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## Disability Rights and Labor: Is This Conflict Really Necessary?\*

SAMUEL R. BAGENSTOS‡

The relationship between the American labor movement and identity-based social movements has long been a complicated one. Organized labor has often been an ally of civil rights struggles, and major civil rights leaders have often supported the claims and campaigns of organized labor. Recall the reason Dr. Martin Luther King was in Memphis on the day he was assassinated—to lend his support to a strike by unionized sanitation workers.<sup>1</sup> But unions and civil rights groups have found themselves on the opposite sides of intense battles as well. These battles have included fights over race and sex discrimination and harassment in union-dominated workplaces (which pitted civil rights groups against the public-safety-worker and craft unions that themselves often had a history of discrimination), as well as the struggles over sex-specific protective labor legislation (legislation supported by a wide swath of the labor movement, but that severely limited job opportunities for women).<sup>2</sup>

The relationship between the labor movement and the disability rights movement is just as complicated. Organized labor has often been an ally of disability rights

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\* Apologies to Roger J. Traynor, *Is This Conflict Really Necessary?*, 37 TEX. L. REV. 657 (1959).

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‡ Frank G. Millard Professor of Law, University of Michigan Law School. This Essay is an annotated version of the William R. Stewart Lecture delivered at the Indiana University Maurer School of Law on April 13, 2016. Thanks so much to Dean Austen Parrish, Professors Ken Dau-Schmidt and Deborah Widiss, and my other terrific hosts, as well as to the editors of this law journal for helping me get this piece into publishable shape. Some of the material in this Essay draws on briefs I drafted in *Harris v. Quinn*, 134 S. Ct. 2618 (2014), and *Home Care Ass'n of America v. Weil*, 799 F.3d 1084 (D.C. Cir. 2015), *cert. denied*, 136 S. Ct. 2506 (mem.), 2016 WL 3461581 (2016).

1. Charlotte Garden and Nancy Leong nicely use Dr. King's assassination, and the reason he was in Memphis, as the entry point for their argument that labor unions and civil rights groups share important interests. See Charlotte Garden & Nancy Leong, "So Closely Intertwined": *Labor and Racial Solidarity*, 81 GEO. WASH. L. REV. 1135, 1136–38 (2013).

2. For discussions of tensions between unions and civil rights advocates in the race and gender contexts, see PAUL FRYMER, *BLACK AND BLUE: AFRICAN AMERICANS, THE LABOR MOVEMENT, AND THE DECLINE OF THE DEMOCRATIC PARTY* 44–69 (2008); WILLIAM B. GOULD, *BLACK WORKERS IN WHITE UNIONS: JOB DISCRIMINATION IN THE UNITED STATES* 15–22 (1977); SOPHIA Z. LEE, *THE WORKPLACE CONSTITUTION FROM THE NEW DEAL TO THE NEW RIGHT* 175–91 (2014); NANCY MACLEAN, *FREEDOM IS NOT ENOUGH: THE OPENING OF THE AMERICAN WORKPLACE* 40–42, 90–103, 275–83, 288 (2006); JOHN DAVID SKRENTNY, *THE IRONIES OF AFFIRMATIVE ACTION: POLITICS, CULTURE, AND JUSTICE IN AMERICA* 196–98 (1996). On labor unions and sexual harassment, see Marion Crain, *Women, Labor Unions, and Hostile Work Environment Sexual Harassment: The Untold Story*, 4 TEX. J. WOMEN & L. 9, 29–45 (1995). For an extensive discussion of the mechanisms by which labor organization in the United States has historically favored white, male workers, see Marion Crain & Ken Matheny, "Labor's Divided Ranks": *Privilege and the United Front Ideology*, 84 CORNELL L. REV. 1542, 1567–90 (1999).

efforts.<sup>3</sup> But in some of the highest-stakes battles for workers and individuals with disabilities, many unions and disability rights groups have opposed each other.<sup>4</sup> Although many commentators have written about the tensions and collaborations between labor unions and civil rights groups promoting race or sex equality, the very similar dynamics of the relationship between unions and disability rights groups have largely escaped comment.<sup>5</sup>

In the past several years, though, the tensions in the labor-disability relationship have become especially acute. As unions (particularly the Service Employees International Union) have pushed for increased wages and benefits for direct-care workers who provide home and community-based services, and state Medicaid cuts have placed pressure on the budgets available to pay those workers, many disability rights activists have worried that labor's agenda will lead to the (re-)institutionalization of people with disabilities. This tension stood in the background of the litigation in *Harris v. Quinn*,<sup>6</sup> in which the Supreme Court addressed the collective-bargaining system some states had set up for personal-assistance workers. And the dispute between unions and (some) disability rights activists broke out in a particularly sharp and nasty way in response to the Department of Labor's recent rules expanding Fair Labor Standards Act (FLSA) protections for home care workers.<sup>7</sup> Although some disability rights groups supported the new rules, which had been a major priority of organized labor, particularly vocal and influential activist groups opposed them—to the point of sending lumps of coal to the house of the Secretary of Labor at Christmas and conducting sit-ins in his home driveway.<sup>8</sup>

These tensions are nothing new. Disability rights activists have long challenged the paternalism of those assigned to “help” or “care” for them, and the unions that represent those workers are thus a natural target for suspicion if not antagonism. And many (though not all) elements of the American labor movement have strongly opposed the deinstitutionalization of people with mental disabilities. The current labor-disability tensions cannot be understood outside of the context of that history.

In this Essay, I hope to do two things: First, I try to put the current labor-disability controversy into that broader context. Second, and perhaps more important, I take a position on how disability rights advocates should approach both the current controversy and labor-disability tensions more broadly. As to the narrow dispute over wage-and-hour protections for personal-assistance workers, I argue both that those workers have a compelling normative claim to full FLSA protection—a claim that disability rights advocates should recognize—and that supporting the claim of those

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3. An important recent example involves a set of cases challenging Medicaid budget cuts under the Americans with Disabilities Act. In these cases, unions have often served as plaintiffs with individuals with disabilities. *See, e.g.,* *M.R. v. Dreyfus*, 663 F.3d 1100 (9th Cir. 2011), *opinion amended and superseded on denial of reh'g*, 697 F.3d 706 (9th Cir. 2012).

4. *See infra* Part I.

5. I did discuss some of these tensions, in a somewhat general way, in Samuel R. Bagenstos, *The Past and Future of Deinstitutionalization Litigation*, 34 *CARDOZO L. REV.* 1, 16–20, 45–49 (2012).

6. 134 S. Ct. 2618 (2014).

7. *See* Application of the Fair Labor Standards Act to Domestic Service, 78 Fed. Reg. 60,454, 60,460–94 (Oct. 1, 2013) (to be codified at 29 C.F.R. pt. 552).

8. *See infra* text accompanying notes 52–60.

workers is pragmatically in the best interests of the disability rights movement. As to the broader tensions, I argue that disability rights advocates go wrong, both normatively and pragmatically, in treating the interests of individuals with disabilities as inevitably superordinate to those of individuals who do the work of providing community-based services and supports. Although this wrong turn is completely understandable in light of the history of paternalist subordination of people with disabilities at the hands of the helping professions, today's situation calls for an accommodation of the legitimate claims of each side.

I should acknowledge from the start that I do not purport to be offering the “view from nowhere.”<sup>9</sup> I have worked in and around the disability rights movement for two decades. As a lawyer pursuing deinstitutionalization efforts that some unions have opposed—and as a lawyer representing disability rights organizations in supporting labor protections for personal-assistance workers—I have participated in some of the controversies I discuss here. My argument takes as a basic premise that the goals of the American disability rights movement—that people with disabilities should have the same opportunity to live in and participate as full members of the broader community as everyone else—state a powerful normative claim.<sup>10</sup> I ask what stance people who agree with those goals should take toward the claims of workers who provide services to individuals with disabilities. I argue that even firm disability rights supporters should, in many cases, support the claims of those workers—including in recent disputes over unionization and FLSA protection.

I begin in Part I by describing the conflict, both its roots in earlier fights over deinstitutionalization and its recent instantiations in fights over labor protections for attendant-services workers. In Part II, I make a normative argument for disability rights activists to accommodate the legitimate claims of the workers who provide personal-assistance services. In Part III, I make a pragmatic argument for such an accommodation.

## I. THE CONFLICT

This Part introduces the conflict between organized labor and disability rights activists. Although that conflict has been expressed most recently in fights over unionization and pay protections for personal-assistance workers, it has much deeper roots. To understand the current controversy, one must start with those roots. I begin by discussing the American disability rights movement's critique of the “helping” professions, a critique that, at an ideological level, underlies the skepticism many disability rights advocates have toward the unions that represent members of those professions. I then discuss the role of public-employee unions, particularly the American Federation of State, County, and Municipal Employees (AFSCME), in opposing the deinstitutionalization of individuals with mental disabilities. Finally, I turn to the more current controversy. I show how the realities of Medicaid budget politics, combined with the suspicions that linger from prior conflicts, lead disability

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9. The obligatory cite is to THOMAS NAGEL, *THE VIEW FROM NOWHERE* (1986).

10. On the diverse goals of the participants in the disability rights movement, and the core consensus on equality, empowerment, and integration, see SAMUEL R. BAGENSTOS, *LAW AND THE CONTRADICTIONS OF THE DISABILITY RIGHTS MOVEMENT* 12–33 (2009).

rights advocates to worry that efforts to improve the pay of personal-assistance workers will limit opportunities for people with disabilities to live full, independent lives in their homes and communities.

*A. The Disability Rights Movement, the Critique of Paternalism, and the Creation of Consumer-Directed Personal-Assistance Services*

For many American disability rights activists, the principal engine of disability inequality has been paternalism. Nondisabled individuals, particularly parents and members of the professions, have treated individuals with disabilities as the objects of charity and pity. Although this treatment often stemmed from generous impulses, the result was to confine persons with disabilities to lives as perpetual sick people, with services designed to care for them rather than to promote opportunities for individuals with disabilities to make and realize their own choices about how to live their lives.<sup>11</sup>

This paternalism was often fed by widespread stereotypes about disability. In particular, perceptions of individuals with disabilities are marked by what scholars have called the “spread effect”—the (perhaps implicit or unconscious<sup>12</sup>) assumption that persons who experience limitations on performing some tasks are broadly incompetent to act and choose for themselves.<sup>13</sup> Indeed, for many disability rights activists, it is these stereotype-driven attitudes, combined with social decisions about how to design structures and institutions, that in fact create disability by making particular physical or mental impairments disabling.<sup>14</sup>

As it coalesced in the last third of the twentieth century, the American disability rights movement devoted much of its effort to countering these stereotypes and to fighting the paternalism of parents and professionals.<sup>15</sup> Movement adherents argued that law and policy should be premised on a social model of disability—in which disability is created by the interaction between a physical or mental condition and hostile or inaccessible attitudes or environments.<sup>16</sup> They pushed for policy approaches that would promote independence and integration of people with disabilities—approaches that centered on civil rights laws rather than charity or medical care.<sup>17</sup>

Movement adherents recognized that people with disabilities might rely on services or supports to participate fully in society, but they advocated for service delivery models that would promote independence and integration. “Independence,”

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11. See Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1, 17 (2004).

12. On implicit bias and disability, see Dale Larson, Comment, *Unconsciously Regarded as Disabled: Implicit Bias and the Regarded-As Prong of the Americans with Disabilities Act*, 56 UCLA L. REV. 451 (2008).

13. See Samuel R. Bagenstos, *Subordination, Stigma, and “Disability,”* 86 VA. L. REV. 397, 423–24 (2000); Samuel R. Bagenstos & Margo Schlanger, *Hedonic Damages, Hedonic Adaptation, and Disability*, 60 VAND. L. REV. 745, 779 (2007).

14. See Bagenstos, *supra* note 13, at 426–36.

15. See Samuel R. Bagenstos, *The Americans with Disabilities Act as Welfare Reform*, 44 WM. & MARY L. REV. 921, 1010–12 (2003); Bagenstos, *supra* note 11, at 13–14.

16. See Bagenstos, *supra* note 13, at 428–30.

17. See Bagenstos, *supra* note 11, at 10–18.

for participants in the American disability rights movement, had a particular meaning. It did not consist in the ability to perform tasks without help—what you might call physical independence—but instead in the ability to make effective choices about how to live one’s life.<sup>18</sup> These choices stem from the most major decisions about how to construct one’s life projects all the way to the most mundane day-to-day decisions about what kind of snack to get from the fridge, and when to do so. If a person with a disability can make these life choices, big and small, and make them stick, then she is independent in this sense even if she must rely on the assistance of others to put these choices into effect (by helping her get dressed for work, for example, or by physically fetching the snack from the refrigerator).<sup>19</sup>

This latter understanding of independence, which you might call decisional independence, occupies a central place in the thinking of most American disability rights advocates.<sup>20</sup> Many of these advocates developed the model of consumer-directed personal-assistance services to put the ideal of decisional independence into practice.<sup>21</sup> “Personal-assistance services” is the phrase that these advocates decided to use to describe what others would call home-based care. The idea is that “care” is something that elevates the caretaker above the person who is being taken care of, and that it treats the cared-for person as simply an object, rather than as a subject with projects of her own. “Assistance,” by contrast, highlights the important principle that it is the disabled person whose projects and choices matter; the worker is there to assist her with realizing them.<sup>22</sup> The model of consumer direction puts that principle into practice: by requiring the personal assistant to do what the disabled person—and not a family member, treatment provider, or anyone else—wants her to do at any given moment, and by giving the disabled person the power to hire, fire, and otherwise control the working conditions of the assistant.<sup>23</sup>

Under the model of consumer-directed personal-assistance services, individuals with disabilities who need assistance with basic activities of daily living receive that assistance in their own homes and communities from workers whom they can hire and fire, and whom they could direct on a day-to-day and even minute-to-minute basis. Relying on consumer-directed personal assistance, in the view of disability rights activists, serves the independence of individuals with disabilities. Those who

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18. See Bagenstos, *supra* note 15, at 991–1000.

19. See *id.* at 992–93.

20. I owe the term “decisional independence” to Elias S. Cohen, *What Is Independence?*, GENERATIONS, Winter 1992, at 49. See also Adrienne Asch, *Disability, Bioethics, and Human Rights*, in HANDBOOK OF DISABILITY STUDIES 297, 313 (Gary L. Albrecht, Katherine Seelman & Michael Bury eds., 2001) (arguing that “independence need not be viewed in physical terms” but instead that “self-direction, self-determination, and participation in decision making about one’s life are more genuine and authentic measures of desirable independence”).

21. See Andrew I. Batavia, *A Right to Personal Assistance Services: “Most Integrated Setting Appropriate” Requirements and the Independent Living Model of Long-Term Care*, 27 AM. J.L. & MED. 17 (2001); Andrew I. Batavia, Gerben DeJong & Louise Bouscaren McKnew, *Toward a National Personal Assistance Program: The Independent Living Model of Long-Term Care for Persons with Disabilities*, 16 J. HEALTH POL. POL’Y & L. 523 (1991); A.E. Benjamin, *Consumer-Directed Services at Home: A New Model for Persons with Disabilities*, HEALTH AFF., Nov./Dec. 2001, at 80.

22. See Batavia et al., *supra* note 21, at 530.

23. See Batavia, *supra* note 21, at 19; Batavia et al., *supra* note 21, at 530.

perform personal-assistance work are essentially tools to achieve the ends chosen by the individuals with disabilities themselves.<sup>24</sup>

### *B. Deinstitutionalization and Organized Labor*

It is not hard to see how the ideological critique of paternalism might have brought disability rights activists into conflict with labor unions that represented professionals who provide services to individuals with disabilities. The very concrete effort to shift power from service providers to disabled consumers necessarily sharpened the tension. But conflict came from the union side as well. Public-employee unions—particularly AFSCME—were the major opponents of disability rights advocates’ efforts in the 1970s and 1980s to end the confinement of people with mental disabilities in institutions.<sup>25</sup>

Deinstitutionalization has been an urgent priority for disability rights activists. As Justice Ginsburg explained in her opinion for the Supreme Court interpreting the Americans with Disabilities Act (ADA) to prohibit unnecessary institutionalization, confining individuals with disabilities to institutions feeds the stigma attached to disability at the same time that it denies institutionalized individuals the opportunity to participate as full members of the community:

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.<sup>26</sup>

Although the number of people with mental disabilities in state-operated institutions has dropped substantially in the past fifty years, thousands remain in those facilities.<sup>27</sup> And thousands more individuals with mental or physical disabilities are institutionalized in privately or state-operated nursing homes and other settings. Deinstitutionalization, thus, has remained a centerpiece of disability rights advocacy.

As deinstitutionalization efforts picked up speed in the 1970s, public-employee unions were typically their principal opponents. Although those same unions had often been responsible for bringing to light the institutional abuses that catalyzed deinstitutionalization litigation,<sup>28</sup> their opposition to deinstitutionalization should hardly have been surprising. State-operated institutions for individuals with disabilities were (and have remained) heavily unionized, while most of the programs that

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24. See, e.g., Batavia et al., *supra* note 21, at 529 (describing the assistant as “an extension of the disabled person”).

25. See Bagenstos, *supra* note 5, at 18–20.

26. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 600–01 (1999) (citations omitted).

27. For statistics, see Bagenstos, *supra* note 5, at 8–9; Margo Schlanger, *Anti-Incarcerative Remedies for Illegal Conditions of Confinement*, 6 U. MIAMI RACE & SOC. JUST. L. REV. 1, 24 (2016).

28. See Bagenstos, *supra* note 5, at 17–18.

provide services to those same individuals with disabilities in their homes and communities are nonunion workplaces.<sup>29</sup> Unions can be expected to fight efforts to shift work from unionized to nonunion workplaces. Indeed, they would be properly subject to criticism if they did *not* fight those efforts.

And unions fought deinstitutionalization not simply out of an immediate effort to protect union jobs in institutions. They also feared the *political agenda* of deinstitutionalization. Although disability rights advocates believed that institutions should be replaced by robust public services provided in the community, crucial support for deinstitutionalization came from fiscally conservative state politicians.<sup>30</sup> Those politicians sought to use deinstitutionalization as a tool for budget cutting and disinvestment in public services. Efforts at deinstitutionalization thus threatened both specific union jobs in existing institutions and the more general project of public service provision to which public-employee unions were committed.<sup>31</sup>

Deinstitutionalization, and the priority disability rights activists placed on it, thus stoked powerful suspicions between those activists and labor unions. And those suspicions have not gone away. As I note in Part I.C, some union and disability rights groups have worked together to find ways of reconciling each other's interests in this area. The Service Employees International Union (SEIU) has been particularly forward-looking in supporting disability rights while fighting for the interests of its members.<sup>32</sup> But a strong undercurrent of conflict remains. In those states that continue to maintain large populations of individuals with disabilities in state-operated institutions—not coincidentally, these tend to be heavily unionized states—efforts at serving those individuals in their homes and communities continue to provoke sharp responses from AFSCME and related unions.<sup>33</sup>

### C. The Current Controversy

To a large extent, disability rights forces won the earlier conflicts over deinstitutionalization. Home- and community-based services now make up the majority of Medicaid spending on long-term care services.<sup>34</sup> Many more people with disabilities receive services in their homes and communities than in state-operated

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29. *See id.* at 18–19.

30. *See id.* at 20–21.

31. *See id.*

32. *See id.* at 48.

33. *See id.* at 47.

34. *See* STEVE EIKEN, KATE SREDL, BRIAN BURWELL & PAUL SAUCIER, TRUVEN HEALTH ANALYTICS, MEDICAID EXPENDITURES FOR LONG-TERM SERVICES AND SUPPORTS (LTSS) IN FY 2013: HOME AND COMMUNITY-BASED SERVICES WERE A MAJORITY OF LTSS SPENDING (2015), <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/downloads/ltss-expenditures-fy2013.pdf> [<https://web.archive.org/web/20160829213353/https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/downloads/ltss-expenditures-fy2013.pdf>]; JENNIFER RYAN & BARBARA EDWARDS, HEALTH AFF., REBALANCING MEDICAID LONG-TERM SERVICES AND SUPPORTS (2015), [http://healthaffairs.org/healthpolicybriefs/brief\\_pdfs/healthpolicybrief\\_144.pdf](http://healthaffairs.org/healthpolicybriefs/brief_pdfs/healthpolicybrief_144.pdf) [<https://perma.cc/6FKE-ERQN>].



institutions.<sup>35</sup> And people with disabilities and their families now expect and demand that they not be forced into institutions to receive needed services.

But those disability rights victories have set the stage for the current controversies. The workers who provide home- and community-based supports to disabled people are part of what has been described as the “fastest-growing” employment sector in the United States—the so-called home-care sector.<sup>36</sup> According to Bureau of Labor Statistics projections, employment in the home-care sector is expected to grow by more than fifty percent in the decade leading up to 2024—eight times faster than employment in general is expected to rise.<sup>37</sup> And wages for workers in that sector are extremely low. According to the National Employment Law Project, “[i]n 2013, the country’s two million home care workers had average annual earnings of \$18,598. Average annual earnings for all wage and salary workers in the United States were \$46,440.”<sup>38</sup>

This state of affairs raises serious moral concerns: Is it fair to treat *any* workers this way? Do these wages reflect the importance of personal-attendant work to its clients and society? Does such low pay for workers who provide home- and community-based services limit the effectiveness of those services and thus compromise our nation’s promise to the people with disabilities whom we have freed from unnecessary institutionalization? And the concerns extend beyond the register of morality. When many personal-assistance workers depend on public assistance to make ends meet,<sup>39</sup> that places pressure on public budgets.<sup>40</sup>

The increasing importance of the personal-assistance sector also creates an organizing opportunity. Jobs providing direct services to people with disabilities in their homes cannot be sent to right-to-work states or overseas.<sup>41</sup> And the workers

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35. See Bagenstos, *supra* note 5, at 48–49 (“The overwhelming majority of people with disabilities are no longer served in large state institutions, and, as a practical matter, they never again will be.”).

36. NAT’L EMP’T LAW PROJECT, GIVING CAREGIVERS A RAISE: THE IMPACT OF A \$15 WAGE FLOOR IN THE HOME CARE INDUSTRY (2015), <http://www.nelp.org/content/uploads/2015/03/Giving-Caregivers-A-Raise.pdf> [<https://perma.cc/Y55B-FNHM>].

37. See News Release, Bureau of Labor Statistics, Employment Projections—2014-24 (Dec. 8, 2015), <http://www.bls.gov/news.release/pdf/ecopro.pdf> [<https://perma.cc/V3PQ-WCJS>] (presenting, in Table 3, more than 760,000 “home health care” jobs predicted to be added to the 2014 base of just over 1.26 million, for a compound annual growth rate of 4.8%, which is eight times greater than the .6% compound annual growth rate Table 2 predicts for employment as a whole).

38. NAT’L EMP’T LAW PROJECT, *supra* note 36, at 1 (footnote omitted).

39. See *id.* at 2 (“A significant number of home care workers rely on public assistance because their earnings are not enough to make ends meet. Among home care workers, nearly 50 percent live in households that receive public assistance benefits such as Medicaid, food stamps, and housing and heating assistance.”).

40. See KEN JACOBS, IAN PERRY & JENIFER MACGILLVARY, UNIV. OF CAL. BERKELEY CTR. FOR LABOR RESEARCH & EDUC., THE HIGH PUBLIC COST OF LOW WAGES (2015), <http://laborcenter.berkeley.edu/pdf/2015/the-high-public-cost-of-low-wages.pdf> [<https://perma.cc/MMB6-EECT>]. For a general discussion of the harms that low-wage work exacts on our economy, see Nick Hanauer, *Confronting the Parasite Economy*, AM. PROSPECT, Summer 2016, at 34.

41. See EILEEN BORIS & JENNIFER KLEIN, CARING FOR AMERICA: HOME HEALTH WORKERS

who do these jobs have very legitimate complaints about their wages and working conditions. Although it was historically very difficult to organize workers who were so geographically separated from one another, the SEIU and the AFSCME developed techniques for doing so.<sup>42</sup>

The increasing success of SEIU and AFSCME in organizing home-services workers has inevitably led to conflicts with disabled activists. The conflict has focused on two big issues. The first is control: Who controls what a personal-assistance worker does during work time? The second is money: How will increased wages for personal-assistance workers, in an age of limited resources, affect the access of people with disabilities to their services? These conflicts have drawn on, and at the same time fed, disability rights activists' longstanding distrust about the agenda of unions.

These conflicts play out directly in legal and policy fights concerning the structure for unionizing attendant-services workers. As SEIU and AFSCME proceeded with their efforts to unionize workers in this sector, disability rights activists understandably feared a loss of control over the most intimate, day-to-day choices in their lives. They feared, in particular, that unions would work out the terms and conditions of personal-assistance employment with the state (which pays for these services through Medicaid) or with private home-care agencies. Such a result would cut to the heart of the "Independent Living" philosophy that so much of the American disability rights movement has endorsed.<sup>43</sup>

After extensive organizing and negotiations, disability rights and labor groups eventually worked out a representation mechanism that would take account of the interests of both disabled persons and the workers who served them.<sup>44</sup> The workers would have the right to organize and bargain collectively with the state over the dollars-and-cents aspects of work that the state controlled, but the individual clients

IN THE SHADOW OF THE WELFARE STATE 185 (2012) ("Care work organizing was never easy, but it seemed more promising than unionizing any of the declining sectors. . . . Capital flight and offshore production reshaped manufacturing and business services, like data processing and sales, but care work was among those jobs—health care, distribution and transport, janitorial and hotel, retail and restaurant, security, and personal services—that, we have noted, were harder to export."). See generally Tyson B. Roan, *Anything but Doomed: Why Restrictions on Offshoring Are Permissible Under the Constitution and Trade Agreements*, 13 EMP. RTS. & EMP. POL'Y J. 209, 211 (2009) ("With the mass exodus of manufacturing jobs in the U.S., unions, such as those in the Change to Win Federation (CTW), are now turning their efforts toward organizing the service sector.").

42. For a nice analysis, see Nari Rhee & Carol Zabin, *Aggregating Dispersed Workers: Union Organizing in the "Care" Industries*, 40 GEOFORUM 969 (2009).

43. See *supra* text accompanying notes 18–24. On the especial importance of control to disability rights advocates, see JAMES I. CHARLTON, NOTHING ABOUT US WITHOUT US: DISABILITY OPPRESSION AND EMPOWERMENT 3 (1998) ("Control has universal appeal for DRM [disability rights movement] activists because the needs of people with disabilities and the potential for meeting these needs are everywhere conditioned by a dependency born of powerlessness, poverty, degradation, and institutionalization. This dependency, saturated with paternalism, begins with the onset of disability and continues until death.").

44. See BORIS & KLEIN, *supra* note 41, at 194–96, 215; Nari Rhee & Carol Zabin, *The Social Benefits of Unionization in the Long-Term Care Sector*, in ACADEMICS ON EMPLOYEE FREE CHOICE: MULTIDISCIPLINARY APPROACHES TO LABOR LAW REFORM 83, 85–87 (John Logan ed., 2009).

with disabilities would retain the power to choose their own personal assistants and to direct their work on a day-to-day and minute-to-minute basis. This reconciliation involved important concessions on both sides, and it would not have occurred without longstanding and deep relationships between labor and disability rights activists in California.<sup>45</sup> The model soon spread from California to a number of other states.<sup>46</sup>

But that model of representation ultimately got caught up in more general antiunion politics. From the union perspective, a crucial aspect of the California model was that it allowed all personal assistants providing a particular sort of services within a state's Medicaid program to join together in a single bargaining unit—and that the union would be empowered to both bargain with the state and collect a fair-share fee from all of the workers in the unit it represented. In *Harris v. Quinn*, right-to-work groups challenged the collection of agency fees under such arrangements.<sup>47</sup> When *Harris* got to the Supreme Court, there was a bit of a controversy within the disability community concerning what position disability rights activists should take. Collective bargaining limits managerial prerogatives, and in the case of attendant services, it is the people with disabilities who are, in some sense, the managers. As a result, some within the disability community favored the position of the antiunion groups.<sup>48</sup> But many others took the view that disability rights activists should defend the compromise they had so painstakingly worked out with the labor movement. I represented a broad array of disability rights groups from across the country who took this view, and we filed a brief in support of the unions' position in the Supreme Court.<sup>49</sup> But the Supreme Court in its 2014 *Harris* decision rejected that position,<sup>50</sup> and we are still working out precisely what the fallout will be.<sup>51</sup>

Another arena in which these conflicts play out is the application of the FLSA to personal-assistance workers. The conflict here is obviously about money. If standard wage-and-hour rules apply to personal-assistance workers, it will be more expensive to hire them.<sup>52</sup> But the conflict is also about control, because overtime protections may force individuals with disabilities to hire more personal assistants than they would prefer.<sup>53</sup> For years, exclusions in the FLSA had been read to exempt most

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45. See Rhee & Zabin, *supra* note 42, at 973.

46. See BORIS & KLEIN, *supra* note 41, at 205–09.

47. 134 S. Ct. 2618 (2014).

48. See Janine Bertram Kemp, *Harris v. Quinn Case Dividing Disability Community, Unions*, INDEPENDENCE TODAY, Feb. 2014, at 3, [http://www.itodaynews.com/pdf/issue\\_45.pdf](http://www.itodaynews.com/pdf/issue_45.pdf) [<https://perma.cc/N662-8F8Y>].

49. See Brief of the American Ass'n of People with Disabilities et al. as Amici Curiae in Support of Respondents, *Harris*, 134 S. Ct. 2618 (No. 11-681), 2013 WL 6907715.

50. See *Harris*, 134 S. Ct. at 2634–44.

51. For criticism of *Harris* shortly after the decision, see Harold Pollack, *The Supreme Court Would Prefer People with Disabilities Receive Care from Disgruntled, Low-Wage, High-Turnover Workers*, NEW REPUBLIC (June 30, 2014), <http://newrepublic.com/article/118489/supreme-courts-harris-decision-hurts-disabled> [<https://perma.cc/Y85M-RW2Q>].

52. See Corrected Brief for ADAPT and the National Council on Independent Living as Amici Curiae Supporting Appellees at 6, *Home Care Ass'n of Am. v. Weil*, 799 F.3d 1084 (D.C. Cir. 2015), *cert. denied*, 136 S. Ct. 2506 (mem.), 2016 WL 3461581 (2016) (No. 15-5018), 2015 WL 1534374, at \*6.

53. See *id.* at 7–8, 2015 WL 1534374, at \*7–8.

attendant-services workers from the full protection of the statute.<sup>54</sup> Unions and worker advocates had increasingly pressed to narrow these exclusions. In the 2007 *Coke* case,<sup>55</sup> the Supreme Court held that the decision to narrow these exclusions was up to the Department of Labor. President Obama took office shortly after the *Coke* decision, at a time when using the Department of Labor's power to solve the problem stood as a major union priority.<sup>56</sup>

When the Department began to move on this issue, it took some steps that raised especial concern among disability rights advocates. The Regulatory Impact Analysis submitted with the Department's proposed rule blithely suggested that a result of the new rules would be the reinstitutionalization of some people with disabilities.<sup>57</sup> Disability rights activists, led by the direct action of the organization known as ADAPT—the most aggressive grassroots disability rights organization<sup>58</sup>—protested the Department of Labor building, shutting down its entrances.<sup>59</sup> They even protested at Secretary of Labor Tom Perez's house and sent lumps of coal to his home mailbox at Christmas.<sup>60</sup>

The Department, nonetheless, finalized the regulations, and a trade association of home-care providers immediately filed suit. ADAPT, the National Council on Independent Living, and other disability rights organizations supported the lawsuit, which was successful in the District Court for the District of Columbia.<sup>61</sup> On appeal to the D.C. Circuit, the American Association of Persons with Disabilities (AAPD)—a group made up of, by, and for people with disabilities—filed an amicus brief in support of the Department of Labor regulations.<sup>62</sup> (I served as their counsel on the

54. See *Home Care Ass'n of Am.*, 799 F.3d at 1087–89.

55. *Long Island Care at Home, Ltd. v. Coke*, 551 U.S. 158 (2007).

56. See Dave Jamieson, *Home Care Workers Urge Obama To Follow Through on Granting Minimum Wage Protections*, HUFFINGTON POST (Dec. 13, 2012, 10:22 AM), [http://www.huffingtonpost.com/2012/12/13/minimum-wage-protections\\_n\\_2292442.html](http://www.huffingtonpost.com/2012/12/13/minimum-wage-protections_n_2292442.html) [https://perma.cc/9B37-G7UD].

57. See Application of the Fair Labor Standards Act to Domestic Service, 76 Fed. Reg. 81,190, 81,224, 81,230 (proposed Dec. 27, 2011) (to be codified at 29 C.F.R. pt. 552) (mentioning that increase in prices for home health services may result in “search for lower cost alternatives, including . . . institutionalizing the patient” and later that “higher prices [may] result in patients finding alternatives to home health care services (e.g., accessing the grey market for services or institutionalizing the patient)”).

58. See JOSEPH P. SHAPIRO, NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT 127–29 (1993).

59. See Tim Wheat, *My Action Journal: Wednesday, April 24, 2013*, ADAPT: ACTION REPORT (Apr. 24, 2013), <http://www.adapt.org/freourpeople/2013/report05.php> [https://perma.cc/9ZGA-6X5A].

60. Josh Eidelson, *Raise Pay for Home-Care Aides? Disability-Rights Groups Say No Way*, BLOOMBERG BUSINESSWEEK (Oct. 23, 2014, 7:13 AM), <http://www.bloomberg.com/news/articles/2014-10-23/raise-pay-for-home-care-aides-disability-rights-groups-say-no-way> [https://perma.cc/642F-QJKC]; see *Tom Perez He Stole Christmas—A Call for ADAPT Action!*, FERRETRIX ADVOCACY (Dec. 27, 2013), <http://ferretrex.com/?p=1054> [https://perma.cc/VQX7-V54X].

61. See Corrected Brief for ADAPT and the National Council on Independent Living as *Amici Curiae* Supporting Appellees, *supra* note 52.

62. See Brief for the American Ass'n of People with Disabilities as *Amicus Curiae*

brief.) That filing created a major conflict within the disability rights community—and indeed led to the spectacle of one disability rights group (ADAPT) organizing the protest of another (AAPD).<sup>63</sup> Spurred by that controversy, the Secretary of Labor issued a letter that emphasized that states—which finance the bulk of attendant services for disabled persons—must implement the new rules in a way that protects the rights guaranteed by the ADA.<sup>64</sup>

The D.C. Circuit upheld the regulations, and the Supreme Court denied certiorari.<sup>65</sup> Disability rights groups—both those who supported and those who opposed the new regulations—are now closely monitoring the implementation of those regulations to ensure that they do not cause adverse effects on people with disabilities. In some key states—notably California—implementation seems to have gone relatively well for both disabled persons and the workers who serve them.<sup>66</sup> In others—notably Illinois—aggressive state-level austerity politics have interacted with the new regulations in a way that has clearly harmed individuals with disabilities.<sup>67</sup>

## II. THE NORMATIVE ARGUMENT

We can expect that interest groups will pursue their own particular ends in the political process. There is nothing to criticize in that. But that does not mean that a group's claims should be immune from normative assessment. All the more so, I would suggest, when the group is a social-justice movement. The fundamental goals of the disability rights movement, most attractively understood, are not to elevate disabled persons above the nondisabled, but to achieve equal citizenship status.<sup>68</sup> When the claims of disability rights advocates bring them into conflict with another social-justice movement, such as the movement to empower workers, it is both appropriate and necessary to engage in a normative evaluation of those claims—one that takes seriously the interests on both sides.

That is true not just for a “detached observer”—should such a person exist—but also for movement participants themselves. Participants in a social-justice movement

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Supporting Appellants, *Home Care Ass'n of Am. v. Weil*, 799 F.3d 1084 (D.C. Cir. 2015), cert. denied, 136 S. Ct. 2506 (mem.), 2016 WL 3461581 (2016), (No. 15-5018), 2015 WL 848080.

63. See *Disability Orgs Square off over Companionship Message*, LEAD ON NETWORK, (Mar. 26, 2015), <http://leadonnetwork.org/wordpress/2015/03/26/3969/>.

64. See *id.*

65. *Home Care Ass'n of Am.*, 799 F.3d 1084.

66. For a nice overview of implementation questions, see Rachel M. Cohen, *With New Protections Tied Up in the Courts, Home Health-Care Workers Aren't Waiting Around*, AM. PROSPECT (Apr. 2, 2015), <http://prospect.org/article/new-protections-tied-courts-home-health-care-workers-arent-waiting-around> [<https://perma.cc/QN5M-GDSM>].

67. See Michael J. Bologna, *SEIU Challenges Illinois Home Health Care Overtime Rules*, 89 Daily Lab. Rep. (BNA) A-10 (May 9, 2016).

68. It should be no surprise that the Americans with Disabilities Act, the child of that movement, adopts that equal-citizenship goal. See *Tennessee v. Lane*, 541 U.S. 509, 536 (2004) (Ginsburg, J., concurring) (“The Americans with Disabilities Act of 1990 (ADA or Act), 42 U. S. C. §§ 12101–12213, is a measure expected to advance equal-citizenship stature for persons with disabilities.”).

are doing more than simply waging a war to serve their own interests. They are claiming a place in the broader community, seeking access to the community's processes of mediating between the interests of different groups and individuals, and calling on that community to respond to their claims based on principles that transcend particular interests. It is thus normatively essential for social-justice movement actors to take fair account of the interests of other groups when making their claims.

In this Part, I offer a normative assessment of the claims of disability rights movement actors who have lined up in opposition to organized labor groups. I argue that the claims of disability rights movement actors were righteous in the effort to promote deinstitutionalization and build community-service systems, and that those claims properly trumped the interests of unions in maintaining the existence of the congregate institutions in which their members worked. But opposing the continued existence of congregate institutions is a very different thing than opposing the extension of basic worker protections—such as minimum-wage, maximum-hour, and collective-bargaining requirements—to the individuals who provide services and supports in community settings. Where these basic worker protections are concerned, the normative case for allowing disability rights interests to trump is much weaker.

#### *A. The Normative Argument for Deinstitutionalization*

When union groups opposed deinstitutionalization in the 1970s and 1980s, they defended their opposition based on concern for the welfare of individuals with disabilities.<sup>69</sup> In those instances in which union groups oppose deinstitutionalization today, they tend to make the same arguments. I believe these arguments have been offered in all good faith. But there is no denying the strong self-interest that unionized workers had in opposing deinstitutionalization. Public, congregate institutions for disabled persons are typically unionized workplaces; the providers of community-based services, who are generally private entities, are typically not. As union density in the private sector has declined, and public-sector unionism has become relatively more central to the American labor movement, the closure of large, unionized, public-sector workplaces can be understood to pose a particular threat to labor. And—as today's controversies highlight—the wages for workers in public institutions have tended to be significantly higher than those in community-based settings. So simply out of the interests of their members, one would expect public-employee unions to oppose deinstitutionalization.<sup>70</sup>

Overall, the opposition to deinstitutionalization has largely been vanquished. The combination of civil-liberties litigation and budgetary politics in the 1970s and 1980s, aided by the adoption of the ADA in 1990 and the Supreme Court's 1999 *Olmstead* decision—not to mention the continued refinement of successful models for providing community-based services and supports—has turned American policy decisively against the institutionalization of individuals with disabilities, even as some pockets of resistance remain.<sup>71</sup> And American policy has been right to turn against institutionalization. Disabled Americans live better, freer, fuller lives; are

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69. See, e.g., Bagenstos, *supra* note 5, at 20.

70. See *supra* text accompanying note 29.

71. See generally Bagenstos, *supra* note 5.

more centrally a part of the community; and can more effectively enjoy full and equal citizenship when they are not forced to live apart from the rest of us, in facilities limited to people with disabilities.<sup>72</sup>

As against the interest of hundreds of thousands of individuals with disabilities in living full lives as part of the community, the interest of workers in maintaining specific jobs in specific institutions should carry much less weight. If the choice were stark—a full life for people with disabilities or good jobs for workers who provide them services, and you can't have both—it would be a tragic one. Even then, though, I would be hard pressed to say that the interests of a group of workers in good jobs outweighed the human cost of keeping a group of people in institutions.

Fortunately, we do not face such a stark choice. Disabled persons do not need to be kept in institutional confinement in order to ensure that service workers have good jobs; the state can ensure that the workers who provide community-based services are just as well compensated and treated as the workers in institutions. And, though *Harris v. Quinn* places some limitations on *how* a state can achieve this end, the state can also create structures to facilitate the organization of community-service workers into unions that they select, and it can engage in collective bargaining with them. The most visionary architects of deinstitutionalization, from disability rights activists, to government officials, to some union leaders themselves, have sought to structure community-based services in ways that will ensure that the workers who provide those services have stable, well-paying jobs.<sup>73</sup> That was the genesis of the arrangements that have led to our current controversies. Certainly, if it's possible to serve *both* the interests in disability equality *and* worker protection, there is no reason to choose the latter over the former. And to choose the *certain* continued institutionalization of disabled persons to avoid the *risk* of weakening worker protections is not to accommodate the interests of people with disabilities and the workers who serve them; it is to sacrifice the interests of disabled persons entirely to those workers. That is not a sacrifice disability rights activists could ever be expected to endorse, nor should they be.

But, of course, union leaders who opposed deinstitutionalization offered an argument that was framed in terms of the interests of people with disabilities themselves. I have discussed that argument at length in other work.<sup>74</sup> For this Essay's purposes, I would simply note three points. First, as I have summarized in my other work, the evidence shows that on balance deinstitutionalization has been far better for disabled persons than institutionalization. That is true even when fully considering the real harms that some people have experienced after deinstitutionalization. Second, when harms *have* occurred after deinstitutionalization, they have resulted precisely from the failure to invest in adequate and appropriate community-based services. We know how to serve people with even the most significant disabilities in their own homes—and how to do so in ways that promote full lives and equal membership in the community. That our governments have at times failed to put their money behind that knowledge is not an indictment of deinstitutionalization but of that failure to invest. Finally, note that the argument supporting institutionalization

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72. *See id.* at 13, 47–48.

73. *See supra* text accompanying notes 44–46.

74. *See generally* Bagenstos, *supra* note 5.

here is the essence of paternalism. To tell disabled people that they must live in segregation, but that it's for their own good, is not to treat them as equal citizens with an equal right to determine their own interests. It should hardly be surprising that the disability rights movement rejected that admonition.<sup>75</sup>

### *B. The Normative Argument for Worker Protection*

The very success of the movement for deinstitutionalization means that the current iteration of the disability rights–labor conflict has very different normative stakes. Where opposition to deinstitutionalization places the interests of disabled persons in a subordinate position to those of the workers who provide them services, opposition to labor protections for those workers places the interest of disabled persons in a superordinate position. But both people with disabilities and the workers who serve them have important interests that a just society should take into account. Indeed, the precise reason that deinstitutionalization did *not* present a tragic choice between the interests of these two groups was the prospect that workers who provide community-based services could receive adequate protections. Opposition to those protections would unnecessarily transform deinstitutionalization into a conflict between disabled persons and the workers who provide them services.

Although far too many people with disabilities remain institutionalized, the overall trend is clear: The overwhelming majority of disabled Americans who receive services and supports receive them—and will continue to receive them—in the community.<sup>76</sup> And although there are periodic efforts, from opinion elites and grassroots lobbyists, to reverse the tide of deinstitutionalization, there is little reason to believe that the trends of the last fifty years will in fact be reversed.<sup>77</sup>

But disability rights activists legitimately fear that labor protections for the workers who provide community services will impede the move toward freedom and integration of people with disabilities. For one thing, collective bargaining by personal assistants threatens to upend the consumer control that is so central to independent living. The more that working conditions of those providing community-based services are subject to negotiation, the less control that the disabled person has over what happens in her day-to-day life. Given the importance of these day-to-day choices to independence and equality, and the often extremely intimate tasks that personal assistants must perform, many disability rights activists are understandably wary of allowing collective bargaining into the relationship. That is particularly true because ceding control to those who provide services to disabled persons seems to mark a return to the paternalism of the helping professions that was a principal target of the independent-living movement.

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75. See *supra* text accompanying notes 11–17 (describing strong antipaternalist commitments of the American disability rights movement).

76. See Bagenstos, *supra* note 5, at 48–49.

77. For recent calls to return to institutionalization, see Dominic A. Sisti, Andrea G. Segal & Ezekiel J. Emanuel, *Improving Long-Term Psychiatric Care: Bring Back the Asylum*, 313 JAMA 243 (2015); Christine Montross, *The Modern Asylum*, N.Y. TIMES (Feb. 18, 2015), <http://www.nytimes.com/2015/02/18/opinion/the-modern-asylum.html> [<https://perma.cc/8VYC-APW7>]. For a response, see Harold Pollack & Samuel Bagenstos, *We Don't Need "Modern Asylums,"* AM. PROSPECT, Summer 2015, at 18.



But the choice is hardly so dire. As I described earlier, disability rights activists and union leaders, working together, were able to develop a unique model of collective bargaining that accommodates the key interests of both individuals with disabilities and their assistants. That model leaves control over day-to-day working conditions, and hiring and firing, with the disabled person, while it empowers the workers to band together to negotiate with the state over dollars-and-cents matters such as wages—matters that generally turn on state decisions in any event, as it is the state that typically pays for personal-assistance services through Medicaid. Given the availability of this accommodation of interests, opposition to collective-bargaining rights must rest on a determination that any interest of people with disabilities must necessarily take priority over all interests of the workers who serve them. Just as when workers placed their interests above those of disabled persons in their opposition to deinstitutionalization, that is a position that has little to be said for it normatively.

The controversy over wage-and-hour protections implicates not just the question of control, but the question of whether personal-assistance services will remain available. By granting attendant workers overtime-pay rights, the Department of Labor's new regulations will either make personal-assistance services more expensive or require some disabled individuals who had previously employed only one attendant to now employ two or more. To the extent that personal assistance becomes more expensive, people with disabilities—and the state Medicaid programs that often are the ultimate payors—will become less able to afford it. The result will be that disabled people do not receive the services that are necessary for full and equal participation in the community. In many cases, an individual with a disability will be able to get by with less-than-full service coverage. But in others, the cutbacks may make the difference between being able to stay in the community and effectively being forced to enter an institution to receive necessary supports. In its regulatory impact analysis of its original home care rule proposal, the Department of Labor suggested that the rule would result in some reinstitutionalization, though the benefits would outweigh those and other costs.<sup>78</sup> It's therefore no surprise that many disability rights activists responded so harshly to the proposal.

Even if individuals with disabilities can avoid the extra costs of overtime by capping each individual worker's hours and hiring more of them, that step itself has costs. Individuals with disabilities rely on personal assistants to carry out their most basic, private, day-to-day choices. It is difficult to find workers who can reliably perform these tasks in a trustworthy manner. When a person must look for two or more such workers, the task may be impossible.

But there is another side to the story. The workers who provide personal-assistance services have the same interest in receiving fair pay—and in having time for other commitments in their lives, their families, and their communities—as do all workers.<sup>79</sup> The wage-and-hour protections of the FLSA are the principal way that our society has chosen to protect workers' interests in fair pay and time away from work. To be sure, those protections have never reached all workers. In part this is

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78. *See supra* note 57.

79. *See* Samuel R. Bagenstos, *Employment Law and Social Equality*, 112 MICH. L. REV. 225, 271–72 (2013).

because of political compromises—like the exclusion of agricultural and domestic workers. But these compromises have drawn great criticism, and appropriately so. Many of the jobs excluded from FLSA coverage, like agricultural and domestic jobs, are those that have often been performed by women and minorities. And the maintenance of male domination of family economic life—and of white supremacy in the Jim Crow South—were key goals of those who pushed for those exclusions.<sup>80</sup>

As a normative matter, we ought not to make exceptions to FLSA protections except in two general circumstances: First, where there is a good reason to think that a class of employees does not need the statute's wage-and-hour protections, an exemption may be appropriate. The statute's "white collar" exemptions are an example of this category—or at least they would be if the earnings threshold were set high enough.<sup>81</sup> The lower minimum wage for tipped workers also is sometimes justified in this way, though accumulating evidence suggests that workers who come within that exemption in fact have a particularly strong need for protection.<sup>82</sup>

Second, where there is something about the class of employment—whether about the job, or about the people who are performing the job—that makes it economically unsustainable to provide full FLSA protections, *and* there is some particular reason why it is important that the class of employment exists, an exemption may also be appropriate. The overtime exemption for firefighters in small departments is plausibly an example.<sup>83</sup> Many have sought to justify the minimum-wage exemption for certain disabled workers in these terms, but disability rights advocates have in recent

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80. See JEFFERSON COWIE, *THE GREAT EXCEPTION: THE NEW DEAL AND THE LIMITS OF AMERICAN POLITICS* 126–27 (2016); IRA KATZNELSON, *FEAR ITSELF: THE NEW DEAL AND THE ORIGINS OF OUR TIME* 143 (2013); Marc Linder, *Farm Workers and the Fair Labor Standards Act: Racial Discrimination in the New Deal*, 65 *TEX. L. REV.* 1335 (1987); Suzanne B. Mettler, *Federalism, Gender, and the Fair Labor Standards Act of 1938*, 26 *POLITY* 635 (1994); Premilla Nadasen, *Citizenship Rights, Domestic Work, and the Fair Labor Standards Act*, 24 *J. POL'Y HIST.* 74, 77 (2012).

81. See 29 U.S.C. § 213(a)(1) (2012 & Supp. II 2015). The Obama Administration recently issued final rules raising the salary threshold to qualify for this exemption. See *Defining and Delimiting the Exemptions for Executive, Administrative, Professional, Outside Sales and Computer Employees*, 81 *Fed. Reg.* 32,391 (May 23, 2016) (to be codified at 29 C.F.R. pt. 541). On the importance of this change, see Ross Eisenbrey, *What Will an Updated Overtime Rule Mean for Millions of Workers?*, *ECON. POL'Y INST. WORKING ECON. BLOG* (May 17, 2016, 3:51 PM), <http://www.epi.org/blog/updated-overtime-rule-could-mean-salary-increases-for-millions-of-employees/> [<https://perma.cc/6F9C-TFF9>] (“[By] guarantee[ing] overtime pay to anyone working more than 40 hours in a week if their salary is less than \$47,500 a year or \$913 a week[,] . . . [the new rule will ensure that a]bout 12.5 million employees will either be newly entitled to overtime pay or will have their rights strengthened so that they don't have to rely on a complicated analysis of their job duties to determine that they have a right to time and a half for their overtime hours.”).

82. See 29 U.S.C. § 203(m) (2012 & Supp. II 2015). For criticism of this provision, see SYLVIA A. ALLEGRETTO & DAVID COOPER, *ECON. POL'Y INST., TWENTY-THREE YEARS AND STILL WAITING FOR CHANGE: WHY IT'S TIME TO GIVE TIPPED WORKERS THE MINIMUM WAGE* (2014), <http://www.epi.org/files/2014/EPI-CWED-BP379.pdf> [<https://perma.cc/2Y8M-JEWR>].

83. See 29 U.S.C. § 213(b)(20).

years aggressively urged that that exemption is not in fact justified—with increasing success in persuading policy makers.<sup>84</sup>

An overtime exemption for personal-assistance workers clearly does not fit the first category. Workers who provide attendant services are often poor, they often must work second jobs to feed their families, and they often are members of disempowered minority and immigrant groups.<sup>85</sup> If anyone has a need for the wage-and-hour protections of the Fair Labor Standards Act, these workers have a strong claim.

Does the exemption fit the second category? I don't think so. Granting the importance of personal-assistance work to the independence and empowerment of people with disabilities, there is nothing economically unsustainable about providing full FLSA protection to those who do that work. Because the money to pay personal assistants who serve disabled persons largely comes from the state, the basic question is one of political will. If we decide to invest in an adequate attendant-services system, we can readily operate it while according workers their basic protections.

But perhaps that is an idealistic response. In the world we have, political pressures are conspiring to cut, rather than invest in, Medicaid. Disability rights activists can join with workers' advocates to urge increased investments. Until that effort succeeds, some degree of conflict between the interests of people with disabilities and the workers who serve them may be inevitable. But there is no good normative basis for preferring one side of the conflict over the other. For both disabled people and attendant-services workers define groups that experience some significant disadvantage and have a valid claim on social goods.

### III. THE PRAGMATIC ARGUMENT

Having read up to this point, you might agree that there are important interests on both sides here. But, you might say, all that shows is that there is a conflict; it doesn't show how that conflict ought to be resolved. After all, regardless of which side we favor in any particular policy choice, we may well be, at the margins, favoring one legitimate interest over another perfectly legitimate interest. And that's particularly true in our fallen world, where we are quite far from implementing the ideal set of arrangements that could in fact accommodate the legitimate interests of both warring sides here.

In this last Part, I will move from the idealistic register of normative analysis to a more hard-headed pragmatism. I will argue that, for two pragmatic reasons, disability

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84. See 29 U.S.C. § 214(c) (2012). For criticism of this provision, see RUTHIE-MARIE BECKWITH, *DISABILITY SERVITUDE: FROM PEONAGE TO POVERTY* 107–08 (2016); Samuel R. Bagenstos, *The Case Against the Section 14(c) Subminimum Wage Program* (2012) (unpublished manuscript prepared for the National Federation of the Blind), [http://www.ct.gov/dds/lib/dds/employment/the\\_case\\_against\\_14c\\_sub\\_mininum\\_wage\\_program.pdf](http://www.ct.gov/dds/lib/dds/employment/the_case_against_14c_sub_mininum_wage_program.pdf) [<https://perma.cc/4KJG-LE96>].

85. See Rebecca Beitsch, *As Demand Grows, States Consider Better Pay, Benefits for Home Care Workers*, PEW CHARITABLE TRUST: STATELINE (June 5, 2015), <http://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2015/6/05/as-demand-grows-states-consider-better-pay-benefits-for-home-care-workers> [<https://perma.cc/37PG-E26K>] (stating that the home-care “workforce is mostly female and minority and many workers live near or below the poverty level”).

rights advocates will better serve the interests of the disability rights movement by advocating for employment-law protections for personal-assistance workers. One reason has to do with labor markets; employment-law protections can be crucial to attracting and retaining high-quality attendant-services workers. The other reason has to do with politics. The disability rights movement needs allies, and the labor movement can be a very helpful ally in arguing for the expansion of the services on which disabled people rely to promote full inclusion in the community.

Start with labor markets. We know that consumer-controlled personal-assistance services are a key tool for achieving independence and integration for disabled people. But adequate personal-assistance services depend on having a stable labor force of people willing to serve as personal assistants. And individuals with disabilities have often found it difficult to attract and retain workers for those positions. One set of researchers found that “[c]onsumers of PAS [personal-assistance services] consistently report difficulty in recruiting and retaining personal assistants.”<sup>86</sup> Others have described attendant-services positions as marked by “unacceptably high rates of vacancies and turnover.”<sup>87</sup>

As a result of this labor-market “churning,” many disabled individuals are unable to find people willing to provide personal-assistance services.<sup>88</sup> Even when disabled individuals can find workers, frequent turnover means frequently facing the burden of identifying, hiring, and training new attendant-services workers.<sup>89</sup> High vacancy and turnover rates thus have what one set of researchers calls “a profoundly negative effect on consumers’ ability to achieve full community integration.”<sup>90</sup> And they place many individuals with disabilities at risk of reinstitutionalization.<sup>91</sup>

And why are there such high vacancy and turnover rates for personal-assistance positions? Because too few workers are willing to do these jobs at the rates they are paid.<sup>92</sup> Attendant-services work is stressful and grueling, and many people will

86. Brian J. Stout, Kristofer J. Hagglund & Mary J. Clark, *The Challenge of Financing and Delivering Personal Assistant Services*, 19 J. DISABILITY POL’Y STUD. 44, 45 (2008).

87. Rhee & Zabin, *supra* note 44, at 84.

88. Robyn I. Stone, *The Direct Care Worker: The Third Rail of Home Care Policy*, 25 ANN. REV. PUB. HEALTH 521, 525 (2004) (noting that “problems with attracting and retaining direct care workers may translate into poorer quality and/or unsafe care, major disruptions in the continuity of care, and reduced access to care” and that “reduced availability and frequent churning of home care workers may affect clients’ physical and mental functioning”).

89. See CHARLENE HARRINGTON, TERENCE NG, STEPHEN H. KAYE & ROBERT NEWCOMER, CTR. FOR PERS. ASSISTANCE SERVS., *Home and Community-Based Services: Public Policies To Improve Access, Costs, and Quality* 18 (2009), [http://www.tilrc.org/assests/news/publications/hcbs\\_public\\_policies\\_to\\_improve\\_access\\_costs\\_quality%200109.pdf](http://www.tilrc.org/assests/news/publications/hcbs_public_policies_to_improve_access_costs_quality%200109.pdf).

90. Stout et al., *supra* note 86, at 45.

91. See Peggie R. Smith, *The Publicization of Home-Based Care Work in State Labor Law*, 92 MINN. L. REV. 1390, 1395 (2008).

92. See Brian R. Grossman, Martin Kitchener, Joseph T. Mullan & Charlene Harrington, *Paid Personal Assistance Services: An Exploratory Study of Working-Age Consumers’ Preferences*, 19 J. AGING & SOC. POL’Y 27, 36–37 (2007). In issuing its final rule extending FLSA coverage to home-care workers, the Department of Labor specifically noted this high turnover rate. See *Application of the Fair Labor Standards Act to Domestic Service*, 78 Fed. Reg. 60,454, 60,543 (Oct. 1, 2013) (to be codified at 29 C.F.R. pt. 552) (observing that “the

choose not to do it if they can find better-paying alternative jobs. An array of studies finds that low wages and poor benefits are the most significant reason for the churning in this part of the labor market.<sup>93</sup>

Increased wage protections and unionization can therefore serve the interests of people with disabilities by stemming the turnover among personal assistants. Reduced turnover is exactly what we have seen in states that have provided collective-bargaining rights and wage increases to attendant-care workers.<sup>94</sup> At least this is true when they have not sought to comply on the cheap. When states have imposed strict hourly caps on personal-assistance work, as Illinois has recently, they have actually harmed the interests of both workers *and* disabled people.<sup>95</sup> But when states have

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turnover rate (those leaving and entering home care work) for workers in the home care industry has been estimated to range from 44 to 65 percent per year,” and that “[o]ther studies have found turnover rates to be much higher, up to 95 percent and, in some cases, 100 percent annually” (footnotes omitted)).

93. See Grossman et al., *supra* note 92, at 37 (consumers surveyed “attributed the shortage of workers and the high turnover rates to inadequate wages (ranging from \$7–\$10 per hour) and benefits paid by public [personal-assistance services] programs”); H. Stephen Kaye, Susan Chapman, Robert J. Newcomer & Charlene Harrington, *The Personal Assistance Workforce: Trends in Supply and Demand*, 25 HEALTH AFF. 1113, 1114 (2006) (noting that poor compensation for personal assistants made it “problematic to attract and retain qualified workers”); Lisa Morris, *Quits and Job Changes Among Home Care Workers in Maine: The Role of Wages, Hours, and Benefits*, 49 GERONTOLOGIST 635, 646 (2009) (finding that employee compensation [coded as LogWage07] had the highest beta coefficient value and so was the most significant factor accounting for turnover among home care workers); Kristin Smith & Reagan Baughman, *Caring for America’s Aging Population: A Profile of the Direct-Care Workforce*, MONTHLY LAB. REV., Sept. 2007, at 20 (describing the personal-assistant workforce as “a low-wage workforce with correspondingly low levels of health insurance coverage and high levels of turnover”); Stone, *supra* note 88, at 522 (arguing that poor compensation, among other factors, “contribute[s] to high vacancy and turnover rates among direct care workers”); Lynn May Rivas, A Significant Alliance: The Independent Living Movement, the Service Employees International Union and the Establishment of the First Public Authorities in California 3 (unpublished manuscript for the World Institute on Disability), <https://worldinstituteondisabilityblog.files.wordpress.com/2016/01/a-significant-alliance-il-and-seiu.pdf> [<https://perma.cc/H2L5-NR2W>] (“While the low wages created hardship for the workers, consumers also found it difficult to attract and retain attendants with such low wages.” (footnotes omitted)).

94. See Nancy Folbre, *Demanding Quality: Worker/Consumer Coalitions and “High Road” Strategies in the Care Sector*, 34 POL. & SOC’Y 11, 24 (2006) (“Unionization clearly improved wages and benefits, and also gave clients greater choice of caregivers.”); Candace Howes, *Upgrading California’s Home Care Workforce: The Impact of Political Action and Unionization*, in THE STATE OF CALIFORNIA LABOR: 2004, at 71, 80–81 (Ruth Milkman ed., 2004), <http://www.irle.ucla.edu/publications/stateofCALabor.php> [<https://perma.cc/35JT-YT8X>] (noting that increased compensation after unionization of personal-assistance workers in California led to decreased turnover); Rhee & Zabin, *supra* note 44, at 91 (wage and benefit increases after unionization of personal assistants in Illinois, Oregon, and Washington State led to “significantly lower worker turnover, greater availability of qualified workers, and shorter gaps in services for consumers”).

95. See *supra* text accompanying note 67.

taken increased wages as an occasion for increased investment in community services, the result has been a win-win. As a purely pragmatic matter, then, disability rights advocates should favor worker protections—not just to serve the interest of the workers, but to serve their own interests.

But there is more to the pragmatic argument than just policy wonkism. As some of my discussion to this point suggests, the political landscape facing disability rights advocates these days is a particularly challenging one. As the disability rights movement has recognized that public services, along with civil rights, are crucial to promoting integration and empowerment for people with disabilities, it has repeatedly confronted the incredibly harsh budget politics of our current era. We live in an era of austerity, particularly at the state level.<sup>96</sup> Medicaid, which finances personal-assistance services for disabled persons, is one of those entitlement programs, and it is perpetually threatened by cuts at the state and federal level. Indeed, the political pressures on Medicaid have only increased with the adoption of the Affordable Care Act<sup>97</sup>—which dramatically expanded the program—and the Supreme Court’s *National Federation of Independent Business* decision<sup>98</sup>—which made the expansion optional for each state.<sup>99</sup> Many states with Republican-controlled legislatures refused to participate in the expansion, and the entire controversy highlighted the political pressures on the Medicaid program as a whole.<sup>100</sup>

In a world like this, disability rights advocates need allies. And unions can be important allies in the effort to defend and enhance spending on programs like Medicaid. When disability rights advocates defend the rights of workers in Medicaid programs, that cements an alliance with the representatives of those workers to defend and expand those programs. In the end, the answer to the problem of limited resources is not for disability rights activists and labor to fight increasingly pitched battles over allocation of a smaller and smaller pie. The only answer is to engage in political activism that will increase the resources that the state devotes to community-based services for people with disabilities. Increased resources will promote the independence and full citizenship of disabled Americans at the same time it provides stable and well-paying jobs for personal-assistance workers. And the only way to engage in successful advocacy on this front is for people with disabilities and the labor movement—the interests that gain the most from expanded investments—to work together.

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96. See Alana Semuels, *The Folly of State-Level Tax Cuts*, ATLANTIC (Mar. 10, 2016), <http://www.theatlantic.com/business/archive/2016/03/state-budget-crisis/473157> [https://perma.cc/K4L8-RDBG].

97. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010) (codified as amended at 42 U.S.C. § 18001 (2012)).

98. *Nat’l Fed’n of Indep. Bus. v. Sebelius*, 132 S. Ct. 2566 (2012).

99. See *id.* at 2607–08 (opinion of Roberts, C.J.).

100. For an analysis of the state-level politics of the Medicaid expansion, see Alexander Hertel-Fernandez, Theda Skocpol & Daniel Lynch, *Business Associations, Conservative Networks, and the Ongoing Republican War over Medicaid Expansion*, 41 J. HEALTH POL. POL’Y & L. 239 (2016).

## CONCLUSION

In this Essay, I hope to have shed light on an interesting and important conflict between the disability rights and labor movements. Disability rights activists fought long and hard to obtain freedom from institutionalization, and independent living in the community. Robust protections for the workers who provide personal-assistance services understandably may seem to threaten the availability of those services and the key principle of consumer control. But disability rights activists should nonetheless work to accommodate the legitimate interests of those workers. The success of the independent-living project may depend on it.