

# CARE AND COMMUNITY EMPOWERMENT: COALITION-BUILDING BETWEEN HOME CARE WORKERS AND DISABILITY RIGHTS ACTIVISTS

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## *Abstract*

*This Note looks closely at the issues facing home care workers and the persons with disabilities and older persons who consume that care. It argues that without seriously taking into account the unique intersectional needs of both care providers—predominately low-income women of color—and care consumers—generally persons who have disabilities, are elderly, or both—advocates will fail to create empowering care partnerships. The Note discusses the ways in which a purely feminist or disability rights lens fails to take into account the complex dynamics of the home care relationship, and suggests that scholars who have integrated the needs of care workers and care consumers have provided what should be considered foundational theories for home care empowerment activism. It implores advocates to continue to look to theorists that holistically incorporate feminist scholarship and disability rights scholarship in order to best understand the complex, multi-dimensional issues facing participants to relationships of care. The Note also examines advocates and organizations already doing this kind of integrated work and argues that they should be promoted and emulated, to the extent that their efforts have been successful. Finally, the Note lays out several possible policy solutions that would serve the needs of home care workers and care consumers, empowering and elevating all care participants, and contends that these should be prioritized in advocacy efforts going forward.*

## INTRODUCTION

“My [personal assistant] is my right-hand, she’s my angel.” - Joann Vitiello, care consumer<sup>1</sup>

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*“Workers like me face tough decisions all the time – should we pay the tuition bill or fix the oven that broke right before Thanksgiving? Can we put gas in the car to take our consumers to medical appointments or do we need to save that money for groceries?”*  
- Alantris Muhammed, home care worker<sup>2</sup>

*“You can’t teach compassion. That’s why we need a raise—so that people like me can afford to do the work we love.”* - Liliana Cordero, home care worker<sup>3</sup>

A home care worker in Seattle, who juggles paid work as an aide to an elderly woman with dementia with unpaid work for her own son with autism, finds that her paychecks barely cover her basic household expenses.<sup>4</sup> An in-home aide to a child with multiple disabilities in St. Paul, Minnesota recalls how she was only able to take one week off from work after the birth of her own son, as she was unable to afford to miss any more hours.<sup>5</sup> A home care worker in Chicago, without any paid sick leave, must choose between exposing her elderly clients to her cold or flu, and missing out on crucial wages to support her children.<sup>6</sup> An in-home aide in Brainerd, Minnesota estimates that she has logged over two hundred hours of unpaid work since her employer began to cap her hours; she does not want her bedridden clients to go without crucial services in her absence, as they have no one else to whom they can turn for their care needs.<sup>7</sup>

These stories are not unusual among home care workers, nor among low-wage women

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care and interdependence. And finally, thank you to the countless home care workers (especially my mom, Dianne), labor activists, and disability rights activists who advocate every day for quality, empowering, and sustainable care.

1 *Testimonials - From Founding Consumers*, CONCEPTS OF INDEPENDENCE, INC., <http://www.coiny.org/testimonials.php> [<https://perma.cc/5TXW-825Y>].

2 Paraprofessional Healthcare Institute, *Paying the Price: How Poverty Wages Undermine Home Care in America*, QUALITY CARE THROUGH QUALITY JOBS, (Feb. 2015), <http://phinational.org/sites/phinational.org/files/research-report/paying-the-price.pdf> [<https://perma.cc/PY5N-S2EE>] [hereinafter *Paying the Price*].

3 *Id.* at 6.

4 *Id.* at 12.

5 *Id.* at 11.

6 *Id.* at 6.

7 Chris Serres, *New Home Care Rule Intensifies Caregiver Shortage*, DISABILITY SCOOP (June 8, 2016), <https://www.disabilityscoop.com/2016/06/08/new-rule-caregiver-shortage/22388/> [<https://perma.cc/QLZ7-UCPQ>].

workers in general. With one in seven low-wage women working as a home care aide,<sup>8</sup> this is not only the reality for the home care workers' industry—made up predominately of low-income women of color<sup>9</sup>—but instead represents the lived experience of many working class women in the United States. Home care aides are largely comprised of some of the most vulnerable workers in the United States. Overwhelmingly women, significantly women of color and immigrant women, this population earns among the lowest wages in the service industry, and has historically been excluded from labor and employment protections.<sup>10</sup> Because they work within the home and thus out of the public eye, domestic workers—including home care workers—are at high risk of exploitation and abuse.<sup>11</sup>

However, the realities of the home care industry do not only affect the women who provide care to older people and people with disabilities. The consumers of that care—people who rely on personal aides coming into their homes on a regular basis in order to maintain their independence—are equally shortchanged by a system that chronically undervalues their aides—and in doing so, undervalues their own right to live independently and comfortably at home. Care consumers thus have an equal stake in an issue that is necessary for their autonomy, comfort, and general well-being.

Issues relating to persons requiring in-home care, and the workers who provide that care, will only become more pressing in the coming years, as “[t]he demand for home care workers is expected to nearly double over the next seven years, when more of the Baby Boomer generation will age into their seventies and eighties in addition to the forty million elderly Americans today.”<sup>12</sup> The care business is therefore a critical site for continued

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8 *Paying the Price*, *supra* note 2, at 13.

9 See, e.g., Vann R. Newkirk II, *The Forgotten Providers*, THE ATLANTIC, Sept. 29, 2016, <https://www.theatlantic.com/politics/archive/2016/09/home-health-care-workers-wages/502016/> [https://perma.cc/ZG64-2QUC]; Christine Owens, *Home Care Workers' Long March to Justice*, THE HILL (July 1, 2016), <http://thehill.com/blogs/congress-blog/healthcare/286135-home-care-workers-long-march-to-justice> [https://perma.cc/AW4S-WXUK]; see also Eva Feder Kittay, *When Caring Is Just and Justice Is Caring: Justice and Mental Retardation*, 13 PUB. CULTURE 557, 560–61 (2001) [hereinafter Kittay, *When Caring is Just and Justice is Caring*].

10 Owens, *supra* note 9.

11 Linda Turnham & Nik Theodore, *Home Economics: The Invisible and Unregulated World of Domestic Work*, NATIONAL DOMESTIC WORKERS ALLIANCE, 20, 28, 30 (2012), <https://www.domesticworkers.org/sites/default/files/HomeEconomicsEnglish.pdf> [https://perma.cc/5LT5-XH9F].

12 Shirley Lin, ‘*And Ain’t I A Woman?*’: *Feminism, Immigrant Caregivers, and New Frontiers For Equality*, 39 HARV. J.L. & GENDER 67, 96 (2016).

scholarship and activism.

Moreover, care is an industry with major social, political, and economic repercussions. It is also a social value, a belief system. Care is “a multifaceted term. It is a labor, an attitude, and a virtue.”<sup>13</sup> Critically, there are two major parties to any relationship of care—she who administers the care, and she who receives it. Because care work has been systemically undervalued in our society,<sup>14</sup> so have its participants.<sup>15</sup> In addition to the overwhelming percentage of care workers who are women, a disproportionate number of care consumers are also women, due in part to longer life expectancy and higher instances of certain physical and mental impairments.<sup>16</sup> Because the majority of care consumers are also women, their interests, along with the interests of their caregivers, must be of explicit concern to feminist scholars and activists.

Unfortunately, when the rights of care workers or care consumers *have* been promoted, it has often been without explicit regard to the rights of their counterparts.<sup>17</sup> Because

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13 Kittay, *When Caring is Just and Justice is Caring*, *supra* note 9, at 560.

14 Turnham & Theodore, *supra* note 11, at 5.

15 See, e.g., Anne-Marie Slaughter, *The Work That Make Work Possible*, THE ATLANTIC, Mar. 23, 2016, <https://www.theatlantic.com/business/archive/2016/03/unpaid-caregivers/474894/> [<https://perma.cc/RA3B-XN7J>].

16 *Women & Long-Term Care*, AARP PUB. POL’Y INST., [http://assets.aarp.org/rgcenter/il/fs77r\\_ltc.pdf](http://assets.aarp.org/rgcenter/il/fs77r_ltc.pdf) [<https://perma.cc/8XZB-PYF4>] [hereinafter *Women & Long-Term Care*]. There may also be discrepancies in the amount of spousal care that wives receive compared to husbands in heterosexual marriages, with wives generally receiving less care. See, e.g., Claire Noël-Miller, *Longitudinal Changes in Disabled Husbands’ and Wives’ Receipt of Care*, 50 GERONTOLOGIST 681 (2010).

17 See, e.g., Melissa Bailey, *Report Finds Caregiver Fraud Widespread*, DISABILITY SCOOP (Nov. 8, 2016), <https://www.disabilityscoop.com/2016/11/08/report-caregiver-fraud-widespread/22995/> [<https://perma.cc/VR Y3-C4X2>]; Bryce Covert, *Why It Matters that Home Care Workers Just Got New Labor Rights*, THINKPROGRESS (Sept. 17, 2013), <https://thinkprogress.org/why-it-matters-that-home-care-workers-just-got-new-labor-rights-9ee6c2e7b078#7mzpf874l> [<https://perma.cc/PY7G-HKU9>]; Michelle Diamant, *Wage Protections for Home Care Workers Reinstated*, DISABILITY SCOOP (Aug. 21, 2015), <https://www.disabilityscoop.com/2015/08/21/wage-protections-reinstated/20587/> [<https://perma.cc/KH8F-A36D>] [hereinafter Diamant, *Wage Protections for Home Care Workers Reinstated*]; Serres, *supra* note 7; *Home Care Overtime Rule*, DISABILITY RIGHTS WASHINGTON, <http://www.disabilityrightswa.org/sites/default/files/uploads/Overtime%20Rule%202016.pdf> [<https://perma.cc/TH5J-UJSG>]; *Home Care Workers Take Fight for \$15 and Union Rights to Nation’s Capital*, FIGHT FOR 15: HOME CARE, <http://fightfor15homecare.org/home-care-workers-take-fight-15-union-rights-nations-capital/> [<https://perma.cc/ayM8-4TNC?type=image>]; *Paying Home Care Workers \$15/Hr Would Put an Extra \$16.5 Billion in their Pockets and Add Tens of Thousands of Jobs to American Economy*, NAT’L EMP. L. PROJ. (Feb. 24, 2015), <http://www.nelp.org/news-releases/paying-home-care-workers-15hr-would-put-an>

domestic care work, like any employee-employer relationship, can create or perpetuate unequal power dynamics, many workers' advocates have rightfully focused on how these dynamics can be especially exploitative in the home care context.<sup>18</sup> Similarly, many disability scholars and activists have, out of concern for the long-standing violence and injustices perpetrated against them in the name of care, sought to reduce such assistance to its most mechanical functions.<sup>19</sup> Thus, it is not surprising that the movements for more independence and agency for persons with disabilities, and for workplace improvements and empowerment for home care workers, respectively, have not always been undertaken jointly. While neither demographic has expressed open hostility toward the other, their interests are often expressed independently in ways that might not fully consider the potential repercussions to their partners in care.<sup>20</sup>

Failing to examine the nuanced ways in which both care workers *and* care consumers experience societal disempowerment is, however, a flawed approach.<sup>21</sup> To advocate for a person who requires care “without also advocating for those who are entrusted with her well-being is at once unjust and uncaring toward the caregiver.”<sup>22</sup> Similarly, to advocate for the care worker without promoting the rights and autonomy of the care consumer is equally unjust and uncaring.

Although feminism has often failed to capture the holistic complexity of the home care sphere, it may be useful in better understanding this phenomenon. Feminism can, for example, offer a robust theoretical framework of care and of the challenges facing many

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extra-16-5-billion-in-their-pockets-and-add-tens-of-thousands-of-jobs-to-american-economy/ [https://perma.cc/8M4E-9J4L].

18 Turnham & Theodore, *supra* note 11, at 8.

19 See, e.g., CHRISTINE KELLY, DISABILITY POLITICS AND CARE: THE CHALLENGE OF DIRECT FUNDING 4 (2016) [hereinafter KELLY, DISABILITY POLITICS AND CARE]; Jenny Morris, *Community Care or Independent Living?*, 14 CRITICAL SOC. POL'Y 24, 27 (1994).

20 Sharon Keigher, *The Interests of Three Stakeholders in Independent Personal Care for Disabled Elders*, 23 J. HEALTH & HUM. SERVS ADMIN. 136, 154 (2000). Keigher also uses the term “stakeholders in care,” referring to not only the care worker and the care consumer but also the primary relative of the care consumer, who is often intimately involved in the care dynamic. In this Note, I focus only on the care consumer and the care worker, but Keigher’s work is extremely valuable for both its theoretical and ethnographic exploration of the care trifecta.

21 *Id.* at 141, 158.

22 Kittay, *When Caring is Just and Justice is Caring*, *supra* note 9, at 560–61.

women who provide it.<sup>23</sup> It can also provide a foundation for why care is important and should be valued—not only on a personal level, but on a societal level as a standard that “reject[s] violence and domination.”<sup>24</sup> Further, it can center the experiences of the women who provide and who consume care, elevating their narratives and emphasizing that the personal is, in so many ways, political.<sup>25</sup> An intersectional lens that critically considers home care policies and practices on the basis of gender and disability—along with race and class—is thus vital to creating coalitions that will empower both the providers and consumers of care.

Coalition-building, then, may be beneficial to both sides of the care partnership. As one scholar asks, “[w]hy should either ‘side’—workers or disabled persons—have to view the needs of the other as in competition when they must rely upon each other for so much?”<sup>26</sup> At a time when people in power have shown overt hostility to people with disabilities,<sup>27</sup> women,<sup>28</sup> low-wage workers,<sup>29</sup> and immigrants<sup>30</sup>—and particularly people who fall into more than one of these categories<sup>31</sup>—it is more important than ever that these various

23 See, e.g., Deborah Rutman, *Child Care as Women's Work: Workers' Experiences of Powerfulness and Powerlessness*, 10 GENDER & SOC'Y 629 (1996); *Controversies in Care: How Women's Work Is Made 'Invisible'*, 91 AM. J. NURSING 17 (1991).

24 VIRGINIA HELD, *THE ETHICS OF CARE: PERSONAL, POLITICAL, AND GLOBAL* 3 (2006); see also CAROL GILLIGAN, *IN A DIFFERENT VOICE: PSYCHOLOGICAL THEORY AND WOMEN'S DEVELOPMENT* (1982).

25 See generally VIRGINIA HELD, *THE ETHICS OF CARE: PERSONAL, POLITICAL, AND GLOBAL* (2006).

26 Keigher, *supra* note 20, at 157.

27 See, e.g., Anderson Cooper 360, *Trump Mocks Reporter With A Disability*, CNN, Nov. 26, 2015, <http://www.cnn.com/videos/tv/2015/11/26/donald-trump-mocks-reporter-with-disability-berman-sot-ac.cnn> [<https://perma.cc/JC2H-SCL9>].

28 See, e.g., Claire Cohen, *Donald Trump Sexism Tracker: Every Offensive Comment in One Place*, TELEGRAPH, <http://www.telegraph.co.uk/women/politics/donald-trump-sexism-tracker-every-offensive-comment-in-one-place/> [<https://perma.cc/GMC7-QEA2>].

29 See Jim Puzzanghera, *Obama Saw Low-Wage Workers as Struggling Moms. Trump May See Them as Suburban Teens*, LOS ANGELES TIMES, Feb. 5, 2017, <http://www.latimes.com/business/la-fi-trump-low-wage-workers-20170205-story.html> [<https://perma.cc/W4CH-24RA>].

30 See, e.g., Daniel Politi, *Donald Trump in Phoenix: Mexicans are 'Taking Our Jobs' and 'Killing Us'*, SLATE, July 12, 2015, [http://www.slate.com/blogs/the\\_slatest/2015/07/12/donald\\_trump\\_in\\_phoenix\\_mexicans\\_are\\_taking\\_our\\_jobs\\_and\\_killing\\_us.html](http://www.slate.com/blogs/the_slatest/2015/07/12/donald_trump_in_phoenix_mexicans_are_taking_our_jobs_and_killing_us.html) [<https://perma.cc/U5QE-5RDL>].

31 Melissa Blake, *Disabled, Shunned and Silenced in Trump's America*, N.Y. TIMES, Feb. 15, 2017, <https://www.nytimes.com/2017/02/15/opinion/disabled-shunned-and-silenced-in-trumps-america.html> [<https://perma.cc/8UBC-HDSN>].

groups come together to acknowledge and take advantage of their shared interests.

Although there are a handful of umbrella organizations and coalitions that bring together home care workers and care consumers,<sup>32</sup> these entities continue to be the exception, rather than the rule, in the care industry. Working together to advocate for sufficient public funding, increased labor and employment protections, and more consumer-directed care programs, home care worker activists and disability rights activists would better ensure that home care work is improved intentionally, holistically, and sustainably.

This Note argues that such collaboration and coalition-building is the best way forward. Part I provides a background on disability rights and the independent living movement. Part II describes the realities of home care work, including the demographics of those who perform most of its labor. Part III delves into several of the most common types of home care employment relationships, illuminating the complicated advantages and drawbacks that each arrangement can have for the primary parties involved. Part IV lays out the legal landscape of home care work, starting with a discussion of key pieces of legislation that have contributed to the de-institutionalization of many people with disabilities, as well as key pieces of litigation and their effect (or lack thereof) on establishing a right to home- and community-based long-term care. It also describes home care workers' fight for labor rights through unionization and regulation. Parts V and VI present theoretical tensions between some disability activist-scholars and much of mainstream feminism, and show how these theoretical tensions have played out in concrete ways, particularly when society allocates limited resources toward home care work generally. Finally, Part VII presents opportunities for coalition-building and mutual support, highlighting existing collaboration between care consumer groups and care provider advocates. It urges the widespread adoption of such cooperative practices, and suggests a variety of concrete solutions that might best align with the goal of mutually empowering both participants in care.

## **I. Background on Disability Rights & the Independent Living Movement**

### **A. Disability Demographics**

As of 2010, about 56.7 million people in the United States, or 18.7% of the population,

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32 See, e.g., Eileen Boris & Jennifer Klein, *Organizing Home Care: Low-Waged Workers in the Welfare State*, 34 POL. & SCI. 81, 93–94 (2006) (describing how home care union organizers in California and Oregon forged alliances with care consumers' advocacy groups in crafting public sector union legislation, and noting that these coalitions were not without controversy).



had a disability.<sup>33</sup> Of those, about 38.3 million people, or 12.6% of the U.S. population, had a severe disability.<sup>34</sup> As of 2014, 12.6% of the non-institutionalized U.S. population had a disability.<sup>35</sup>

Most consumers of in-home care are elderly.<sup>36</sup> As the American population continues to age, so too will age-related disabilities become more prevalent. In 2003, there were nearly 36 million Americans, representing 12% of the population, that were 65 years old and older. By 2030, projections show that 72 million Americans, or 20% of the total population, will be 65 years old or older.<sup>37</sup>

Additionally, most consumers of long-term care are women.<sup>38</sup> Because women, on average, live longer and experience “higher rates of disability and chronic health problems,”<sup>39</sup> they frequently find that they have need for long-term care—both in institutions and at home—as more than seventy percent of nursing home residents and nearly two-thirds of informal, at-home care consumers are women.<sup>40</sup> Further, among persons 75 years old or older, “women are 60 percent more likely than men to need help with one or more activities of daily living, such as eating, bathing, dressing, or getting around inside the home.”<sup>41</sup>

Because women often outlive their husbands, and are thus less likely to have spouses or partners at home to provide informal daily care, they are also more likely to need someone

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33 See Matthew W. Brault, *Americans With Disabilities: 2010*, U.S. CENSUS REPORT (July 5, 2012), <https://www.census.gov/content/dam/Census/library/publications/2012/demo/p70-131.pdf> [<http://perma.cc/HG8Y-VUWU>].

34 See *id.*

35 *Disability Characteristics, 2014 American Community Survey 1-Year Estimates*, U.S. CENSUS BUREAU (2014), <https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk> [<https://perma.cc/7BP8-9V8M?type=image>].

36 See Peggy R. Smith, *Aging and Caring in the Home: Regulating Paid Domesticity in the Twenty-First Century*, 92 IOWA L. REV. 1835, 1837–38 (2007) [hereinafter Smith, *Aging and Caring in the Home*].

37 *Id.* at 1843–44.

38 *Women & Long-Term Care*, *supra* note 16, at 1.

39 *Id.*

40 *Id.*

41 *Id.*



to come into their homes to help them with day-to-day tasks.<sup>42</sup> Indeed, while only 22% of men over age 75 live by themselves, 48% of women in that age category live alone.<sup>43</sup>

## B. Competing Models of Disability

Under the Americans with Disabilities Act (ADA), “disability” is defined as “a physical or mental impairment that substantially limits one or more of the major life activities of such individual.”<sup>44</sup> Disability rights scholars and activists have also put forth a variety of sometimes conflicting definitions that emphasize the move away from a “medical model” of understanding disability toward a more “social” model of disability.<sup>45</sup> It is important to understand the continuing relevance of the medical model, as well as its tension with the social model and the latter’s progeny, in order to better conceptualize the conflicts between current and historical long-term care policies and the goals of many disability rights activists.

### 1. The Medical Model

The medical model of disability sees a person’s impairment as a “sickness” that must be treated in order to return the person to a condition of “health” and “normalcy”—usually through extensive medical intervention or institutionalization.<sup>46</sup> In the absence of a cure, person with such impairments are considered “unproductive” or “nonnormative,” with their own bodies being the site of the problem.<sup>47</sup> Further, the medicalization of disability “positions medicine as a social gatekeeper, forcing many individuals with disabilities to acquiesce to diagnostic categorizations to receive work-related benefits, insurance coverage,

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42 *Id.*

43 *Id.*

44 Americans with Disabilities Act of 1990, 42 U.S.C. § 12102 (2008). The ADA also includes “(B) a record of such an impairment; or (C) being regarded as having such an impairment” in its definition of disabled for purposes of its anti-discrimination framework.

45 See also Adam M. Samaha, *What Good is the Social Model of Disability?*, 74 U. CHI. L. REV. 1251, 1255 (2007) (“No restatement of the social model can satisfy everyone. It has no natural form and the volume of writing on the model is almost staggering. This variety of versions yields complications. For some observers, all or nearly all disadvantage suffered by people with physical or mental impairments is attributable to their environment. For others, the causal picture is not so tilted.”).

46 Sayatani DasGupta, *Medicalization*, in KEYWORDS FOR DISABILITY STUDIES 120 (2015) (citing ARTHUR FRANK, *THE WOUNDED STORYTELLER: BODY, ILLNESS, AND ETHICS* (1995)).

47 See *id.*

access to therapies, rehabilitation, or prosthetic and mobility-related equipment.”<sup>48</sup>

The medical model, historically the predominant model, is still largely reflected in the so-called “institutional bias” that remains present in the Medicaid funding structure. Today, about half of all Medicaid long-term care funding is spent on nursing homes.<sup>49</sup> Currently, people with disabilities do not have a federal entitlement to in-home care—only to nursing home care.<sup>50</sup> They can receive in-home care only if their state has a special waiver from the federal government to do so.<sup>51</sup> Nearly all states offer these home and community-based services waivers (“HCBS waivers”).<sup>52</sup> Research on whether in-home care costs more or less than corresponding care in a nursing home has been inconclusive; the question is “complicated and unresolved” and needs further research,<sup>53</sup> particularly to the extent that it is used to justify a continuing institutional basis.

## 2. The Social Model

The disability rights movement has pushed back strongly against the medical model. Under one articulation of the social model, a person’s physiological conditions are considered “impairments,” while “disabilities” are the interactions between these impairments and societal barriers.<sup>54</sup> The site of disadvantage and oppression is therefore not the individual’s body, but rather the attitudes, policies, and physical barriers that fail to

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48 *Id.* at 121.

49 Howard Gleckman, *End Medicaid’s Institutional Bias for Long-Term Care*, FORBES, Sept. 25, 2013, <http://www.forbes.com/sites/howardgleckman/2013/09/25/end-medicaids-institutional-bias-for-long-term-care/#1b293f7059ed> [<https://perma.cc/V97K-H4W3>].

50 *Id.*

51 *Id.*

52 *Home and Community-Based Services 1915(c)*, MEDICAID.GOV, <https://www.medicaid.gov/medicaid/hcbs/authorities/1915-c/index.html> [<https://perma.cc/C58V-USNK>].

53 Gleckman, *supra* note 49.

54 See, e.g., DasGupta, *supra* note 46; Jenny Morris, *Impairment and Disability: Constructing an Ethics of Care that Promotes Human Rights*, 16 HYPATIA 1, 2 (2001). Note that, even among social model theorists and activists, there is some conflict between the use of “disabled person” and “person with disability.” Although I understand and respect the distinction between impairment and disability, and its resulting use of “disabled person,” I will nevertheless use people-first language throughout this paper. I believe that there are numerous benefits of using people-first language, and that most people who hear “disabled person” will not associate it with the impairment/disability distinction, but rather with more traditional dis-empowering notions of disability-as-defect.

take into account a wide variety of abilities and needs.<sup>55</sup>

The social model, however, is merely a starting point in guiding activists and policymakers toward articulating policies that will best situate people with disabilities within the larger society.<sup>56</sup> A variety of different, yet related, theories have emerged since the social model was first articulated, building on its view of societal barriers as the proper target for reform, and further developing avenues for change. Two such theories are the “civil rights” model<sup>57</sup> and the “independent living” model.<sup>58</sup> Unlike the medical model and the social model, which merely define disability, the civil rights and independent living models seek to advance particular policymaking approaches that will affect and empower people with disabilities.

The independent living model is part of the larger disability rights movement and social model of disability, which “developed as a reaction to the perceived paternalism and oppression that attended a welfare-based response to disability.”<sup>59</sup> The independent living model, as described by some of its advocates, assumes that all human life is valuable; that all persons are capable of exerting choices; that persons disabled by society’s reaction to their physical, intellectual, and sensory impairments have the right to control their own lives; and that people with disabilities have the right to fully participate in society.<sup>60</sup>

Crucial to the independent living model, therefore, is the availability of committed, skilled home care aides. In order to exert choices, control their own lives, and participate fully in society, many people with disabilities require part- or full-time personal aides to perform many of the activities of daily living that the care consumer is unable to perform unattended. Care is thus merely a means to an end: independence and autonomy.

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55 See DasGupta, *supra* note 46, at 121.

56 See, e.g., Samaha, *supra* note 45, at 1252 (“Despite the apparent connection between the social model and social change, there just is no necessary relationship there.”).

57 The “civil rights” model “focuses on how society has treated—and should treat people with disabilities. Its premise is that it is how society sees the disabled individual that needs to change, and not disabled people themselves.” Adam A. Milani, *Living in the World: A New Look at the Disabled in the Law of Torts*, 48 CATH. U.L. REV. 323, 329 (1999).

58 See, e.g., Jenny Morris, *Creating a Space for Absent Voices: Disabled Women’s Experience of Receiving Assistance with Daily Living Activities*, 51 FEMINIST REV. 68, 74 (1995) [hereinafter Morris, *Creating a Space for Absent Voices*].

59 Samuel R. Bagentos, *The Future of Disability Law*, 114 YALE L.J. 1, 5 (2004).

60 Morris, *supra* note 58.

However, many disability activists and scholars view traditional frameworks of care as antithetical to this goal, viewing care “as a byword for dependency and so a means by which disabled people’s lives are colonized and controlled.”<sup>61</sup> Even the term “care” can be “much more heavily associated with the ‘taking charge of’ definition of care than it is with the ‘caring about’ definition.”<sup>62</sup> The alternative to this oppressive paradigm of care has been the provision of personal assistants (PAs), in which “[t]he PA works for and with the disabled person, providing him/her with assistance in a neutral, informed manner.”<sup>63</sup> To some persons with disabilities, “an attendant is like their arms and legs, or memory. The services provided simply make up for the functional limitations the disability imposes.”<sup>64</sup>

Many disability scholars continued to utilize the language and concept of care, however, while acknowledging and critiquing its many historical and contemporaneous flaws.<sup>65</sup> For these disability rights scholars and activists who embrace the language and ethos of care—whether skeptically or with more optimism—care must evolve so that it is structured in such a way as to not deny its consumers the essential agency needed to lead actively participatory, autonomous lives. A healthy care partnership—in which the consumer is not merely a passive recipient of the caregiver’s actions—is thus a fundamental aspect of independent living.

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61 Nick Watson et al., *(Inter)Dependence, Needs, and Care: The Potential for Disability and Feminist Theorists to Develop an Emancipatory Model*, 28 *SOCIOLOGY* 331, 335 (2004); see also CHRISTINE KELLY, *DISABILITY POLITICS AND CARE: THE CHALLENGE OF DIRECT FUNDING* 4 (2016) (“Paternalistic and ‘caring’ approaches to disability pervade popular perceptions and shape individual encounters between nondisabled and disabled people.”).

62 Jenny Morris, *Community Care or Independent Living?* 14 *CRITICAL SOC. POL’Y* 24, 27 (1994).

63 Watson et al., *supra* note 61.

64 Stephanie Thomas, *A Disability Perspective on Home Health Care*, ADAPT, <http://www.adapt.org/older/homehealth> (last visited Nov. 13, 2016) [<https://perma.cc/6YMB-ZUJZ>].

65 See, e.g., TOM SHAKESPEARE, *DISABILITY RIGHTS AND WRONGS: REVISITED* 167, 174–75, 214, (London: Taylor & Francis Group 2006); Kittay, *When Caring is Just and Justice is Caring*, *supra* note 9. But see TOM SHAKESPEARE, *HELP* (Venture Press 2000) (arguing that the term “care” should be replaced with “help” to reduce the other-ing and objectifying of people with disabilities). Although I appreciate the concerns raised by scholars and activists in this rich debate, I will continue to use the term “care” throughout the paper to refer to both the labor of in-home personal aides, as well as the daily assistance tasks directed by people with disabilities, in attempt to bridge the gap between these two populations and empower both. I acknowledge, however, that for some, histories of institutionalization, medicalization, and paternalism (some of which remain extremely contemporary) render the concept of “care” irredeemable. Because these histories are, by and large, beyond the scope of this Note, I would encourage anyone who wishes to dive further into this topic to read some of the many insightful pieces that have been written on this topic, including KELLY, *DISABILITY POLITICS AND CARE*, *supra* note 19, and CUNNINGHAM, *supra* note 65.

## II. Background on Home Care Work

### A. Home Care Worker Demographics

In order for persons with disabilities to live independently and at home, many require the services of a home care worker. These workers, also called personal aides or personal assistants (PAs), can provide a wide range of services, from simple companionship and light housework to significant personal hygiene and medical care.

Today, there are approximately 2 million home care workers in the United States.<sup>66</sup> Home care workers in this country are and have historically been predominately women, and are disproportionately working class, immigrants, and women of color.<sup>67</sup> Between 1870 and 1940, domestic work was the largest employer of women in the U.S., and between the 1890s and 1920s, this work became dramatically racially stratified.<sup>68</sup> By the 1920s, more than half of all Black women across the country—and between 84–91% of Black women in northern cities—were domestic workers.<sup>69</sup> By the 1970s, employment of immigrant women in domestic work had increased dramatically, as many Black women had left the profession after the Civil Rights Era.<sup>70</sup> Today, 90% of home care workers are women, and 56% are women of color.<sup>71</sup>

Many care workers today are also immigrants, particularly in certain regions—for example, immigrant women make up 83% of care workers in the Miami-Hialeah, Florida area; 74% in the New York and Northeastern New Jersey metropolitan area; and 69% in the McAllen-Edinburg-Pharr-Mission, Texas region.<sup>72</sup> An estimated 21% of foreign-

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66 Rebecca Beitsch, *States Consider Better Pay, Benefits for Home Care Workers as Demand Grows*, HUFFINGTON POST, June 5, 2015, [http://www.huffingtonpost.com/2015/06/05/home-workers-pay\\_n\\_7519656.html](http://www.huffingtonpost.com/2015/06/05/home-workers-pay_n_7519656.html) [https://perma.cc/JGZ5-RKVM].

67 Turnham & Theodore, *supra* note 11; Lin, *supra* note 12, at 75.

68 Lin, *supra* note 12, at 75.

69 *Id.* at 75.

70 *Id.* at 76.

71 Lin, *supra* note 12; Peggy R. Smith, *The Publicization of Home-Based Care Work in State Labor Law*, 92 MINN. L. REV. 1390, 1396 (2008) [hereinafter Smith, *The Publicization of Home-Based Care Work in State Labor Law*].

72 Lin, *supra* note 12, at 97–98; Smith, *The Publicization of Home-Based Care Work in State Labor Law*, *supra* note 71, at 1396.

born direct care workers providing long-term care for the elderly are undocumented.<sup>73</sup> In 2013, after intense lobbying by immigrant home care worker activist groups, Congress included a path to citizenship for immigrant home health workers in S.744: the “W visa.”<sup>74</sup> However, female undocumented immigrant home care workers still face compounded difficulties in making a living wage, with 47% reporting a minimum wage violation within the past week.<sup>75</sup> Additionally, undocumented home care workers may face worse working conditions than workers whose immigration status is secure.<sup>76</sup>

### B. The Economic Realities of Home Care Work

*“When it comes to home care workers, you live in poverty. You work in poverty. You retire poor, hoping you will qualify for the services you have provided for so many years to others. Then, you die in poverty.” - Patricia Evans, home care worker<sup>77</sup>*

Many home care workers struggle to make ends meet as they juggle multiple clients, find themselves unable to fill unpaid hours between clients, and spend their own money on transportation costs between clients’ homes.<sup>78</sup> Home care workers are among the lowest earners of all service professionals in the United States, with one in four home care workers living below the poverty line,<sup>79</sup> and between thirty and thirty-five percent of single-parent

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73 Lin, *supra* note 12, at 97–98. But note that corresponding figures for the in-home care industry are not available. *Id.*

74 *Id.* at 90.

75 *Id.*

76 Turnham & Theodore, *supra* note 11, at 20.

77 *Paying the Price*, *supra* note 2, at 18.

78 Beitsch, *supra* note 66.

Care worker Agnes Maitland, 61, also of New York City, must juggle multiple clients. The Barbados native said between subway fare, low pay and unpaid hours between clients, she sometimes struggles to buy a bag of rice. She’s open to working as many as 60 hours a week but that doesn’t usually happen. In addition to low pay and job instability, workers also can be injured on the job, often from lifting clients. But conditions are improving for O’Hara and Maitland: They belong to a local union that’s helped negotiate higher pay, and even some health benefits.

*Id.*

79 Lin, *supra* note 12, at 97. Additionally, as of “2006, they earned less per hour than workers employed as

home-care workers receiving food stamps.<sup>80</sup> Many home care workers make little more than minimum wage, and live-in workers may actually make less than minimum wage.<sup>81</sup>

In 2014, the national median hourly wage for all home care workers was \$9.38,<sup>82</sup> with women of color in the domestic work industry tending to make less than white women doing this work, and undocumented immigrant workers making less than women with secure immigration status.<sup>83</sup> The median weekly wages for home care workers are \$308.<sup>84</sup> The median annual earnings of female home health care workers—\$16,016—approximately half of the median income of the general female workforce in the United States<sup>85</sup>—are even less sustainable, due in part to the difficulty that many home care workers have in finding full-time placements.<sup>86</sup> The majority of home care workers lack any sort of benefits, including health insurance, further exacerbating their poor economic position.<sup>87</sup>

Most home care workers also lack any paid sick or vacation time.<sup>88</sup> Being forced to choose between earning crucial income and endangering their own health—not to mention exposing their often-vulnerable clients to sickness—is a common dilemma for workers.<sup>89</sup>

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locker room and coatroom attendants, gaming-booth cashiers, meter readers, and bicycle repairers. In addition, most home-based care workers do not receive job-related benefits such as health insurance, medical leave, or retirement plans.” Smith, *The Publicization of Home-Based Care Work in State Labor Law*, *supra* note 71, at 1397.

80 Smith, *Aging and Caring in the Home*, *supra* note 36, at 1849.

81 Turnham & Theodore, *supra* note 11, at 18.

82 Beitsch, *supra* note 66.

83 Turnham & Theodore, *supra* note 11, at 20–21.

84 Lin, *supra* note 12, at 97.

85 *Id.*

86 Smith, *Aging and Caring in the Home*, *supra* note 36, at 1848–49.

87 *Id.* Although many home care workers may be eligible for significant healthcare subsidies under the Affordable Care Act, this option may still be less desirable than employer-provided healthcare plans. See Carolyn McClanahan, *Employer Based Coverage or Obamacare Plan? Which is Better?*, FORBES, June 23, 2013, <http://www.forbes.com/sites/carolynmcclanahan/2013/06/23/employer-based-coverage-or-obamacare-plan-which-is-better/#46d7e21ddb7> [<https://perma.cc/YWG3-4ZHT>].

88 *Paying the Price*, *supra* note 2, at 7.

89 *Id.*



Yet despite its poor compensation, home care work is hardly “unskilled labor;”<sup>90</sup> in addition to the para-medical training that many must continually receive in order to administer certain types of care, 40% of home care workers have either a high-school diploma or its GED equivalent, and 38% have some level of collegiate education<sup>91</sup>—making home care workers a particularly educated subset of low-wage service workers. This begs the question: why are care workers paid so little for the work that they do?

### C. Ongoing Struggle: The Intersectional Undervaluing of Home Care Work

There are deeply gendered and racialized reasons why home care workers find themselves at the bottom of the labor ladder.<sup>92</sup> First, home care workers “suffer from society’s perception that family caregiving is unskilled labor with limited economic value, and the belief that women should perform such activities not for money, but out of love.”<sup>93</sup> Research has shown that this social and economic devaluation of care work subjects individuals with caregiving jobs to a subsequent wage penalty.<sup>94</sup> Second, domestic work has historically been performed by low income women of color and immigrant women, populations whose work is chronically undervalued.<sup>95</sup> Broadly speaking, care work is seen as a familial duty when performed by women within their own homes, and as low-wage, unskilled labor when performed by women of color in other women’s homes.<sup>96</sup>

Additionally, concerns about privacy have contributed to the exclusion of home

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90 *Id.* at 10.

91 Smith, *Aging and Caring in the Home*, *supra* note 36, at 1849.

92 See, e.g., Turnham & Theodore, *supra* note 11, at 5, 10; *Paying the Price*, *supra* note 2, at 9.

93 Smith, *The Publicization of Home-Based Care Work in State Labor Law*, *supra* note 71, at 1397; see also *Paying the Price*, *supra* note 2, at 9.

94 Smith, *The Publicization of Home-Based Care Work in State Labor Law*, *supra* note 71, at 1397.

95 “The U.S. caregiving economy’s roots in a racist legacy of slavery provided the legal and social underpinnings for the caste-like system we have today, one actively shaped through state-based acts and omissions that fortify class and immigration status distinctions among women.” Lin, *supra* note 12, at 76; see also *Paying the Price*, *supra* note 2, at 9.

96 Sarah Leberstein et al., *Upholding Labor Standards in Home Care: How to Build Employer Accountability Into America’s Fastest-Growing Jobs*, NAT’L EMP. L. PROJ. (Dec. 2015), <http://www.nelp.org/content/uploads/Report-Upholding-Labor-Standards-Home-Care-Employer-Accountability.pdf> [https://perma.cc/CLN7-P6HC].

care work, as part of the larger domestic service industry, from most labor legislation.<sup>97</sup> There are gendered, racialized, and class-based underpinnings to this argument as well, as some (predominately white) women have claimed that regulating domestic service would jeopardize the home and family spheres.<sup>98</sup>

### III. Employment Relationships & Arrangements

#### A. Informal Familial and Social Care Relationships

Despite the extensive network of paid care workers in the United States, informal familial and social care relationships continue to make up the majority of care arrangements, with sixty-five percent of older persons with long-term care needs relying exclusively on family and friends to provide care.<sup>99</sup> The average family caregiver is a 49-year-old woman caring for an older relative.<sup>100</sup> The value of the informal care provided by women is at least \$148 billion per year.<sup>101</sup> But because states' financial support for family caregivers is extremely limited and tends to be means-tested, it provides assistance only to families in the most dire financial straits.<sup>102</sup>

Additionally, as previously noted, women—particularly older women—are less likely than men to have a living spouse to take care of them in the home.<sup>103</sup> Thus, unless provided by children or other family members, informal, intra-familial caregiving may be less available to women.

#### B. Home Care Agencies

Many care consumers—women and men—rely on paid, non-familial workers to

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97 Smith, *Aging and Caring in the Home*, *supra* note 36, at 1857–58.

98 *Id.*

99 Family Caregiver Alliance, *Women and Caregiving: Facts and Figures*, NAT'L CTR. ON CAREGIVING (Dec. 31, 2004), <https://www.caregiver.org/women-and-caregiving-facts-and-figures> [<https://perma.cc/KX8M-2DDN?type=image>].

100 Dhruv Khullar, *Who Will Care for the Caregivers?*, N.Y. TIMES, Jan. 19, 2017, <https://www.nytimes.com/2017/01/19/upshot/who-will-care-for-the-caregivers.html>? [<https://perma.cc/X52A-TW6P>].

101 Family Caregiver Alliance, *supra* note 99.

102 Kittay, *When Caring is Just and Justice is Caring*, *supra* note 9, at 571–72.

103 *Women & Long-Term Care*, *supra* note 16.

provide the care they need. Whether they are paying out of pocket or through public funds (such as Medicaid), a significant portion of families turn to home care agencies to find skilled, reliable workers. Home care agencies provide care that is either publicly or privately funded. Under both models, the agency usually “hires, trains, supervises, and assigns workers to provide publicly funded services to eligible clients. In such a scenario, the agency qualifies as the worker’s employer.”<sup>104</sup> However, some quasi-agencies take a more hands-off approach, including many of those that operate solely as websites.<sup>105</sup> These agencies may attempt to classify the home care workers they employ as “independent contractors” rather than full employees, “denying them basic workplace protections and benefits.”<sup>106</sup> This is almost always a legally incorrect classification, and can theoretically be challenged by workers through the court system<sup>107</sup>—though in reality, home care workers may lack the time and resources to bring such claims.

The home care agency industry is highly profitable; after the Department of Labor exempted agency-employed home care workers from wage protections in 1975, the agency industry grew into a \$90 billion industry.<sup>108</sup> Today, individual franchise branches of top agencies may take in over \$1 million in gross revenue, with 30–40% profit margins.<sup>109</sup> In the past decade, home care agency revenues have doubled.<sup>110</sup> Much of this funding comes from Medicaid.<sup>111</sup> Despite this massive revenue, agency-based home care workers earn only a portion of the hourly rate paid by the care consumer to the agency—often less than half.<sup>112</sup>

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104 Smith, *Aging and Caring in the Home*, *supra* note 36, at 1862–63.

105 Leberstein et al., *supra* note 96, at 16.

106 *Independent Contractor Classification in Home Care*, NAT’L EMP. L. PROJ. (May 2015), <http://www.nelp.org/content/uploads/Home-Care-Misclassification-Fact-Sheet.pdf> [<https://perma.cc/LLL9-9G4R>].

107 *Id.*

108 *Special Report: Senior Care Franchises*, FRANCHISE BUS. REV. 5 (Spring 2014), [https://franchisebusinessreview.com/content/files/FBR\\_2014-TopSeniorCareFranchises-web.pdf](https://franchisebusinessreview.com/content/files/FBR_2014-TopSeniorCareFranchises-web.pdf) [<https://perma.cc/QK4W-MKQ3>].

109 Lin, *supra* note 12, at 96.

110 *Id.*

111 *Id.*

112 Jane Gross, *Home Health Aides: What They Make, How Much They Cost*, N.Y. TIMES, Dec. 30, 2008, <https://newoldage.blogs.nytimes.com/2008/12/30/home-health-aides-what-they-make-what-they-cost/> [<https://perma.cc/4KXG-PQTJ>].

### C. Publicly Funded Long-Term Care

Many care consumers—particularly older women, who tend to have fewer resources to pay for long-term care<sup>113</sup>—rely on public programs to fund their care needs. In 2005–2006, women age 75 or older who live alone had a median income of only \$14,600, and Black and Latina women in that age group were more likely than white women to have incomes below the poverty level.<sup>114</sup> In some cases, this may qualify an individual for various forms of means-tested long-term care funding.

Today, the vast majority of paid home care is publicly funded—83% is funded by programs like Medicaid, Medicare, the Department of Veterans’ Affairs, workers’ compensation, or state-based long-term care programs.<sup>115</sup> In 1981, the independent living model made significant strides when Congress established the optional Home and Community-Based Care Waiver Program through section 1915(c) of the Social Security Act.<sup>116</sup> This allowed states to deviate from Medicaid’s traditionally rigid requirements, letting them provide community-based services to individuals who would otherwise require institutional care, so long as the average annual cost of such services does not exceed the annual cost of institutional services.<sup>117</sup> States apply for a specific number of waiver slots, informing Medicaid recipients of their long-term care options, and allowing those who qualify for home- and community-based services to choose this option.<sup>118</sup>

Medicaid remains a major source of funding for long-term care—both in institutional and community-based settings. It currently accounts for 40% of spending in that area,<sup>119</sup> contributing \$152 billion to long-term services and support (LTSS).<sup>120</sup> The percentage of

113 *Women & Long-Term Care*, *supra* note 16.

114 *Id.*

115 Leberstein et al., *supra* note 96.

116 Andrew A. 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, 24 (2001).

117 *Id.*

118 *Id.* But note that the number of individuals choosing this option cannot exceed the number of waiver slots applied for and granted to the State.

119 Julia Paradise, *Medicaid Moving Forward*, THE HENRY J. KAISER FAM. FOUN. (Mar. 9, 2015), <http://kff.org/health-reform/issue-brief/medicaid-moving-forward/> [<https://perma.cc/C4XS-HTL7>].

120 Steve Eiken, et al., *Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2014: Managed LTSS Reached 15 Percent of LTSS Spending*, TRUVEN HEALTH ANALYTICS 3–4 (Apr. 15, 2016), <https://>

Medicaid's long-term care funding that goes to providers of community-based care has been steadily increasing over the past few decades, and only in recent years has community-based care made up the majority of Medicaid's LTSS funding. As of 2014, Home and Community-Based Services (HCBS) accounted for 53.1% of Medicaid long-term care spending, due to a 7.7% increase in HCBS spending from the previous year.<sup>121</sup> This is a significant improvement from just 20 years ago, when HCBS spending was only 20% of Medicaid long-term care spending.<sup>122</sup> Disability activists are largely responsible for this shift, as the independent living movement has continually advocated for the move away from institutional care.<sup>123</sup>

The availability of Medicaid funding for long-term care has been critical for many care consumers, but it is not a perfect system. First, a large portion of care consumers are ineligible for its benefits. Medicaid, like Social Security Income, is a means-tested welfare program, meaning that any individual who satisfies the Social Security Act's definition of "disability" and whose income and assets fall below a federal means test, is entitled to a monthly cash benefit.<sup>124</sup> Second, Medicaid does not provide meaningful oversight of individual care partnerships, failing to require reports from employers regarding the salary or working conditions of home care workers.<sup>125</sup> Both care providers and care consumers may therefore find themselves vulnerable under this system.

#### D. Consumer-Directed Care

Consumer-directed care is gaining significant traction, as it is seen as giving the care consumer maximum control over the care relationship.<sup>126</sup> In New York State, Consumer-

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[www.medicaid.gov/medicaid/ltss/downloads/ltss-expenditures-2014.pdf](http://www.medicaid.gov/medicaid/ltss/downloads/ltss-expenditures-2014.pdf) [<https://perma.cc/4YBK-6BNG>].

121 *Id.* Institutional funding, meanwhile, remained constant.

122 Batavia, *supra* note 116, at 23.

123 *Id.*

124 Bagentos, *supra* note 59, at 11-12.

125 Leberstein et al., *supra* note 96.

126 *See, e.g.*, Consumer Directed Personal Assistance Program (CDPAP), N.Y. STATE DEP'T OF HEALTH (July 2016), [https://www.health.ny.gov/health\\_care/medicaid/program/longterm/cdpap.htm](https://www.health.ny.gov/health_care/medicaid/program/longterm/cdpap.htm) [<http://perma.cc/F33B-N646>]; Consumer Directed Services (CDS), TEX. HEALTH AND HUM. SVCS., <https://hhs.texas.gov/doing-business-hhs/provider-portals/long-term-care-providers/consumer-directed-services-cds> (last visited Apr. 5, 2017) [<https://perma.cc/XA5Y-223N?type=image>]; Consumer-Directed Care, LIFE PATH OPTIONS FOR INDEPENDENCE, <http://lifepathma.org/services/services-for-elders/consumer-directed-care> (last visited Apr.

Directed Personal Assistance Programs (CDPAP) have grown in popularity among working-age individuals with disabilities or other chronic conditions in recent years.<sup>127</sup> CDPAP is a Medicaid program designed to give eligible consumers more control over their care.<sup>128</sup> The CDPAP system, which aligns itself closely with the goals of the independent living model, “delegates to the client some responsibility for recruiting, hiring, training, and supervising the worker.”<sup>129</sup> Thus,

individuals receive services in their homes from one or more personal assistants who are not trained as health care workers or supervised by health care professionals. Typically, the consumer advertises for assistants in a local newspaper, interviews them, and informs them of the requirements and benefits of the position. The individual receiving the service is considered an autonomous, self-directed consumer (rather than a patient), who hires, trains, supervises and, if necessary, fires his or her personal assistant(s).<sup>130</sup>

Because the CDPAP system gives consumers significant control over their care, it has the potential to be a substantial departure from both the medical model and systems of informal support, under which individuals or entities other than the consumer control the “timing and manner in which services are provided.”<sup>131</sup> Indeed, the CDPAP system is in many ways in direct opposition to a paternalistic “medical” or “professional” model, instead emphasizing “individual autonomy and support of individual preference.”<sup>132</sup>

Arrangements designated as “consumer-directed” care can include a variety of

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5, 2017) [<https://perma.cc/Y9BA-NV69>]; Consumer-Directed Service Options, OHIO DEPT. OF AGING, [http://aging.ohio.gov/resources/publications/consumer\\_direct\\_serv\\_opt.pdf](http://aging.ohio.gov/resources/publications/consumer_direct_serv_opt.pdf) (last visited Apr. 5, 2017) [<https://perma.cc/8WWH-DXRW>].

127 Batavia, *supra* note 116, at 18–19.

128 Consumer Directed Personal Assistance Program (CDPAP), N.Y. STATE DEP’T OF HEALTH, *supra* note 126.

129 Smith, *Aging and Caring in the Home*, *supra* note 36, at 1862–63.

130 Batavia, *supra* note 116, at 18–19.

131 *Id.*

132 Charles P. Sabatino & Simi Litvak, *Liability Issues Affecting Consumer-Directed Personal Assistance Services - Report and Recommendations*, 4 ELDER L.J. 247, 256 (1996).

situations, as “neither selection nor management are all or nothing functions.”<sup>133</sup> For instance, the care consumer may be limited to a choice between a few agency-approved individuals, or may handle only some management tasks (e.g. scheduling and assigning tasks), while a case manager may handle other tasks (e.g. supervision, monitoring, and approving payment).<sup>134</sup> Along this “continuum of consumer control,” a “pure” CDPAP model would give to the consumer a cash benefit to use as she chooses.<sup>135</sup> Such direct cash payments and vouchers may be more cost-effective than home care agencies, causing federal policymakers to take a closer look at them.<sup>136</sup> However, given that many consumers may be unable to self-manage their care to this extent, administrative assistance from fiscal intermediaries or other organizations may be desirable or even necessary.<sup>137</sup>

While CDPAP is undoubtedly a more empowering option for care consumers, this may negatively affect workers’ ability to unionize and bargain collectively. Under the CDPAP model, the high level of control over care workers exercised by the clients means that the clients may qualify as the employer.<sup>138</sup> If the state considers the client to be the sole employer, this would limit the employer-employee relationship to be between each individual care provider and care consumer.<sup>139</sup> But if a state public authority coordinates payment of Medicaid funds to home care workers for their labor, the workers would likely still be able to bargain collectively, targeting the public authority as their “employer” for unionization purposes.<sup>140</sup>

### E. Privately Funded Care

Finally, some families that do not qualify for Medicaid may privately hire a home care worker who is not affiliated with an agency. Although this would theoretically provide the

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133 *Id.*

134 *Id.*

135 *Id.* at 255.

136 *Id.* at 253.

137 *Id.* at 255. For an example of a fiscal intermediary, see *About Us*, CONCEPTS OF INDEPENDENCE, <http://www.coiny.org/aboutus.php> (last visited Dec. 30, 2016) [<https://perma.cc/UDR4-435W>].

138 Leberstein et al., *supra* note 96, at 12; Smith, *Aging and Caring in the Home*, *supra* note 36, at 1862–63.

139 Leberstein et al., *supra* note 96, at 12.

140 *Id.*



most control to both the care provider and the care consumer in determining their working relationship, in reality it can leave both parties with little recourse if the relationship becomes exploitative or otherwise goes sour. In such situations, the worker likely would have no ability to unionize or otherwise formally represent herself in a bargaining situation with the employer.

## V. The Legal Dimensions of Home Care

### A. Legislating Disability & Long-Term Care

#### 1. Early Legislation: the Developmentally Disabled Assistance and Bill of Rights Act and Section 504 of the Rehabilitation Act of 1973

The independent living and social models of disability have influenced much of the legislation on disability that has emerged in the last few decades, and this legislation has in turn contributed to the increase in home- and community-based care. Three of the major national pieces of legislation on disability rights—the Developmentally Disabled Assistance and Bill of Rights Act (DDABRA), section 504 of the Rehabilitation Act of 1973, and the Americans with Disabilities Act of 1990 (ADA)—require that long-term care services be provided in the “most integrated setting appropriate” to the consumer’s needs.<sup>141</sup>

The Developmentally Disabled Assistance and Bill of Rights Act, as amended in 2000, “provides federal financial assistance to states and public and nonprofit agencies to support community-based delivery of services to persons with developmental disabilities to create and enhance opportunities for independence, productivity, and self-determination.”<sup>142</sup> It establishes Councils on Developmental Disabilities in each state made up of volunteers appointed by the governor to determine the most pressing issues facing people with developmental disabilities in that state.<sup>143</sup> Additionally, it “authorizes the Family Support Program to promote and strengthen the implementation of comprehensive State systems for in-home supports for families caring for individuals with disabilities.”<sup>144</sup>

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141 Batavia, *supra* note 116, at 19–20.

142 The Arc, AIDD, AUDD, UCP, NACDD, and SABE, *Fact Sheet: Developmental Disabilities Assistance and Bill of Rights Act*, 2011 DISABILITY POLICY SEMINAR (Feb. 2, 2011), <http://www.thearc.org/document.doc?id=2925> [<https://perma.cc/CAF4-HR67>].

143 *Id.*

144 *Id.*

Section 504 of the Rehabilitation Act, meanwhile, prohibits any “qualified individual with a disability” from being excluded from, denied the benefits of, or subjected to discrimination under any program or activity that receives Federal funding or is conducted by an Executive agency.<sup>145</sup> It is the foundation of much disability rights litigation, as it reaches a broad swath of programming run by State and local governments, as well as private entities—so long as they receive Federal funding. Successful Section 504 claims—as well as voluntary compliance with its mandates—have increased accessibility in physical spaces, education, and employment alike<sup>146</sup>—thus contributing to the further integration (and de-institutionalization) of much of the disability community.

## 2. The Americans with Disabilities Act

The most sweeping piece of disability rights legislation, however, has been the Americans With Disabilities Act (ADA). The ADA, passed in 1990, was a landmark achievement in the national disability rights movement. Titles I through III of the ADA provide its primary anti-discrimination and accommodation frameworks. Title I of the ADA prohibits employment discrimination on the basis of disability and requires employers to provide reasonable accommodations—in physical spaces and internal policies—for their employees with disabilities.<sup>147</sup> Title II mandates nondiscrimination in public services, including state and local governments.<sup>148</sup> Title III provides that public accommodations facilities must remove barriers, if readily achievable, and must ensure that new construction and remodeling include accessible designs, when possible.<sup>149</sup> Those requiring long-term care would seem to fit squarely under the first prong of the definition of disability under the ADA.<sup>150</sup>

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145 Section 504, Rehabilitation Act of 1973, 29 U.S.C. § 701.

146 See, e.g., Comment, *Section 504 of the Rehabilitation Act: Analyzing Employment Discrimination Claims*, 132 U. PENN. L. REV. 867 (1984); John D. Briggs, *Safeguarding Equality for the Handicapped: Compensatory Relief under Section 504 of the Rehabilitation Act*, 1986 DUKE L.J. 197 (1986); Laura Rothstein, *Forty Years of Disability Policy in Legal Education and the Legal Profession: What has Changed and What are the New Issues?*, 22 AM. U.J. GENDER SOC. POL’Y & L. 519 (2014); Perry A. Zirkel, *Section 504: Student Eligibility Update*, 82 THE CLEARING HOUSE 209 (2009).

147 42 U.S.C. § 12112. Nowhere in the ADA, however, are employers required to provide in-home care services or transportation to work, nor are employers required to provide individual employees with health insurance coverage equal to or better than Medicaid. See Bagentos, *supra* note 59, at 1, 4.

148 42 U.S.C. § 12132.

149 42 U.S.C. § 12182.

150 42 U.S.C. § 12102; see Batavia, *supra* note 116, at 29.

In enacting the ADA, Congress was aware of the question of “whether a policy of institutionalization constitutes discrimination requiring qualified individuals to receive community-based care options.”<sup>151</sup> The ADA’s language “indicates that any state policy that is unjustifiably balanced in favor of institutionalization of people with disabilities is suspect under the ADA and may constitute a violation.”<sup>152</sup> In the long-term care context, the ADA built on the foundations laid by the Rehabilitation Act, the DDABRA, and Medicaid, in that it prohibited discrimination against people with disabilities, required that services be provided in the “least restrictive environment,” and recognized the validity of home and community-based care as an option.<sup>153</sup> The ADA also mandates that services must be provided in the “most integrated” and “least restrictive” setting available—reflecting the goals of the independent living movement, and consistent with providing consumer-directed personal assistance services.<sup>154</sup>

## B. Disability & Long-Term Care in the Courts

### 1. *Olmstead v. L. C. by Zimring*

Despite being generally supportive of home-based long-term care, the ADA has not proven to be a strong mandate for home care resource prioritization. Although some case law has provided disability rights advocates with a glimmer of hope for enforcing and enhancing the right to state-funded home care services, it is not likely to be a source of significant change.

The most promising case brought before the Supreme Court on this issue was *Olmstead v. L. C. by Zimring*, in which the Court in 1999 found that unjustified institutionalization constituted discrimination.<sup>155</sup> This appeared to be a landmark decision establishing States’ obligations to provide community-based care under Title II of the ADA. The Majority recognized two reasons for why unjustified institutional isolation is discriminatory:

First, ‘institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so

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151 Batavia, *supra* note 116, at 28.

152 *Id.*

153 *Id.* at 30.

154 *Id.* at 28.

155 *Olmstead v. L. C. by Zimring*, 527 U.S. 581 (1999).

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>156</sup>

However, the promise of *Olmstead* was significantly limited by the Court’s proclamation that, in making determinations regarding an individual’s ability to receive care in the community, a State can take into account its own resources and the needs of others with mental disabilities.<sup>157</sup> Advocates worried that states would likely take advantage of this loophole by arguing that resources were a legitimate limit on their ability to provide for community-based care.

Additionally, *Olmstead* failed to dictate which model of community-based long-term care is required. Consequently, it is likely that different states will opt for different approaches to care. Health care providers may attempt to ensure that services are based on the medical model. Disability rights advocates will likely demand that services be provided under the independent living model. The states, meanwhile, will argue that states’ rights principles and the Medicaid program’s general nature and rules allow them significant leeway in how they choose to structure their community-based services, and that “the home and community-based waiver program implicitly recognizes that states have enormous flexibility in determining the model of service delivery.”<sup>158</sup> *Olmstead* thus lacks the strong, uncompromising mandate that independent living advocates had hoped it would provide.

## **2. The Limitations of *Board of Trustees of the University of Alabama v. Garrett***

Furthermore, even a broad reading of *Olmstead* was significantly undermined by *Board of Trustees of the University of Alabama v. Garrett*, which held that aspects of the ADA (specifically Title I) exceeded Congress’ 14th Amendment, Section 5 power and thus did not abrogate states’ 11th Amendment sovereign immunity, due to an inadequate showing of a pattern or practice of discrimination against people with disabilities sufficient to justify

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156 Batavia, *supra* note 116, at 34–35.

157 *Id.*

158 *Id.* at 40.

Congress' Fourteenth Amendment abrogation of Eleventh Amendment immunity.<sup>159</sup>

Because the *Garrett* Court found that the ADA's legislative record failed to show a history and pattern of irrational employment discrimination against persons with disabilities by the states, some have questioned whether *Garrett* narrows the scope of *Olmstead*, and whether *Olmstead* is even still "applicable and relevant" after *Garrett*.<sup>160</sup> It therefore remains to be seen whether the ADA could be used by advocates to achieve adequate state support for home care services after *Garrett*.

To the extent that such state support is still severely lacking, the judiciary—particularly through ADA litigation—might not be the most promising avenue for change. To increase funding for home- and community-based care, advocates might do better to focus on legislative or labor solutions, discussed further below.

### C. Home Care Workers' Fight for Unionization & Regulation

#### 1. Exclusion from Labor and Employment Protections

Home care workers, meanwhile, are excluded from many labor and employment laws and regulations,<sup>161</sup> including anti-discrimination and anti-harassment laws. This means they are not afforded the protections established in Title VII of the Civil Rights Act of 1964 and in workplace safety laws.<sup>162</sup> One study found that home care workers reported startling rates of workplace violence and harassment—including physical violence (44%), psychological abuse (65%), sexual harassment (41%), and sexual violence (14%).<sup>163</sup> Even when home care workers *are* covered by certain labor and employment laws, they often lack the power to assert the rights guaranteed therein.<sup>164</sup>

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159 *Bd. of Trs. of the Univ. of Ala. v. Garrett*, 531 U.S. 356 (2001). The result is that state employees now may not directly sue their employer under Title I of the ADA; however, such employees may file complaints with the DOJ and EEOC, who can then sue on their behalf.

160 *Batavia*, *supra* note 116, at 37–38.

161 *Turnham & Theodore*, *supra* note 11, at 5.

162 *Lin*, *supra* note 12, at 97.

163 *Id.*

164 *Turnham & Theodore*, *supra* note 11, at 5.

## 2. The Rise of Home Care Unions

Additionally, states continue to vary widely in their payment and treatment of home care workers. In the at least nine states with home care unions, collective bargaining power has led to increased pay and better benefits.<sup>165</sup> Oregon, for instance, where public sector home care workers are members of the SEIU Local 503,<sup>166</sup> is one of the higher-paying states for home care workers, particularly those within the Medicaid program.<sup>167</sup> As a result of union bargaining, these workers earn a statewide median of \$13.75 an hour—a marked difference from the national average.<sup>168</sup> In addition, Oregon’s public sector home care workers receive health insurance that includes vision and dental coverage, and have four paid days off per year, which can be used as sick time.<sup>169</sup> Similarly, in San Francisco, a home care workers’ union formed in 1996 led to a near doubling of wages over several years—and a sharp decrease in turnover.<sup>170</sup>

In the past decade, unionization of the home care industry has steadily increased—thanks in large part to immigrant women workers who “organized state-by-state campaigns to improve the domestic work industry, and have steadily built political power by allying with labor unions.”<sup>171</sup> However, unionized workers still represent only a fraction of all home care workers—approximately 25%.<sup>172</sup> Even within states that have strong home care worker unions, in-home aides who are not paid through Medicaid—including many who work for agencies or are hired privately by individual clients—are usually ineligible for membership in the public sector union, and are thus unable to enjoy the increased wages and benefits afforded to unionized workers.

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165 Leberstein et al., *supra* note 96; *Homecare Workers Win \$15 and Consumers Win Quality Care Improvements!*, SEIU LOCAL 503 (Apr. 10, 2017), <http://www.seiu503.org/2015/08/homecare-workers-win-15-and-consumers-win-quality-care-improvements/> [<https://perma.cc/2BKV-AUWE?type=image>]; *Overview of Homeware Collective Bargaining*, SEIU LOCAL 503 (Apr. 10, 2017), <http://www.seiu503.org/2013/12/overview-of-homecare-collective-bargaining/> [<https://perma.cc/FC54-AYT8>].

166 *Homecare, Who We Are*, SEIU LOCAL 503, <http://www.seiu503.org/category/my-worksite/care-providers/homecare/> (last visited Jan. 24, 2017) [<https://perma.cc/G2SW-F46R>].

167 Beitsch, *supra* note 66.

168 *Id.*

169 *Id.*

170 *Paying the Price*, *supra* note 2, at 16.

171 Lin, *supra* note 12, at 70.

172 Lin, *supra* note 12, at 96–97.

### 3. *Harris v. Quinn*: A Significant Setback

Home care worker unions were dealt a significant setback in 2014 with *Harris v. Quinn*, in which the Supreme Court held that public home care worker unions were unique from other public unions, and therefore could not compel non-members to pay union dues.<sup>173</sup> In stating that agency fees were less important for home care worker unions than for other types of unions, the majority in *Harris v. Quinn* disregarded empirical evidence that agency fees *are* necessary for unions to function, and that there is no reason to think this would be any different for home health care workers.<sup>174</sup>

### 4. Inclusion in Federal Employment Regulations

Unionization has not been the only front for enhanced home care worker protections. New federal regulations now include home care workers in federal minimum wage and overtime protections, thanks in large part to significant advocacy efforts by home care labor activists.<sup>175</sup> The rule mandates that most home care workers be paid the federal minimum wage (\$7.25 per hour) and qualify for time-and-a-half when they work more than 40 hours per week, and applies to approximately two million workers.<sup>176</sup>

Enforcement of the rule, which took effect January 1, 2015, was delayed for six months after considerable outcry from states, disability groups, and home-care agency lobbyists.<sup>177</sup> The U.S. Department of Labor announced its subsequent intention to exercise prosecutorial discretion until December 2015 in determining whether to bring enforcement actions.<sup>178</sup> In June 2016, the U.S. Supreme Court denied *certiorari* from for-profit home care agencies that sought to challenge the regulations on the grounds that the agency failed

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173 *Harris v. Quinn*, 656 F. 3d 692 (2014).

174 See Catherine L. Fisk & Margaux Poueymirou, *Harris v. Quinn and the Contradictions of Compelled Speech*, 48 LOY. L.A. L. REV. 439, 460 (2014). Some have argued that, in addition to being detrimental to home care workers' unions, *Harris v. Quinn* departed from prior precedent, was somewhat incoherent, and misinterpreted First Amendment law. See *id.*

175 See *Department of Labor Regulations for Home Care Workers*, NATIONAL DOMESTIC WORKERS ALLIANCE, <https://www.2016.domesticworkers.org/departement-of-labor-regulations-for-home-care-workers> (last visited Apr. 7, 2017) [<http://perma.cc/3DX2-2JSD>].

176 Michelle Diament, *Feds Delay Enforcement of New Caregiver Rule*, DISABILITY SCOOP, Oct. 10, 2014, <https://www.disabilityscoop.com/2014/10/10/feds-delay-pay-rule/19748/> [<https://perma.cc/3ESK-SKT9>].

177 *Id.*

178 *Id.*



to meaningfully address the issues of unaffordability and inadequate state funding for long-term care,<sup>179</sup> thus leaving intact a decision by the U.S. Court of Appeals for the District of Columbia Circuit that the regulations were valid.<sup>180</sup>

However, courts have not been so accommodating of home care workers' attempts to collectively vindicate their rights to overtime pay. In August 2016, after home care workers in New York tried to bring a class action against a home care agency to recover unpaid overtime and minimum wages, the Eastern District denied class certification.<sup>181</sup> The court explained that, due to the complexities of the regulations—specifically the companionship exemption, which excludes certain tasks from overtime and wage requirements—each home care worker's hours and wages would need to be calculated individually, negating the presence of common factual questions and answers.<sup>182</sup> Requiring home care workers to bring such claims individually will likely prove to be a significant obstacle; the time, energy, and resources—particularly attorneys' fees—required to do so may be prohibitive for many, causing wage and overtime theft to often go unaddressed.

## VI. Theoretical Tensions

### A. Care Workers and Care Consumers: A False Dichotomy

Home care workers and independent living advocates have drawn much of their theoretical and organizational support from feminist movements and disability rights movements, respectively.<sup>183</sup> But to posit these two fields as distinct is, in and of itself, a problematic assumption. Separating out “women” and “people with disabilities” is a falsely dichotomous starting point, erasing the experiences of *women* with disabilities. Similarly, one might view “feminism” and “disability rights” as necessarily separate schools of thought, but this would obfuscate the much-needed overlap between the two

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179 *Home Care Ass'n Am. v. Weil*, SCOTUSBLOG (June 27, 2016), <http://www.scotusblog.com/case-files/cases/home-care-assn-of-america-v-weil/> [<https://perma.cc/AGD3-JG6W>].

180 *Home Care Ass'n Am. v. Weil*, 799 F.3d 1084 (2015); *see also* Diament, *Wage Protections for Home Care Workers Reinstated*, *supra* note 17.

181 *Cowell v. Utopia Home Care, Inc.*, No. 2:2014cv00736, E.D.N.Y. (Order Denying Class Certification, Aug. 8, 2016), <http://law.justia.com/cases/federal/district-courts/new-york/nyedce/2:2014cv00736/352072/57/> [<https://perma.cc/LQX5-BJWM>].

182 *Id.*

183 Jane Aronson & Sheila M. Neysmith, “*You’re Not Just in There to Do the Work*”: *Depersonalizing Policies and the Exploitation of Home Care Workers’ Labor*, 10 GENDER & SOCIETY 59, 61 (1996).

movements. Many feminists who have written about care have failed to meaningfully account for the fact that not only are most “carers” women, but most of the “cared for” are as well.<sup>184</sup> Because women tend to live longer and be more disabled in old age than men, women disproportionately find themselves on both sides of the care paradigm.<sup>185</sup> Further, many home care workers, who may spend years or even decades without reliable preventative health care while engaging in physically demanding work, might eventually find themselves on the other side of the care partnership.<sup>186</sup>

### B. Feminism’s Incomplete and One-Sided Approach to Care

Although feminism has long been concerned with issues of care, its analysis has often been one-sided or incomplete. In attempt to formulate a more empowering view of paid care workers, feminists have sometimes undermined the agency of care consumers by situating their analysis as outside of, or ignoring entirely, the disability rights discourse. When care work is discussed in feminist literature, it is often examined exclusively from the perspective of the home care worker, ignoring the possibly countervailing interests of the care consumer.<sup>187</sup> Even the framework of care may have negative implications for the care consumer: once “personal assistance is seen as ‘care’ then the ‘carer’, whether a paid worker or an unpaid relative or friend, becomes the person in charge, the person in control. The disabled person is seen as being dependent on the carer, and incapable even of taking charge of the personal assistance s/he requires.”<sup>188</sup> Further, feminism has until recently been somewhat silent to the fact that most care *consumers* are in fact women—making both sides of the care relationship explicitly feminist issues.<sup>189</sup>

Feminism has also tended to “valorize the caring relationship for its potential to symbolize and be the very embodiment of genuine intimacy and reciprocity that cannot find expression in a society dominated by the male imaginary.”<sup>190</sup> This is often at odds

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184 Jenny Morris, *Feminism and Disability*, 43 FEMINIST REV. 57, 62 (1993) [hereinafter Morris, *Feminism and Disability*].

185 Margaret Lloyd, *The Politics of Disability and Feminism: Discord or Synthesis*, 35 SOCIOLOGY 715, 721 (2001); Family Caregiver Alliance, *supra* note 99.

186 Keigher, *supra* note 20, at 154.

187 Watson et al., *supra* note 61.

188 Morris, *Creating a Space for Absent Voices*, *supra* note 58, at 74.

189 Morris, *Feminism and Disability*, *supra* note 184, at 60.

190 Bill Hughes et al., *Love’s Labours Lost? Feminism, the Disabled People’s Movement and an Ethic of*

with the disability rights movement's perspective, in which care is "often demonized and its organization is regularly represented as a significant barrier to the emancipation and independence of disabled people."<sup>191</sup>

The answer to this problem, however, is not simply to "add on" the experience of disability and old age to existing feminist theory.<sup>192</sup> There must be a more holistic integration of these two identities in order to more fully conceptualize how longstanding societal views of gender, ability (and disability), care, and work continue to function in shaping our views of this arena.<sup>193</sup>

### C. White Feminism and Its Inattention to Paid Care Work

Feminism has also at times been inattentive to the needs of the women who have historically (and presently) been responsible for the majority of paid care work: women of color, poor women, and immigrant women (and of course the many women for whom more than one of these categories applies).<sup>194</sup> The tension between second-wave white feminists' desire to work outside of the home in the non-domestic paid care labor market, and the needs of women of color and immigrant women to have their paid care work valued, has often resulted in a fragmentation of feminists' approach to home care.<sup>195</sup> The same care work from which white, second-wave feminism has sought to liberate women in their own homes becomes the low-wage, undervalued domain of working women of color.<sup>196</sup>

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*Care*, 39 *SOCIOLOGY* 259, 260 (2005).

191 *Id.*

192 Morris, *Feminism and Disability*, *supra* note 184, at 59.

193 *Id.*

194 *See, e.g.*, DOROTHY E. ROBERTS, *Racism and Patriarchy in the Meaning of Motherhood*, 1 *AM. U. J. GENDER & SOC. POL'Y & L.* 1 (1993).

195 *See, e.g.*, Hannah Seligson, *The True Cost of Leaning In*, *THE DAILY BEAST*, Mar. 22, 2013, <http://www.thedailybeast.com/articles/2013/03/22/the-true-cost-of-leaning-in.html> [<https://perma.cc/WS7Q-NH32>]; Sarah Jaffe, *Trickle Down Feminism*, *DISSENT MAG.*, Winter 2013, <https://www.dissentmagazine.org/article/trickle-down-feminism> [<https://perma.cc/6YZY-AGZM>].

196 *See, e.g.*, Aronson & Neysmith, *supra* note 183, at 61. The relationship between paid care workers and unpaid familial workers is complex; for example, when paid aides are not available for any number of reasons, it is usually a female family member—often a daughter—who must take time out of her other paid work to care for the relative in need of care. Women lose as much as \$300,000 in lifetime wages due to lost work when caring for elderly relatives—thus, the availability and quality of paid care work has a direct effect on the labor of the aides themselves, as well as the labor of women employed in non-care industries. *See Paying the Price*,

#### D. Disability Advocates and the Disembodiment of the Personal Aide

Disability activists, meanwhile, have largely been concerned with “developing a model of the relationship between carer and cared for that restores the independence of the latter.”<sup>197</sup> In order to move beyond the “least restrictive alternative” toward what some have termed the “Most Liberating Alternative,”<sup>198</sup> care consumers will often need to have significant control over the actions of their personal aides.

While the personal assistant model has in many ways succeeded at providing persons with disabilities and older persons with increased autonomy, it raises two problems: “[f]irst, the caring/helping relationship is conceived primarily in mechanical, instrumental terms and this may underplay the reciprocity and emotional involvement invested by both parties in the relationship.” And “[s]econd, the empowerment of the disabled person does not offer protection from exploitation to the assistant.”<sup>199</sup> For example, the direct payment personal assistance system has been criticized as largely managerial and “devoid of a language of mutuality, partnership and interdependence.”<sup>200</sup>

In an attempt to move away from traditional relationships of care, in which the carer is the benevolent actor, and the people receiving that care are merely the “objects” of it, some disability activists have sought to establish a system in which “PAs do not require continuous instruction, nor do they require repeated expressions of gratitude.”<sup>201</sup> The goal, under this PA model, “is for PA to be a cash service, controlled by the disabled person, where workers perform the tasks which the disabled person cannot do . . . In a sense, the worker becomes a robot, the arms and legs of the individual who has impairments.”<sup>202</sup>

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*supra* note 2, at 13.

197 Watson et al., *supra* note 61, at 338.

198 Elias S. Cohen et al., *Consumer Directed Personal Care: An Inquiry Into Programming for Elderly Cognitively Impaired*, CENTER FOR OUTCOME ANALYSIS 4 (2000), <http://www.eoutcome.org/Uploads/COAUploads/PdfUpload/ConsumerDirectedPersonalAssistantCare.pdf> [https://perma.cc/7238-GC2E] (defining “Most Liberating Alternative” as “that which provides the greatest degree of freedom in all salient elements of the individual’s life”).

199 *Id.*

200 *Id.*

201 Watson et al., *supra* note 61, at 336.

202 TOM SHAKESPEARE, *DISABILITY RIGHTS AND WRONGS: REVISITED* 175 (London: Taylor & Francis Group 2006).

Thus, some people with disabilities may view or speak about their personal aides in ways that downplay the agency and humanity of the aide worker. This perhaps stems from what are seen as the two elements of power: “the power to act independently, which in turn is contingent on the power to command.”<sup>203</sup> Individuals with disabilities may describe their personal aides as the “‘the arms, the legs, the eyes etc.’ of their employer, therefore allowing the employer to participate in any activity they choose and be independent. The analogy is of body parts controlled at will by a brain; hence the power to command is a prerequisite of the power to act.”<sup>204</sup>

While this view may be central to the endeavor to empower persons with disabilities, it is not hard to imagine that a care worker, viewed as a mere instrument of the care consumer, loses some essential agency in the relationship, and may be seen as less deserving of workplace empowerment. This is particularly problematic given the overwhelming percentage of home care workers that are women, and the large majority that are women of color, immigrants, or both. These populations, which have long been exploited for their work,<sup>205</sup> may be especially vulnerable to being reduced to their manual labor. Bringing a feminist critique to the personal assistant relationship “could and should help to reshape this discourse in ways that address the discrimination and oppression of both disabled people and their low-paid helpers.”<sup>206</sup>

### E. Bridging the Theoretical Divide

The needs of home care workers and people with disabilities are not necessarily in tension, however, and in recent years, scholars and activists alike have begun to bridge the gaps between these two frameworks. Eva Feder Kittay<sup>207</sup> and Martha Nussbaum,<sup>208</sup> in

203 Clare Ungerson, *Personal Assistants and Disabled People: An Examination*, 13 WORK, EMPLOYMENT, & SOC’Y 583, 586 (1999).

204 *Id.*

205 Gokhan Savas, *Social Inequality at Low-Wage Work in Neo-Liberal Economy: The Case of Women of Color Domestic Workers in The United States*, 17 RACE, GENDER & CLASS 314, 319 (2000); Turnham & Theodore, *supra* note 11.

206 Watson et al., *supra* note 61, at 338.

207 See, e.g., EVA FEDER KITTAY, *LOVE’S LABOR: ESSAYS ON WOMEN, EQUALITY, AND DEPENDENCY* (Routledge Thinking Gender Series 1999); EVA FEDER KITTAY, *THE SUBJECT OF CARE: FEMINIST PERSPECTIVES ON DEPENDENCY* (Eva Feder Kittay & Ellen Feder eds., Rowman & Littlefield Publishers, 2003).

208 See, e.g., Martha Nussbaum, *Capabilities and Disabilities: Justice for Mentally Disabled Citizens*, 30 PHILOSOPHICAL TOPICS 133 (2002).

particular, have articulated the need for a more holistic view of care. Tom Shakespeare has also embraced a relational, mutually beneficial view of the personal assistant relationship, noting that

[t]he disabled person is likely to develop feelings of some kind for the person who assists them. The personal assistant is also an individual human being, with feelings and interests. They are likely to develop some sort of emotional bond with their employer. Moreover, they are not robots or body parts, they are workers, and consequently have rights.<sup>209</sup>

While this holistic view has begun to make its way into advocacy work,<sup>210</sup> it should continue to be integrated into activists' conceptualization of positive change. Home care worker advocates and disability activists would benefit not only from a deepened understanding of and commitment to these theories, but from true coalition-building that puts them concretely into practice.

Indeed, the same empowerment and positive working conditions that benefit home care workers are likely to enhance the care that is provided—and the opposite may be true as well, since “[i]n the absence of some bonding or some attitudinal commitment, the care may be indifferent or even disastrously poor. Those who advocate for vulnerable persons must ask what conditions would encourage an attitude of care in the caregiver—all the while respecting the caregiver’s own needs and desires.”<sup>211</sup>

Advocates for persons with disabilities, especially for those with the kinds of impairments that would bar them from ever living or working independently—even with adequate aide services—“need[] to look beyond liberalism, while still respecting the values of autonomy and liberty propounded by liberal theory.”<sup>212</sup> Such advocates

must seek conditions that are just to the caregiver as well as conducive to good care and justice for the charge. To advocate for caregivers is to insist that significant resources be set aside to pay for the services of caregivers, to provide them with the same benefits as other workers, to invest in

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209 TOM SHAKESPEARE, *DISABILITY RIGHTS AND WRONGS: REVISITED*, *supra* note 202, at 175–76.

210 *See, e.g., Paying the Price*, *supra* note 2.

211 Kittay, *When Caring is Just and Justice is Caring*, *supra* note 9, at 562.

212 *Id.*

training and the building of skills that will enable those who give care to help their charges develop all their capabilities.<sup>213</sup>

Beyond simply providing care on an individual basis, the valuation of care work speaks to the broader respect and recognition of people with disabilities. “If we want to remove the prejudice and lack of understanding that blights the lives of people with mental retardation,” Eva Feder Kittay writes, “we can begin by treating their caregivers as if their work mattered (because it does) and as if they mattered (because they do).”<sup>214</sup>

## VII. Practical Barriers to Coalition-Building

### A. Hours Versus Wages: The Fight Over Limited Resources

Whether or not the theoretical interests of care consumers and care workers are at odds, practical systemic barriers—particularly insufficient public funding—have often created concrete tensions. In light of current funding structures, there is tension between the “right of workers to be paid fair wages” and the fear that in order “[t]o pay those wages, people with disabilities are going to lose their freedom.”<sup>215</sup> Some care consumers utilize up to 400 hours of home care per month.<sup>216</sup> For these consumers in particular, who often struggle to find enough home care workers to fit their needs, policies like overtime caps may be particularly worrisome.<sup>217</sup> Some disability advocates have expressed concern that mandated pay increases for home care workers “could leave people with disabilities without the care they need to remain in the community,”<sup>218</sup> and in a world of limited resources, these fears are not without merit.

There is legitimate concern that mandatory wage increases could result in a reduction

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213 *Id.*

214 *Id.* at 563.

215 Josh Eidelson, *Raise Pay for Home-Care Aides? Disability Rights Groups Say No Way*, BLOOMBERG, Oct. 23, 2014, <http://www.bloomberg.com/news/articles/2014-10-23/raise-pay-for-home-care-aides-disability-rights-groups-say-no-way> [<https://perma.cc/9WFQ-2BAT>].

216 *The New Individual Provider Overtime Rule*, DISABILITY RIGHTS WASHINGTON, <http://www.disabilityrightswa.org/sites/default/files/uploads/Overtime%20Rule%202016.pdf> (last visited Nov. 14, 2016) [<https://perma.cc/Z77E-PHV8>].

217 *Id.*

218 Diament, *Wage Protections for Home Care Workers Reinstated*, *supra* note 17.



in the number of hours of home care service available through the state. Some prominent nationwide disability advocacy organizations, such as the National Council on Independent Living (NCIL), opposed including home care workers in national wage and hour protection regulations, due to fears of the impact this might have on the provision of care.<sup>219</sup> A NCIL spokesperson expressed worry that some states might respond to the regulations by reducing higher pay to minimum wage, and using the savings to cover overtime.<sup>220</sup> Other disability activists have expressed this same sentiment, fearing that state bans on overtime hours would require care consumers to replace their trusted home care aides during these overtime hours.<sup>221</sup> Some states, like Arkansas, proposed initial plans that would limit home care workers to a 40-hour week, and only one client per day—making it difficult for some home care workers to get enough hours, and requiring consumers of significant care to hire multiple aides.<sup>222</sup>

These same advocates and organizations, however, emphasize that they have long supported better pay for home care workers, as it leads to a “higher quality workforce.”<sup>223</sup> The problem, however, arises when these wage and hour protections are imposed by the federal government without a corresponding increase in funding to states.<sup>224</sup>

## B. Overtime Caps and Unpaid Hours

People with disabilities understandably want workers that they trust and know well, which can be difficult to find—a problem that is exacerbated when states impose overtime caps.<sup>225</sup> And in fact, these fears have, in some instances, materialized. In Minnesota, hundreds of care consumers saw disruptions in care, as many home care agencies cut hours and rescheduled employees to avoid paying overtime and travel costs under the new

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219 Beitsch, *supra* note 66.

220 *Id.*

221 *Disability Rights and Worker Rights in the New Home Care Rule: A Social Justice Perspective*, HEALTH & MEDICINE POLICY RESEARCH GROUP (Jan. 21, 2015), <http://www.hmprg.org/Blog+Posts/HomeCareRule> [<https://perma.cc/3LY4-G924>] [hereinafter *Disability Rights and Worker Rights*].

222 Beitsch, *supra* note 66.

223 *Id.*

224 *Id.*

225 *Disability Rights and Worker Rights*, *supra* note 221.

federal rule.<sup>226</sup> As empty shifts remained unfilled, “some people with disabilities report difficulty getting help with basic tasks, from bathing and dressing to being transferred from a wheelchair.”<sup>227</sup>

Overtime caps have been a common response by overburdened states to the federal regulations, just as many disability advocates feared. In early 2014, California proposed limiting its 385,000 public sector home care workers to 40 hours per week to prevent the state from paying overtime.<sup>228</sup> After disability rights groups, workers’ rights activists, and unions lobbied hard to defeat the proposal, the legislature instead capped home care workers at 66 hours per week.<sup>229</sup> Although this was a significant victory for all parties involved in care partnerships, it could cost California hundreds of millions of dollars—even within the first few months of enactment—to comply.<sup>230</sup>

Because of the nature of home care work, overtime hours are often inevitable—for example, when an emergency occurs or someone needs care beyond the 40-hour week—so overtime caps can mean that workers simply do not get paid for additional hours.<sup>231</sup> One care worker in Minnesota estimated that she had logged 200 hours of unpaid work in the few months since her employer had capped her hours, explaining that she felt “obligated to do the extra work because, otherwise, her bedridden clients would go without services.”<sup>232</sup>

This form of wage theft is pervasive in the home care industry, according to Francis Hall, a Minnesota caregiver and executive board member of SEIU Healthcare Minnesota, which represents 20,000 workers statewide.<sup>233</sup> She explains, “[e]very caregiver that I know is donating their time, because they don’t want anything bad to happen to their clients.”<sup>234</sup>

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226 Serres, *supra* note 7.

227 *Id.*

228 Eidelson, *supra* note 215.

229 *Id.*

230 *Id.*

231 Serres, *supra* note 7.

232 *Id.*

233 *Id.*

234 *Id.*

Hiring extra workers is one way to reduce overtime costs, but neither home care workers nor care consumers would likely benefit from the weakening of the relationship between the aides and those they care for—a potential pitfall about which disability rights advocates have been particularly vocal.<sup>235</sup> When there is inadequate funding for home care workers, states are left with a difficult choice—cut care or pay workers less.<sup>236</sup>

## VIII. Opportunities for Coalition-Building and Mutual Support

### A. Some Common Interests: Recruitment, Retention, and Turnover

Among the most obvious and pressing issues affecting care workers and care consumers jointly is the effect of wages and working conditions on recruitment, retention, and turnover. Low wages make it difficult to recruit and retain high-quality home care aides. Although many women, particularly immigrant women, may have few other options and find it difficult to transition into other fields for a variety of reasons, others may choose to leave the industry if they find that they are unable to make ends meet on a home care worker's salary. This is not to say that the women who do—and will continue to—provide home care are not providing quality care just because they have few other options. But given the current shortage of home care aides—which is anticipated to only increase as the U.S. population becomes disproportionately older<sup>237</sup>—it is in everyone's best interest to provide wages and conditions that draw more women (and men) into this industry.

Poor working conditions also lead to high turnover.<sup>238</sup> Such turnover, a constant in the industry, is one of the most concrete repercussions of the current market that deeply affects both care workers and care consumers.<sup>239</sup> Care workers who must leave or change jobs face gaps in pay and healthcare (for the few who do receive healthcare through their employers), scheduling challenges, and emotional upheaval. Care consumers are also seriously affected by turnover. Having to rebuild trusting, mutual relationships with new aides every few weeks or months can disrupt care consumers' sense of control, routine, and comfort in their daily lives.

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235 Eidelson, *supra* note 215.

236 *Id.*

237 *Paying the Price*, *supra* note 2, at 4.

238 *Id.*

239 *Id.*

## B. Possible Solutions

Feminists and disability rights advocates have begun to seriously acknowledge the important coalitions that can be built in the home care sphere,<sup>240</sup> and these partnerships need to continue to develop as they pursue concrete solutions. There is not likely to be a one-size-fits-all solution to the complex issues facing home care workers and care consumers—as evidenced by the wide range of potential remedies that have been put forth by various advocates on both sides. However, in the absence of such a solution, there are at least several possible avenues to developing systems of care that are more empowering for all involved parties.

### 1. Increase Salary and Benefits by Supporting Home Care Worker Unions

Simply increasing the salary and benefits for home care workers is at least a starting point to improve the lives of both the carers and the cared for. Contrary to concerns that increased pay and benefits for home care workers might be counter to the needs of care consumers, many have argued that “higher pay and benefits would increase the number of people choosing this kind of work and make it possible for consumers to terminate undesirable PAs without being afraid that a new PA would not be found.”<sup>241</sup> Pay increases are “crucial for attracting reliable workers,”<sup>242</sup> benefitting care consumers and care workers alike. Improving the quality of home care job benefits is also necessary to “retain and recruit the workforce needed to allow people to remain at home.”<sup>243</sup> Low wages are linked to high turnover—a significant issue, as “half the home care workforce turns over every year, disrupting the continuity of relationships that is essential to quality care.”<sup>244</sup>

In addition to retaining quality workers in the field, better wages and conditions are likely to attract more capable, skilled workers into the profession.<sup>245</sup> The Paraprofessional

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240 See Boris & Klein, *supra* note 32, at 93–94.

241 Sabatino & Litvak, *supra* note 132, at 252.

242 Eidelson, *supra* note 215.

243 *Preparing For the Elder Boom: A Framework for State Solutions*, CARING ACROSS GENERATIONS 13 (Nov. 2016), [https://s3.amazonaws.com/s3.caringacross.org/images/CAG\\_Recommendations\\_for\\_a\\_Statewide\\_Long-Term\\_Home\\_Care\\_Program.pdf](https://s3.amazonaws.com/s3.caringacross.org/images/CAG_Recommendations_for_a_Statewide_Long-Term_Home_Care_Program.pdf) [<https://perma.cc/99X8-6V76>] [hereinafter *Preparing For the Elder Boom*].

244 *Paying the Price*, *supra* note 2, at 1.

245 See Beitsch, *supra* note 66 (explaining that “[s]ome states are trying to improve home care workers’ wages and benefits, aiming to attract and retain more skilled and dedicated workers in a high-turnover industry.”).

Healthcare Institute, which advocates for the direct-care workforce, stresses that wage and hour protections are “necessary to meet the growing demand for in-home care,” a quest that is more important than ever, as finding “skilled, committed workers for caregiving jobs is becoming increasingly difficult.”<sup>246</sup> Advocates for both groups have argued that “[c]reating a \$15 wage floor and ensuring workers benefits, regular hours, good working conditions, and opportunities for advancement would attract the more than 600,000 new home care workers needed by 2024.”<sup>247</sup>

There may be evidence that the kind of worker empowerment that arises out of care worker unionizing has already begun to have a direct positive effect on care relationships. The Service Employees International Union in Oregon, representing 20,000 home care workers, reports that turnover has sharply decreased since they have implemented higher pay and benefits.<sup>248</sup> Decreased turnover can lead to increased emotional, professional, social, and financial stability in both the care worker’s and care consumer’s lives—a mutually beneficial outcome.

## 2. Enhance Customer Control Via Direct Payment Systems

Another option for increasing the agency of care consumers without further exploiting care workers is to shift more resources toward consumer-directed service organizations, encouraging—and perhaps even incentivizing—both care workers and care consumers to seek out care partnerships through these structures. Because these organizations minimize the role of a profit-seeking intermediary, they may be one of the best options for increasing care worker wages while maintaining (or perhaps even decreasing) the financial burden on care consumers or the public entities that fund their care. Importantly, they also allow the care consumer to have maximum control over the manner, time, and place in which their care is provided.

In fact, some disability advocates believe that the distillation of care to direct payments and personal assistance may be the most beneficial to care consumers, as it may break down “the chains of many everyday forms of dependency,” thus emancipating persons with disabilities.<sup>249</sup> Sharon Keigher, an academic who has explored the intersecting needs

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246 Michelle Diamant, *Caregiver Wage Rule Here to Stay*, DISABILITY SCOOP (July 14, 2016).

247 *Preparing For the Elder Boom*, *supra* note 243.

248 Beitsch, *supra* note 66.

249 Hughes et al., *supra* note 190, at 270.

of care workers and care consumers, argues that the expansion of consumer-directed programs would be beneficial to both partners in care.<sup>250</sup>

The independent living movement has argued that consumer control is both a means and an end to increased pay and benefits for home care workers.<sup>251</sup> For the last few decades, the independent living/disability rights movement has pushed for maximum consumer control over home care; this includes “shifting cost savings from more paternalistic, medical-model programs into more consumer-driven program models so that PAs can have higher pay and benefits and the service system expanded.”<sup>252</sup>

However, this must be done without jeopardizing workers’ abilities to organize and advocate for themselves; although the State would likely remain the “employer” for unionizing purposes when Medicaid is funding the care,<sup>253</sup> creative solutions would need to be developed to allow workers to collaborate with individual care consumers in designing mutually beneficial working arrangements.

### 3. Support Home Care Worker-Owned Collectives

States would also do well to promote home care worker-owned collectives. When resources are scarce, it is imperative that care workers and care consumers allocate funds among themselves as efficiently as possible. While home care agencies can provide many benefits to both the consumer and worker—by matching clients with aides, handling schedule and payroll, and so forth—they often pay the worker less than half of what they charge the client.<sup>254</sup> Some of this is eaten up by necessary overhead costs, such as liability

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250 Keigher, *supra* note 20, at 158.

251 Sabatino & Litvak, *supra* note 132, at 251–52.

252 *Id.*

253 Leberstein et al., *supra* note 96, at 12 (“In many consumer-directed programs, the state may be a joint employer along with an intermediary under federal and many states’ worker protection laws, even if it has declared itself otherwise, as the USDOL has made clear in a 2014 Administrator’s Interpretation and other guidance.”).

254 *Why Home Care Workers Struggle With Low Wages*, PBS NEWSHOUR, Mar. 16, 2015, <http://www.pbs.org/newshour/bb/home-health-care-workers-struggle-low-wages/> [<https://perma.cc/YY5V-UBG2>] [hereinafter *Why Workers Struggle With Low Wages*].

insurance, background checks, and coordinator pay.<sup>255</sup> But there is also significant profit,<sup>256</sup> none of which the worker will ever enjoy in a traditional home care agency model.<sup>257</sup> When the agency is worker-owned, however, the benefits of the agency model may be realized by both the consumer and the worker without sacrificing resources to a third-party, profit-seeking corporate entity.<sup>258</sup>

Cooperative Home Care Associates (CHCA), a worker-owned cooperative in New York City, emphasizes both its provision of “quality home care to clients” and its “quality jobs for direct-care workers.”<sup>259</sup> CHCA is a certified B-Corps, meaning that it has made “a public commitment to considering the impact of their decisions on their employees, suppliers, community, consumers, and environment.”<sup>260</sup> CHCA has over 2,050 employees and brings in annual revenue of over \$65 million.<sup>261</sup> In addition to being worker-owned, one of its distinctive features is its guaranteed hours program, where workers who have been with the agency for three years, have accepted all case assignments, and have worked every other weekend, are guaranteed thirty hours a week of pay—regardless of whether their case assignments occasionally drop below that.<sup>262</sup> Since most of their aides work more than thirty-five hours per week,<sup>263</sup> this is rarely an issue, but the peace of mind it gives to workers that they will receive a steady income week to week is significant and beneficial. However, the program comes with several caveats—namely, if a worker continually refuses cases she may no longer be eligible to participate.<sup>264</sup> This reduces the worker’s ability to

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255 *Id.*

256 Lin, *supra* note 12, at 96.

257 See Paula Span, *Wages for Home Care Aides Lag as Demand Grows*, N.Y. TIMES, Sept. 23, 2016, [https://www.nytimes.com/2016/09/27/health/home-care-aides-wages.html?\\_r=0](https://www.nytimes.com/2016/09/27/health/home-care-aides-wages.html?_r=0) [https://perma.cc/7V9F-ZTVB] (explaining how wages have stagnated for home care workers, including those working for home care agencies).

258 *Why Home Care Workers Struggle With Low Wages*, *supra* note 254.

259 COOPERATIVE HOME CARE ASSOCIATES, <http://chcany.org/> [https://perma.cc/C9UU-8N5N?type=image].

260 *Id.*

261 Anne Claire Broughton, *What Are My Hours? How Reliable Scheduling Can Boost the Bottom Line*, FORBES, June 1, 2016, <http://www.forbes.com/sites/thehitachifoundation/2016/06/01/what-are-my-hours-how-reliable-scheduling-can-boost-the-bottom-line/#6cf38455702f> [https://perma.cc/P7KR-CKLW].

262 *Id.*

263 *Id.*

264 *Id.*

choose her assignments and could potentially force workers to accept shifts with clients with whom they do not get along. It is also unclear how much choice this gives to care consumers in selecting their care worker. One would hope that preferences are seriously taken into account in crafting these schedules and establishing these care relationships.

By supporting and promoting these kinds of worker-owned agencies—and perhaps even somehow incentivizing Medicaid recipients to seek out this kind of entity for their care needs—states can help to redistribute the money that is exchanged in a care partnership without sacrificing the agentic or financial well-being of care consumers. Further, if such agencies could adopt many of the consumer-empowering traits of consumer-directed care organizations, they might be doubly-responsive to the needs of both care workers and care consumers.

#### 4. Facilitate and Encourage Mutually Empowered Ex-Ante Contracting

States might also more vigorously encourage or even require contracts between care consumers and care workers. Particularly in consumer-directed or private-pay arrangements, “formal, written employment contracts are crucial. Contracts underscore that, in the most fundamental sense, domestic work is an employment relationship.”<sup>265</sup> This could benefit both parties: establishing guidelines for the relationship and providing and acting as a written record of the scope of work, as well as standing arrangements regarding pay, benefits, and work schedule. These documents are an important step towards increasing the transparency of the employment relationship, and when workplace disputes do arise, they can be helpful in resolving them.<sup>266</sup> Although contracts can of course be broken, and there are likely power dynamics affecting one or both parties’ ability to enforce specific provisions,<sup>267</sup> establishing the particulars of the partnership prior to its inception may provide the ex-ante benefit of enhancing mutual respect between the parties at the outset. Given the heavily gendered, racialized, and class-based profiles of most home care workers, being able to participate in a contracting process with a client at the beginning of a relationship may have particular force. It would also give the care consumer a chance to more explicitly articulate her needs, either independently or with help from her family members. States, working with home care worker unions, should develop, distribute, and encourage the use of model contract templates to reduce the unequal bargaining power

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265 Turnham & Theodore, *supra* note 11, at 24.

266 *Id.* at 28.

267 *Id.* at 26.



between the parties.<sup>268</sup> This would convert an individualized solution into a broader societal solution.

### 5. Advocate for More State and Federal Funding for Long-Term Care

The most obvious solution, perhaps, is simply for state and federal governments to provide more funding for long-term care. Seth Harris, Acting Secretary of Labor for six months under the Obama Administration, argued that rather than choosing between two equally unfair options—cutting care or cutting wages—“the better choice is for legislatures to provide the amount of money that is required to provide all the care that people with disabilities and seniors need.”<sup>269</sup> While it is unlikely that the federal government will choose to allocate more funding to these kinds of social services under the current administration,<sup>270</sup> states may be able to pick up some of the slack. Ultimately, this might even maximize resources for state governments—a study in California showed that raising home care workers’ hourly wages to \$14 per hour would save the state over \$5 billion per year, in part because workers would no longer be as dependent on public benefits to supplement their poverty-level wages.<sup>271</sup>

Caring Across Generations (CAG), a coalition of care workers, care consumers, and families, advocates for solutions that benefit care workers and consumers alike.<sup>272</sup> In addition to advocating for increased federal funding for long-term care, CAG has recommended

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268 At least one state, Massachusetts, already does this, promoting its “Model Domestic Worker Employment Agreement” on its government website. *Model Domestic Worker Employment Agreement*, THE OFFICIAL WEBSITE OF THE ATT’Y GEN. OF MASS., <http://www.mass.gov/ago/docs/workplace/domestic-workers/dw-sample-employment-agreement.pdf> [https://perma.cc/ERZ5-ZDK8].

269 Eidelson, *supra* note 215.

270 Despite campaign promises to the contrary, President Trump has proposed \$800 billion in cuts to Medicaid. See MJ Lee & Tami Luhby, *Trump Budget: \$800 Billion in Medicaid Cuts*, CNN, May 24, 2017, <http://www.cnn.com/2017/05/22/politics/medicaid-budget-cuts/index.html> [https://perma.cc/7WKP-AWFZ]. These cuts are based largely on the presumed passage of a GOP health care reform bill that would make deep cuts to Medicaid, prompting intense protests from disability rights groups. See S.E. Smith, *Why Disability Rights Activists Stormed Mitch McConnell’s Office*, ROLLING STONE, June 22, 2017, <http://www.rollingstone.com/politics/news/why-disability-rights-activists-stormed-mitch-mcconnells-office-w489441> [https://perma.cc/3TXV-BHCP].

271 *Paying the Price*, *supra* note 2, at 6.

272 *Who Is Caring Across Generations?*, CARING ACROSS GENERATIONS, <https://caringacross.org/policy-agenda/> [https://perma.cc/2K6G-C2BX?type=image].

two potential structures that states could utilize in increasing such funding.<sup>273</sup> First, CAG suggests that States establish “an interest yielding long-term care benefits fund. Under this recommendation, all revenue gathered would be placed in this fund to finance the program.”<sup>274</sup> Second, CAG notes that “States can establish this program as a buy-in program within the state Medicaid system. In addition to what states contribute, they can take full advantage of the federal matching funds offered to state Medicaid programs, plus the infusion of added funds from participant contribution.”<sup>275</sup> In order to raise principal funds for this suggested long-term care benefits fund, CAG recommends the following revenue-enhancing measures: increasing progressive taxation of individuals and corporations, as well as increasing estate and inheritance taxes; closing the carried interest loophole, which currently “enables hedge fund managers and private equity firms to claim their income as capital gains instead of income and thus be taxed at a significantly lower rate;” raising taxes on luxury consumption and real estate; reallocating money raised through civil penalties (particularly those imposed on nursing homes, hospitals, and various businesses and industries for misconduct and other illegal actions); and reallocating savings from Medicaid programs.<sup>276</sup>

In addition to allocating more money toward long-term care in general, states may simply need to re-prioritize funding toward home care. State and federal governments must continue the trend of allotting more money toward home- and community-based services, rather than institutional care.

## CONCLUSION

Scholars discussing the intersection between feminist theory and disability rights theory are doing necessary and important work. But this holistic scholarship must continue to be integrated into advocacy practice in order to promote policies that truly empower home care workers and care consumers. Home care labor-rights activists and care consumers’ activists should continue to strengthen the coalitions between their two movements, envisioning a world of care that economically, emotionally, and socially empowers all participants in relationships of care.

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273 *Id.*

274 *Preparing For the Elder Boom*, *supra* note 243, at 22.

275 *Id.*

276 *Id.* at 24-29.

Organizations like the Paraprofessional Healthcare Institute (PHI) are important umbrella organizations for promoting mutually-beneficial services, and while they may not be without criticism, these kinds of entities should be looked to as a starting point for the continued, deepening relationship between home care workers and care consumers. PHI has established nine “Essential Elements for Quality Care,” one of which is that care services and support entities must support “the ability of the consumer and direct-care workers to relate as individuals in mutually respectful relationships with one another in an environment of trust.”<sup>277</sup> This is what feminist and disability activists must strive toward—to conceptualize care both theoretically and practically in a way that is mutually empowering to both members of the care partnership.

Furthermore, given the realities of the marginalization of care consumers and care workers, disability rights groups and home care labor activists should also consider looking beyond a two-way coalition, seeking out additional stakeholders to push forward their objectives. For instance, they could look to the larger women’s rights network—which has seen increased mobilization and visibility since the election and the Women’s March<sup>278</sup>—and to immigrants’ rights groups (particularly those focused on labor issues)—who have also gained more widespread support in recent months<sup>279</sup>—to press for policies and practices that would enrich and empower care partnerships.

Ultimately, if care, and the people who rely on it for their livelihood or their autonomy, is to take on a more prominent and valued role in our society, it is going to take the theoretical and practical support of multiple stakeholders. Home care labor activists and disability-rights advocates should seek to continually understand the needs of the other, and concentrate their efforts on solutions that will empower both. They must recognize both the tensions and the opportunities for mutual agency and respect in order to find a way forward that leaves behind neither partner in care.

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277 *The 9 Essential Elements of Care*, PARAPROFESSIONAL HEALTHCARE INSTITUTE, <http://phinational.org/9-essential-elements-quality-care/> [http://perma.cc/8M6Y-KBG8].

278 Susan Chira & Jonathan Martin, *After Success of Women’s March, a Question Remains: What’s Next?*, N.Y. TIMES, Jan. 22, 2017, [https://www.nytimes.com/2017/01/22/us/after-success-of-womens-march-a-question-remains-whats-next.html?\\_r=0](https://www.nytimes.com/2017/01/22/us/after-success-of-womens-march-a-question-remains-whats-next.html?_r=0) [https://perma.cc/9CLB-SK29].

279 *Labor, Immigrant and Allied Groups Announce 50,000-Person NYC Mobilization on May 1st, May Day*, TEAMSTERS JOINT COUNCIL 16, Apr. 3, 2017, <http://teamsters.nyc/2017/04/03/labor-immigrant-allied-groups-announce-50000-person-nyc-mobilization-may-1st-may-day/> [https://perma.cc/J7R5-FFZP].