advocs., Daniel Initiative, Educ. L. Ctr., Nat’l Ctr. for Youth L., Fed. Sch. Discipline & Climate Coal., Nat’l Disability Rts. Network & Open Soc’y Pol’y Ctr., K–12 Threat Assessment Processes: Civil Rights Impacts 3 (2022), <https://www.ndrn.org/wp-content/uploads/2022/02/K-12-Threat-Assessment-Processes-Civil-Rights-Impacts-1.pdf> [<https://perma.cc/ZFN4-DGZ8>] [hereinafter K–12 Threat Assessment Processes].

484. See *id.* at 5–6.

485. See Model Behavioral Threat Assessment, *supra* note 311, at 10–11 (“Those that may be able to contribute to the threat assessment process include . . . representatives from the IEP team, where appropriate.”). While Florida requires participation by “persons with expertise in counseling, instruction[,] . . . school administration[,] . . . and law enforcement,” it does not require a student’s IEP representative to participate in the threat-assessment process. *Id.*

486. Kara Arundel, Threat Assessments: Preventing School Violence or Creating Student Trauma?, K–12 Dive (Aug. 10, 2021), <https://www.k12dive.com/news/threat-assessments-preventing-school-violence-or-creating-student-trauma/604658/> (on file with the *Columbia Law Review*) (describing concerns that students subject to threat assessments are rarely provided resources following the assessment); Advocs. for Child. of N.Y., Comment Letter on Request for Information Regarding the Nondiscriminatory Administration of School Discipline, Docket No. ED-2021-OCR-0068-0001, at 16 (July 23, 2021), https://www.advocatesforchildren.org/sites/default/files/on_page/ocr_comments_discipline_7.23.21.pdf [<https://perma.cc/4MNK-3MGH>] [hereinafter AFC, Comment Letter] (reporting that protection and advocacy agencies of various states have observed school districts engage in “risk assessments” that require parents to obtain an evaluation that confirms a student does not pose a risk before permitting the student to return to school).

487. See K–12 Threat Assessment Processes, *supra* note 483 (noting how threat assessments are used to impose “off the books” suspensions that circumvent “legally required due process” even though the procedures governing these practices are “vague”). The National Disability Rights Network provides an example of a tenth-grade student who was excluded from school indefinitely pending the results of a “threat assessment.” *Id.* at 5. This caused him to miss almost a month of school without any alternative services in place, violating special education and civil rights laws. *Id.*; see also Arundel, *supra* note 486 (detailing informal removals of students with disabilities until the child is deemed to be not “risky”); Steven Yoder, Do Protocols for School Safety Infringe on Disability Rights?, Hechinger Rep. (Dec. 28, 2022), <https://hechingerreport.org/do-protocols-for-school-safety-infringe-on-disability-rights/> [<https://perma.cc/Z6H6-765F>] (detailing other cases in which students were removed from the school setting while the school conducted a threat assessment and were ultimately prevented from returning to school).

education inferior to that received by their peers in a manner that violates the integration mandate.⁴⁸⁸

3. *Threat-Assessment Processes Violate the ADA.* — Public entities are excused from complying with the ADA regarding people deemed to pose a “direct threat” to others.⁴⁸⁹ There are two things that are notable about the regulations pertaining to direct threat. The first is the requirement that the entity must conduct an individualized evaluation of the risk posed by the individual.⁴⁹⁰ This evaluation must be “based on reasonable judgment that relies on current medical knowledge or on the best available objective evidence.”⁴⁹¹ The regulations prohibit public entities from making decisions that rely on “mere speculation, stereotypes, or generalizations about individuals with disabilities” rather than actual risks.⁴⁹²

The second is that a public entity must also consider how the individual could be accommodated to mitigate that risk.⁴⁹³ That is, a public school must “ascertain[] the nature, duration, and severity of the risk; the probability that the potential injury will actually occur; and whether reasonable modifications of policies, practices, or procedures or the provision of auxiliary aids or services will mitigate the risk.”⁴⁹⁴

Removal as part of threat-assessment processes can take place without the careful, individualized assessment contemplated by the ADA and its regulations.⁴⁹⁵ Indeed, public entities may remove people based on *perceptions* of danger without first providing accommodations to ameliorate the risk.⁴⁹⁶ The behavioral threat-assessment process involves

488. See, e.g., Robert D. Dinerstein & Shira Wakschlag, Using the ADA’s “Integration Mandate” to Disrupt Mass Incarceration, 96 *Denv. L. Rev.* 917, 937 (2019) (describing a pending class action suit in which Georgia was sued for violating the ADA’s integration mandate after instituting a program segregating students with behavior-related disabilities).

489. 28 C.F.R. § 35.139(a) (2023).

490. *Id.* § 35.139(b).

491. *Id.*

492. *Id.* § 36.301(b).

493. *Id.* § 35.139(b).

494. *Id.*

495. See, e.g., AFC, Comment Letter, *supra* note 486, at 5 (reporting on a preteen student with emotional disabilities who had a history of making threats with no intention to carry them out and who was threatened with exclusion from the school until a threat-assessment evaluation was conducted); K–12 Threat Assessment Processes, *supra* note 482, at 3 (observing how threat assessments circumvent civil rights protections).

496. See, e.g., All. for Excellent Educ., Ctr. for Am. Progress, Educ. Tr., Educ. Reform Now, Nat’l Ctr. for Learning Disabilities, Nat’l Urb. League, SchoolHouse Connection, TeachPlus & UnidosUS, Comment Letter on Request for Information Regarding the Nondiscriminatory Administration of School Discipline, Docket No. ED-2021-OCR-0068, at 5 (July 23, 2021), https://downloads.regulations.gov/ED-2021-OCR-0068-3047/attachment_1.pdf [<https://perma.cc/6DRJ-2DEF>] (“We are deeply concerned that threat assessments may be used to label students as threats based on data that has no documented link to violent behavior, such as data on disabilities or those seeking mental health care.”);

identifying “[c]oncerning behavior” that may not rise to the level of an actual threat.⁴⁹⁷ Behavior that may attract the attention of threat-assessment teams include “increased absenteeism, withdrawal from friends or activities, changes in habits or appearance and other mental or emotional health concerns.”⁴⁹⁸ Without engaging in the careful threat assessment contemplated by the ADA, school districts that exclude students prior to conducting an assessment or require that a student obtain an evaluation demonstrating that they do not pose a threat before being permitted to return to school would not be able to rely on the “direct threat” defense.⁴⁹⁹ Indeed, these practices circumvent the protections of and therefore violate the ADA and Section 504.⁵⁰⁰

CONCLUSION:
QUESTIONING SURVEILLANCE, CENTERING INTEGRATION

Surveillance of people with disabilities is often described as being at best beneficial or at worst innocuous. This surveillance is frequently driven by laudable goals: to discharge a duty of care toward vulnerable people with disabilities, to conserve public resources, to protect school communities, and to funnel resources to where they are required. Practically, however, as this Essay demonstrates, disability surveillance can have a profoundly adverse consequence on the integration of people with disabilities into the community. Surveillance systems like cameras in group homes can result in community settings that resemble institutional settings. EVV systems can erode personal care services, placing people who require these services at risk of institutionalization. Threat-assessment teams in schools can result in a punitive environment for students with disabilities and in their removal from school settings.

How, then, can we center integration when developing policies and practices that depend on the surveillance of people with disabilities? This

Off. for C.R., U.S. Dep’t of Educ., Supporting Students With Disabilities and Avoiding the Discriminatory Use of Student Discipline Under Section 504 of the Rehabilitation Act of 1973, at 21 (2022), <https://www2.ed.gov/about/offices/list/ocr/docs/504-discipline-guidance.pdf> [<https://perma.cc/75EG-5UJ8>] (“[Risk] assessments are used to identify students who may pose a threat of physical violence to others at school or at school-sponsored events or to assess the level of risk that a student who previously engaged in serious misbehavior may pose to others in such settings.”).

497. See, e.g., Model Behavioral Threat Assessment, *supra* note 311, at 12.

498. *Id.*

499. See K–12 Threat Assessment Processes, *supra* note 482, at 13–14 (describing the tension between federal laws, threat assessments, and constitutional due process protections for students with disabilities).

500. See AFC, Comment Letter, *supra* note 486, at 4 (noting that under the Individuals With Disabilities Education Act (IDEA) and Section 504, a student with unmet behavioral needs must be provided with supports and services and is entitled to the due process protections of those statutes).

is a crucial question to answer as we move toward a future where surveillance is part of the governing practice of modern society. While scholars have voiced concern about the surveillance creep and its potential to perpetuate and deepen social inequality, it is an “increasingly widely shared view that total surveillance might be ‘necessary’” in some way for what Professors Torin Monahan and David Murakami Wood call “the onward progress of human civilization.”⁵⁰¹

In the face of this inexorable “progress,” one question is whether surveillance systems actually solve the problems that prompt their use. For instance, are surveillance systems an effective solution to the chronic, systemic problem of abuse and neglect in group homes? Do they really keep people with disabilities safe within the community? One problematic consequence of a service-provision model that relies on the use of “granny cams” in group homes is that it presumes residents have family advocates with the “technical, social, and financial wherewithal to install and monitor cameras and the data they gather.”⁵⁰² EMDs’ potential to resolve a systemic problem is thus limited because not all people with disabilities have these support systems.⁵⁰³ Effectively, these systems outsource the burden of safety and oversight to family members rather than the state—an untenable outcome. Rather, as argued above, systemic overhaul may be better achieved by implementing reliable incident-management and investigation protocols and quality-assurance mechanisms to assess the delivery of community-based services within group homes.⁵⁰⁴

A further question is about what surveillance systems may be displacing. Using surveillance systems to create order through rules and official procedures can displace the actual order—how people actually operate to get things done.⁵⁰⁵ EVV technology and the rules that drive its

501. Torin Monahan & David Murakami Wood, Editorial, *Revitalizing Dissent: Imperatives for Critical Surveillance Inquiry*, 20 *Surveillance & Soc’y* 326, 328 (2022).

502. See Levy et al., *supra* note 218, at 333.

503. See *id.* at 332–33 (suggesting that the utility of EMDs becomes limited when the “basic assumptions” upon which their rollout is predicated are not borne out, such as the presence of family members who can install, monitor, and respond to alert systems).

504. See, e.g., HHS, *Joint Report: Group Homes*, *supra* note 214, at 3 (recommending the implementation of “1. reliable incident management and investigation processes; 2. audit protocols that ensure compliance with reporting, review, and response requirements; 3. effective mortality reviews of unexpected deaths; and 4. quality assurance mechanisms that ensure the delivery and fiscal integrity of appropriate community-based services”); see also Ariz. Developmental Disabilities Plan. Council, *Sexual Abuse of Arizonians With Developmental and Other Disabilities 1–2* (2019), https://addpc.az.gov/sites/default/files/media/2019%20ADDPC%20recomendations%20on%20preventing%20abuse_0.pdf [<https://perma.cc/U78Q-X7LG>] (recommending legislation to ensure that group home staff who work with people with disabilities are trained about what abuse and neglect mean and their obligations to report it).

505. See Karen Levy, *Data Driven: Truckers, Technology, and the New Workplace Surveillance* 152 (2023) (“[M]undane life . . . should be interfered with only on pain of screwing things up in a big way. To create apparent order, you kill the actual order. . . . [Y]ou

use clearly do not reflect the reality of people's lives and the way they use home health aide services. A common concern of personal care workers and individuals with disabilities is EVV's punitive lack of flexibility for providing home health aide services—services that, by their nature, are unpredictable and must be tailored to peoples' fluctuating, inconsistent needs. The use of EVV systems in this manner threatens to undermine hard-won protections that the disability community has fought for—in particular, the right of disabled people within the community to exert control over their services rather than being passive recipients of care.

We must also ask if surveillance systems respond to narratives about disability that are rooted in prejudice. Threat-assessment processes feed a popular but inaccurate public narrative linking disability and violence.⁵⁰⁶ Perpetrators of violent behavior—like mass shooters—are deemed mentally ill by media and legislators.⁵⁰⁷ This narrative has shaped the political response to incidents of gun violence in schools.⁵⁰⁸ The reality, however, is that people with disabilities are more likely to be targets of violence than perpetrators.⁵⁰⁹ Substance abuse and a history of exposure to violence and trauma are stronger predictors of shootings than psychiatric disability.⁵¹⁰ Mass violence is a result of a confluence of factors,

efface the tacit mechanisms and social work-arounds that people use to get things done[.]” (second through fifth alterations in original) (internal quotation marks omitted) (quoting Harvey Molotch, *Against Security: How We Go Wrong at Airports, Subways, and Other Sites of Ambiguous Danger* 215–16 (2014))).

506. See, e.g., Lydia Saad, *Americans Fault Mental Health System Most for Gun Violence*, Gallup (Sept. 20, 2013), <https://news.gallup.com/poll/164507/americans-fault-mental-health-system-gun-violence.aspx> [<https://perma.cc/A755-2NGY>] (finding that 48% of Americans believe that the mental health system is “a great deal” to blame for mass shootings).

507. See, e.g., Tori DeAngelis, *Mental Illness and Violence: Debunking Myths, Addressing Realities*, *Monitor on Psych.*, Apr./May 2021, at 31, 32 (“[A] growing body of research shows that when people with serious mental illness commit violent or aggressive acts, other factors besides the illness itself are often at play . . .”).

508. See Maria Konnikova, *Is There a Link Between Mental Health and Gun Violence?*, *New Yorker* (Nov. 19, 2014), <https://www.newyorker.com/science/maria-konnikova/almost-link-mental-health-gun-violence> (on file with the *Columbia Law Review*) (noting that the link between psychiatric disability and violence has, since the Gun Control Act of 1968, resulted in gun control laws that prohibit or otherwise restrict people with psychiatric and intellectual disabilities from purchasing firearms).

509. Katie O'Connor, *Mental Illness Too Often Wrongly Associated With Gun Violence*, *Psychiatric News* (June 15, 2021), <https://psychnews.psychiatryonline.org/doi/full/10.1176/appi.pn.2021.7.23> [<https://perma.cc/U9DK-3V8V>].

510. In a 2002 study of more than 800 people across four states who were being treated for psychosis or major mood disorders, researchers found that almost 13% had committed a violent act in that year. Jeffrey W. Swanson, Marvin S. Swartz, Susan M. Essock, Fred C. Osher, H. Ryan Wagner, Lisa A. Goodman, Stanley D. Rosenberg & Keith G. Meador, *The Social–Environmental Context of Violent Behavior in Persons Treated for Severe Mental Illness*, 92 *Am. J. Pub. Health* 1523, 1523–24 (2002). The likelihood that they committed violence depended on whether they had experienced homelessness, lived in disadvantaged communities, or had suffered from violence themselves. *Id.* at 1528 (finding that, while no

and even proponents of threat-assessment processes acknowledge that youth who engage in violent acts are “behaviorally and psychologically heterogenous” and that “there is no profile or single ‘type’ of perpetrator of targeted violence.”⁵¹¹ Despite this reality, students with disabilities are disproportionately subject to threat-assessment processes, suffering severe legal consequences: incursions into their privacy, disruption to their education, and civil commitment or incarceration.

The ADA’s integration mandate provides a lens through which to consider the impact of surveillance by compelling consideration of the lived experiences of people with disabilities and drawing attention to the downstream effects of surveillance systems and the way surveillance can generate negative stereotypes about disability. The integration mandate contemplates community as more than merely a locale framed in terms of negation. Rather, it is a change in mindset requiring meaningful opportunities to participate in the community and develop relationships.⁵¹² This Essay demonstrates that failure to center integration in debates over the use of surveillance systems can result in a shallow and superficial conception of community, in which surveillance results in the exclusion and isolation of people with disabilities rather than their inclusion.

variable stood out as “the primary explanation” for violence, people receiving treatment for severe mental illnesses were more likely to be violent if they had been exposed to violence and/or homelessness); see also Richard Van Dorn, Jan Volavka & Norman Johnson, *Mental Disorder and Violence: Is There a Relationship Beyond Substance Abuse?*, 47 *Soc. Psychiatry & Psychiatric Epidemiology* 487, 490–92 (2012) (finding, in a 2012 study of more than 34,000 individuals, that just under 3% of people with severe mental illnesses had engaged in violent behavior over the course of the year but noting that this risk was elevated when individuals also abused alcohol or drugs).

511. Marisa Reddy, Randy Borum, John Berglund, Bryan Vossekuil, Robert Fein & William Modzeleski, *Evaluating Risk for Targeted Violence in Schools: Comparing Risk Assessment, Threat Assessment, and Other Approaches*, 38 *Psych. Schs.* 157, 167–68 (2001) (quoting Herbert C. Quay, *Patterns of Delinquent Behavior*, in *Handbook of Juvenile Delinquency* 118, 118 (Herbert C. Quay ed., 1987)).

512. See Ben-Moshe, *Contested Meaning*, supra note 39, at 243–44 (“[I]f one defines ‘community’ as the building of human relationships and not locale of services, then the effects of what became to be known as ‘community living’ should be rethought and problematized given that one can be quite isolated while living ‘in the community.’”).

