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CARE REIMAGINED: TRANSFORMING LAW BY EMBRACING INTERDEPENDENCE

*Robyn M. Powell**

ALL OUR FAMILIES: DISABILITY LINEAGE AND THE FUTURE OF KINSHIP. By *Jennifer Natalya Fink*. Boston: Beacon Press. 2022. Pp. xix, 232. $18.95.

INTRODUCTION

"Do you want to keep her?" The haunting words pierced the air as I entered the world, laden with ableism. Doctors immediately questioned my worth due to my disability, shattering the joy of my birth. Unforeseen and unexpected, my disability became a catalyst for societal devaluation, perpetuating the belief that disabled people[1] are lesser, flawed, and burdensome. Tragically, this experience is all too common for parents of disabled children, who are confronted with a world that diminishes their child's inherent value. These confrontations reflect a prevailing belief that disability is a tragedy to be avoided at all costs, ignoring the undeniable truth that disability is a natural and diverse part of the human experience. This ableist mindset has profound consequences that affect both families facing societal judgment and disabled people who go unrecognized for their strengths, resilience, and humanity.

The question of whether my mom wanted to "keep" me is, in many ways, the sequel to a statement frequently espoused by expectant parents: "I don't care what it is, as long as it's healthy." Although desiring a healthy baby is an understandable goal, the underlying definition of "healthy" is often grounded in ableism.[2] Operating not only within the

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[*] Associate Professor of Law, University of Oklahoma College of Law. I dedicate this Review to my family, who has supported me unconditionally, and to my family's disability lineage who remain unknown to me at this time.

[1] Opinions within the disability community vary about whether person-first (e.g., "person with a disability") or identity-first (e.g., "disabled person") language is more empowering and respectful. *See generally* Erin E. Andrews, Robyn M. Powell & Kara Ayers, *The Evolution of Disability Language: Choosing Terms to Describe Disability*, DISABILITY & HEALTH J., July 2022, at 1 (exploring the evolving language preferences among people with disabilities). I use both interchangeably in this Review.

[2] *See* NIRMALA EREVELLES, DISABILITY AND DIFFERENCE IN GLOBAL CONTEXTS: ENABLING A TRANSFORMATIVE BODY POLITIC 37 (2011); Susan Wendell, *Toward a Feminist Theory of Disability*, HYPATIA, Summer 1989, at 107–10; Daniel Goodley & Katherine Runswick-Cole, *Becoming Dishuman: Thinking About the Human Through Dis/Ability*, 37 DISCOURSE: STUD. IN THE CULTURAL POL. OF EDUC. 1, 4 (2016).

medical profession, ableism is present more broadly in society's collective consciousness, where it reinforces the notion that disability is abnormal and undesirable.[3] Even when disability or illness is not explicitly mentioned, the implicit bias against disabled people persists, subtly suggesting that disability should be avoided or feared.[4] Critical disability studies scholars aptly argue that health challenges and disability are a universal part of life;[5] yet our cultural discourse excessively prioritizes having "healthy" babies.

Jennifer Natalya Fink,[6] a disability studies scholar and mother of an autistic daughter, explores the complexities surrounding disability, family, and care in her thought-provoking and enlightening book, *All Our Families: Disability Lineage and the Future of Kinship*. Fink critiques the frequent substitution of the seemingly desirable but euphemistic concept of "health" for more explicit disability terms, arguing this rhetorical move conceals the persistence of ableist, eugenicist ideologies (p. 103).

In *All Our Families*, Fink challenges the perception that disability is exceptional or tragic, particularly given its prevalence among one-in-five people worldwide (pp. 3–6). By blending personal narratives with extensive socio-historical research, she exposes the intricate societal systems and mechanisms that underlie the marginalization of disabled family members. She traces this back to archaic practices of human categorization that enabled racism, misogyny, and anti-Semitism, including the dark legacy of Nazi eugenics (ch. 2). Fink dissects ableist rhetoric surrounding genetic testing, revealing deep-seated societal fears about disability driven by concerns about care (ch. 3).

Furthermore, Fink argues that the preference for a perpetually "healthy" child reflects gendered attitudes about care work (p. 104). This enables racist and misogynistic structuring of care by avoiding honest conversations about how care responsibilities fall disproportionately and unjustly upon women, especially women of color. Clinging to the ideal of the ever-healthy child allows privileged white families to maintain their status by burdening others with the sacrifices of care work. To address this, Fink argues that openly acknowledging the inevitability of children needing care could help us dismantle the inequitable distribution of labor along gendered and racial lines (pp. 104–05).

Informed by queer theory, critical race theory, disability justice, and critical disability studies, Fink advocates reclaiming disability as a rich tapestry of identity, culture, and shared history. By integrating disability into our sense of belonging, she posits that it can become a catalyst for

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[3] *See* Wendell, *supra* note 2, at 107–13.

[4] *See id.* at 113; Rosemarie Garland-Thomson, *The Case for Conserving Disability*, 9 BIOETHICAL INQUIRY 339, 340 (2012).

[5] *E.g.*, Wendell, *supra* note 2, at 108 ("Unless we die suddenly, we are all disabled eventually.").

[6] Professor of English and core faculty in Disability Studies, Georgetown University.

celebration and a powerful impetus for radically reimagining care systems and kinship structures. Accordingly, *All Our Families* presents a resounding call to action, urging readers to reconsider their understanding of disability in the familial context and chart a transformative course toward repair, inclusivity, and cultivation of a more just framework for care and community.

Although *All Our Families* primarily targets a non-legal audience, it carries significant legal implications, shedding light on the intersections between care and the law and underscoring the urgent need to transform policies and legal frameworks. The law has constantly failed to acknowledge the value of care, often undervaluing or disregarding care within familial relationships altogether.[7] Legal scholar Jonathan Herring argues that this oversight results from the law's emphasis on individual rights, favoring those considered "able, autonomous and unattached" and marginalizing caring relationships and their societal importance.[8] As Herring argues, "Far from legal rights being designed to promote freedom, legal rights should be designed to enable us to undertake our caring responsibilities."[9] Indeed, this approach would support the goals espoused by Fink.

Building upon the foundation laid by *All Our Families*, this Review examines the complex issues surrounding care and their relevance to people with disabilities. Part I delves into the contrasting perspectives of the disability rights movement and disability justice. By juxtaposing independence and interdependence, I unravel the intricate dynamics shaping the care experiences of disabled people. Part II presents a descriptive analysis unveiling the current realities of care. In doing so, I expose the limited availability and access to care, the legal and bureaucratic impediments hindering effective care delivery, and the pervasive inequities faced by both unpaid and paid caregivers. Finally, Part III proposes a normative vision for reimagining care. I suggest strategies for broadening availability and access to care, challenging legal and bureaucratic impediments to care, confronting caregiver inequities, and fostering mutual aid networks within disabled communities. This Review's analysis of care issues and transformative proposals aims to enrich disability, health, and family law discourse and provide valuable insights and shaping discussions and actions toward more inclusive and equitable legal frameworks and practices.

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[7] *See, e.g.*, Albertina Antognini, *Nonmarital Contracts*, 73 STAN. L. REV. 67, 103–04 (2021) (examining how case law refuses to uphold express contracts that involve services provided in the course of a nonmarital relationship for various reasons); *see also* Ella Nilsen, *These Workers Were Left Out of the New Deal. They've Been Fighting for Better Pay Ever Since*, VOX (May 18, 2021, 12:40 PM), https://www.vox.com/22423690/american-jobs-plan-care-workers-new-deal [perma.cc/9YUF-4PC6].

[8] JONATHAN HERRING, CARING AND THE LAW 2 (2013).

[9] *Id.* at 323.

I. Moving Beyond Independence

As Fink explores throughout *All Our Families*, two distinct movements have emerged within disability activism: disability rights and disability justice. While both share a common commitment to equity for disabled people, they diverge in their approaches and underlying priorities. A crucial distinction lies in their contrasting approaches to independence and interdependence.

A. *Disability Rights: Pursuing Independence*

Emerging in the 1970s, the disability rights movement challenged the prevailing medical model of disability that viewed disabilities as defects requiring cure or rehabilitation.[10] Activists argued disability stems primarily from social attitudes and barriers rather than individual bodies.[11] They rejected the "personal tragedy" narrative of disability that breeds paternalism, dependence on others, and exclusion.[12] The disability rights movement focused heavily on challenging the paternalistic attitudes of parents and professions like social work and nursing, which historically treated disabled people as passive recipients of charity and pity.[13] The movement increasingly organized to combat such paternalism and assert disabled people's autonomy and rights.[14]

Accordingly, the disability rights movement primarily concentrates on ensuring disabled people have the same rights and opportunities as nondisabled people. It historically focused on the notion of independence, prioritizing ideals of autonomy, self-determination, and minimizing disabled people's need to depend on others.[15] Indeed, these principles appear in the landmark Americans with Disabilities Act (ADA), where Congress professed that "the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, *independent living*, and economic *self-sufficiency* for such individuals."[16]

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[10] Samuel R. Bagenstos, *Subordination, Stigma, and "Disability*,*"* 86 VA. L. REV. 397, 427 (2000); ANTI-DEFAMATION LEAGUE, A BRIEF HISTORY OF THE DISABILITY RIGHTS MOVEMENT 1–2 (2018) https://www.adl.org/sites/default/files/brief-history-of-the-disability-rights-movement_1.pdf [perma.cc/N787-T4AJ].

[11] Bagenstos, *supra* note 10, at 428–29.

[12] *Id.* at 427.

[13] Samuel R. Bagenstos, *Disability Rights and Labor: Is This Conflict Really Necessary?*, 92 IND. L.J. 277, 279–81 (2016).

[14] *Id.*

[15] *See* JACQUELINE VAUGHN SWITZER, DISABLED RIGHTS: AMERICAN DISABILITY POLICY AND THE FIGHT FOR EQUALITY 55–56 (2003).

[16] 42 U.S.C. § 12101(a)(7) (emphasis added).

However, the ideals of independence and self-sufficiency[17] are challenged when juxtaposed with the reality that many disabled people require assistance.[18] Indeed, this focus on independence has faced criticism, with some considering it unrealistic or hazardous.[19] Fink delves into these tensions, pointing out that denying the need for care and care work hinders our ability to challenge and change issues within care delivery systems (p. 118). Similarly, philosophy scholar Eva Feder Kittay contends, "there is much that is problematic in an approach that extols independence as the route to a dignified life and sees dependence as a denigration of the person."[20] Not every person can live completely without assistance, but that does not mean they cannot have dignity.

Some activists in the disability rights movement recognized disabled people might need services or supports to live in their communities and advocated for service delivery models that emphasized independence and integration.[21] To them, "independence" did not solely refer to the ability to carry out tasks without assistance; it centered on empowering people with disabilities to make meaningful and effective choices about how they wanted to live.[22] Commitment to this independence led to the development of consumer-directed personal assistance services, which allowed disabled people to employ caregivers in their homes and communities, often funded by the government.[23]

Thus, one major critique[24] of the disability rights movement involves the perpetuation of the "myth of independence"—the notion that all people should be completely self-reliant.[25] Not all disabled people can or want to conform to total independence. Overemphasizing this ideal risks excluding and marginalizing those with support needs. Activists also critique the disability rights movement for an overly narrow approach that

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[17] *See* SWITZER, *supra* note 15, at 55–56.

[18] Janice McLaughlin, *Valuing Care and Support in an Era of Celebrating Independence: Disabled Young People's Reflections on Their Meaning and Role in Their Lives*, 54 SOCIOLOGY 397, 408 (2020).

[19] *See, e.g.*, Eva Feder Kittay, *Care and Disability: Friends or Foes*, in THE OXFORD HANDBOOK OF PHILOSOPHY AND DISABILITY 416, 422 (Adam Cureton & David Wasserman eds., 2020).

[20] Eva Feder Kittay, *The Ethics of Care, Dependence, and Disability*, 24 RATIO JURIS. 49, 51 (2011).

[21] Bagenstos, *supra* note 13, at 280–81.

[22] *Id.*

[23] *Id.* at 281–83.

[24] *See* Mia Mingus, *Changing the Framework: Disability Justice*, LEAVING EVIDENCE (Feb. 12, 2011, 1:56 PM), https://leavingevidence.wordpress.com/2011/02/12/changing-the-framework-disability-justice [perma.cc/3N8X-YKWN]. *See generally* Robyn M. Powell, *Beyond Disability Rights: A Way Forward After the 2020 Election*, 15 ST. LOUIS U. J. HEALTH L. & POL'Y 319 (2022) (exploring enduring social, economic, and health inequities experienced by people with disabilities despite the disability rights movement).

[25] Mingus, *supra* note 24 (describing the "myth of independence").

centers on legal tactics, white people's experiences, and physical disabilities while neglecting intersectionality, diverse voices, and grassroots organizing.[26]

B. *Disability Justice: Embracing Interdependence*

Disability justice has emerged as the "second wave" of disability activism, addressing unresolved gaps in the disability rights movement.[27] It reflects a paradigm shift by moving beyond the pursuit of equal access towards the broader goal of wholeness.[28] It emphasizes the importance of collective organization rather than sole reliance on individual rights and aims to redistribute power to marginalized groups within the disability community.[29] This shift acknowledges the intersecting experiences of disability, race, gender, sexuality, and other forms of oppression and recognizes the need for comprehensive and inclusive approaches to address systemic inequities and achieve justice.[30]

Aligning with disability justice principles, *All Our Families* contends disability activism must move beyond legal strategies to transform society's ableist norms. As Fink notes, activists now demand that we "challenge and change all the other, more subtle aspects of society that perpetuate ableism" even amid legal inclusion (p. 43). Likewise, Talila Lewis, a disability justice activist, abolitionist-organizer, and attorney, highlights that disability justice seeks radical reforms affirming all people's right to live and thrive, not just policy fixes.[31] This broader vision, which Fink supports, dismantles ableist structures to foster an inclusive society embracing the diversity of human experiences.

Central to disability justice is universal interdependence, which holds significant implications for reimagining care. As activist and writer

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[26] Patty Berne, *Disability Justice—A Working Draft*, SINS INVALID (June 10, 2015), https://www.sinsinvalid.org/blog/disability-justice-a-working-draft-by-patty-berne [perma.cc/GU23-VEU9].

[27] Doron Dorfman, *Afterword: The ADA's Imagined Future*, 71 SYRACUSE L. REV. 933, 935 (2021); *see also* Berne, *supra* note 26 (explaining that disabled activists of color coalesced to consider a "second wave" of disability activism and ultimately created disability justice).

[28] *See, e.g.*, Shirley Lin, *Bargaining for Integration*, 96 N.Y.U. L. REV. 1826, 1832 & n.21 (2021) ("It is this tension between systemic change and liberalism's individuated approach to civil rights that disability activists increasingly critique as they conceive of disability justice as robust, with particular attention to co-constructed social identities, including race."); Mingus, *supra* note 24 (arguing for a shift away from "individualized and independence-framed notions" of disability access towards more "collective and interdependent" ones).

[29] Mingus, *supra* note 24.

[30] *Id.*

[31] Talila "TL" Lewis, *Disability Justice Is an Essential Part of Abolishing Police and Prisons*, MEDIUM: LEVEL (Oct. 7, 2020), https://level.medium.com/disability-justice-is-an-essential-part-of-abolishing-police-and-prisons-2b4a019b5730 [perma.cc/4RDU-99VY].

Mia Mingus explains, disability justice rejects the flawed "myth of independence" that all can and should be wholly self-reliant.[32] Instead, it acknowledges that all people, disabled or not, fundamentally rely on others in diverse ways. Disability justice fights for embracing interdependence and the truth that no one is completely autonomous.[33] It seeks an inclusive interdependence that honors our shared human needs. This paradigm shift from insisting on independence is profoundly important for transforming care frameworks to recognize mutual reliance.

Fink similarly embraces interdependence, writing, "Our devaluing of care, of interdependence, of disability gain, and our lack of any sense of disability caregiving lineage lead not to freedom but rather to denial and ableism" (p. 118). Thus, Fink asserts we should understand that the "joyous aspects of care and interdependency are key to valuing caregiving—and assur[e] that [caregiving] is done in the most ethical manner" (p. 119). Likewise, disability studies scholar Janice McLaughlin has discussed separating caregiving from the stigma of charity: "Care can be rescued from associations with charity if it is remembered that all those participating in care are nested in sets of reciprocal relations and obligations."[34] Acknowledging the inevitability of vulnerability entails recognizing the significance of interdependency, which differs from charitable notions of dependency and burden.[35] Emphasizing the value of interdependency encourages us to question societal and state structures and moves care from the private realm of the family to the public sphere and citizenship discussions.[36] It also highlights the broader social responsibility for engaging in care practices with diverse people and expands the definition of good citizenship to include active participation in caring interdependent relationships.[37]

Disability justice and its central principle of interdependence are vital to transforming understandings of care. Reframing care as a collective responsibility inherent to human existence, rather than just supporting the "dependent," fosters an inclusive, compassionate approach acknowledging diverse experiences and needs. Embracing interdependence enables envisioning care as holistic networks where people with disabilities are active agents shaping support, not passive recipients. This empowers disabled people as leaders in their own care and care of others.

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[32] Mingus, *supra* note 24.

[33] *Id.*

[34] Janice McLaughlin, *Understanding Disabled Families: Replacing Tales of Burden with Ties of Interdependency*, *in* ROUTLEDGE HANDBOOK OF DISABILITY STUDIES 402, 409 (Nick Watson, Alan Roulstone & Carol Thomas eds., 2012).

[35] *Id.*

[36] *Id.*

[37] *Id.*

II. CONTEMPORARY REALITIES OF CARE

Drawing upon, integrating, and expanding Fink's critical insights about care in *All Our Families*, this Part explores the present realities of care, exposing the daunting challenges faced by disabled people and caregivers. By uncovering these interconnected challenges, this Part offers a comprehensive overview of the current state of care and lays the groundwork for envisioning more inclusive and equitable care structures.

A. *Limited Availability and Access*

Many disabled people lack access to paid care, including home- and community-based services ("HCBS"). Fink argues this reality arises partly from societal perceptions of care: "Because the inevitability of care needs is denied, they are underfunded, cut out of the social and economic fabric of our life and the systems governing it" (p. 111). The absence of accessible community care options perpetuates the institutionalization of disabled people despite the Supreme Court's 1999 *Olmstead v. L.C.*[38] decision mandating integration and service provision in non-segregated settings.[39] Restrictive Medicaid policies worsen this crisis by favoring expensive institutional placements over HCBS, like personal assistants, skilled nursing, and therapies.[40] Although nursing homes are federally mandated, HCBS remains optional for states. This systemic institutional bias pushes disabled people into segregated settings by depriving them of essential supports for integrated living in their communities.[41] Thus, the lack of investment in HCBS perpetuates the institutionalization and segregation that *Olmstead* sought to eliminate.

Fink explores the tragic history of institutions as tools for segregation by drawing on her family's experiences (pp. 21–36). She notes her cousin

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[38] The majority opinion reads:

> [W]e conclude that, under Title II of the ADA, States are required to provide community-based treatment for persons with mental disabilities when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.

Olmstead v. L.C., 527 U.S. 581, 607 (1999).

[39] *See* Maya Sabatello, Scott D. Landes & Katherine E. McDonald, *People with Disabilities in COVID-19: Fixing Our Priorities*, AM. J. BIOETHICS, July 2020, at 187, 188.

[40] Larisa Antonisse, Note, *Strengthening the Right to Medicaid Home and Community-Based Services in the Post-COVID Era*, 121 COLUM. L. REV. 1801, 1832–36 (2021); NGA T. THACH & JOSHUA M. WIENER, OFF. DISABILITY, AGING & LONG-TERM CARE POL'Y, U.S. DEP'T OF HEALTH & HUM. SERVS., AN OVERVIEW OF LONG-TERM SERVICES AND SUPPORTS AND MEDICAID: FINAL REPORT 5 (2018), https://aspe.hhs.gov/sites/default/files/migrated_legacy_files//182846/LTSSMedicaid.pdf [perma.cc/Y5AU-49KS]; *The Institutional Bias: What It Is, Why It Is Bad, and the Laws, Programs, and Policies Which Would Change It*, AUTISTIC SELF ADVOC. NETWORK, https://autisticadvocacy.org/actioncenter/issues/community/bias [perma.cc/AM6P-3SC3].

[41] AUTISTIC SELF ADVOC. NETWORK, *supra* note 40.

Rhona lived in a relatively nice group home founded by Rhona's parents (p. x). In contrast, her cousin "XY"[42] was immediately abandoned to a bleak state institution after birth (pp. ix–x). Despite Rhona's seemingly better living conditions, even kinder institutions inherently "institutionalize" by isolating residents from society and embedding ableism into notions of family (p. 34). Varied experiences do not erase institutions' core purpose of exclusion.

The lack of adequate community-based care options has had devastating consequences for disabled people. Institutional settings have long engendered harmful outcomes like reduced autonomy, poor care access, and high rates of neglect and abuse.[43] Starkly illustrating these dangers, data shows disabled residents of institutions experienced dramatically higher COVID-19 infection and mortality rates than the general public.[44] The disproportionate toll for those segregated from society exhibits the need to remedy the material deprivations and ingrained ableism underlying institutional life.

While approximately 62.5% of Medicaid spending on long-term services in 2020 went to HCBS nationally,[45] access varies considerably across states and disabled populations partly because of systemic inequities.[46] People of color face disproportionate barriers to HCBS access, placing them at higher risk of institutionalization than white people.[47] Factors like implicit bias in assessments, lack of cultural competence in HCBS systems, chronic underfunding in communities of color, and past discrimination likely contribute to these divides.[48] Relatedly, states with

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[42] His actual name is unknown.

[43] Sabatello et al., *supra* note 39, at 188.

[44] *See, e.g.*, Scott D. Landes, Julia M. Finan & Margaret A. Turk, *COVID-19 Mortality Burden and Comorbidity Patterns Among Decedents With and Without Intellectual and Developmental Disability in the US*, 15 DISABILITY & HEALTH J., Oct. 2022, at 1, 6 (finding that people with intellectual disabilities who died from COVID-19 were more likely to be living in a nursing home than others).

[45] CAITLIN MURRAY, MICHELLE ECKSTEIN, DEBRA LIPSON & ANDREA WYSOCKI, MATHEMATICA, MEDICAID LONG TERM SERVICES AND SUPPORTS ANNUAL EXPENDITURES REPORT: FEDERAL FISCAL YEAR 2020 (2023), https://www.medicaid.gov/sites/default/files/2023-10/ltssexpenditures2020.pdf [perma.cc/ZA3H-WR5Z].

[46] Natalie Chong et al., *The Relationship Between Unmet Need for Home and Community-Based Services and Health and Community Living Outcomes*, 15 DISABILITY & HEALTH J., Apr. 2022, at 1, 2, 6 (2022).

[47] *See* Jasmine L. Travers et al., *Demographic Characteristics Driving Disparities in Receipt of Long-term Services and Supports in the Community Setting*, 59 MED. CARE 537, 540–41 (2021); Tetyana Pylypiv Shippee et al., *Evidence for Action: Addressing Systemic Racism Across Long-Term Services and Supports*, 23 J. AM. MED. DIRS. ASS'N 214, 215 (2022).

[48] *See* Lawren E. Bercaw et al., *Assessing Disparities in Medicaid Home- and Community-Based Services: A Systematic Review*, 35 J. AGING & SOC. POL'Y 302, 312 (2023); *Crisis in Our Communities: Racial Disparities in Community Living*, AUTISTIC SELF ADVOC. NETWORK 60, https://autisticadvocacy.org/wp-content/uploads/2022/02/Crisis-in-our-Communities-Racial-Disparities-in-Community-Living-PL.pdf [perma.cc/GC25-E8X2]; *see also* Natalie

more people of color have more institutions and allocate less funding for HCBS.[49] The uneven availability of HCBS appears to drive racial disparities in institutionalization, suggesting inequitable access to services enabling community living.

Furthermore, with states having the freedom to design their own Medicaid HCBS systems, considerable inconsistencies exist from state to state regarding program eligibility, services covered, and the level of assistance provided.[50] Medicaid waitlists and limited enrollment hinder timely access to HCBS.[51] As of 2021, there were over 655,000 people in the United States on Medicaid HCBS waitlists,[52] with an average wait time of 36 months.[53] Thus, in the absence of available HCBS and considerable unmet needs, institutional settings often become the sole option for many disabled people.[54]

Even without waitlists, Medicaid's eligibility restrictions impede HCBS access for some disabled people who require services. Medicaid re-

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M. Chin, *Centering Disability Justice*, 71 SYRACUSE L. REV. 683, 695–705, 730–31 (2021); *Disability and the African American Experience*, MUSEUM DISABILITY HIST., https://www.museumofdisability.org/disability-and-the-african-american-experience [perma.cc/866N-HKG7]; David Barton Smith et al., *Separate and Unequal: Racial Segregation and Disparities in Quality Across U.S. Nursing Homes*, 26 HEALTH AFFS. 1448, 1451–57 (2007).

[49] Zhanlian Feng et al., *Growth of Racial and Ethnic Minorities in US Nursing Homes Driven by Demographics and Possible Disparities in Options*, 30 HEALTH AFFS. 1358, 1361–62 (2011); Smith et al., *supra* note 48; CTR. FOR CONSUMER ENGAGEMENT IN HEALTH INNOVATION, CMTY. CATALYST & LTSS CTR., UNIV. OF MASS. BOS., RACIAL AND ETHNIC DISPARITIES IN ACCESS TO HOME AND COMMUNITY-BASED SERVICES AMONG INDIVIDUALS DUALLY ELIGIBLE FOR MEDICARE AND MEDICAID: AN ENVIRONMENTAL SCAN OF THE LITERATURE 18 (2022), https://communitycatalyst.org/wp-content/uploads/2023/08/Racial-and-Ethnic-Disparities-in-Access-to-Home-and-Community-Based-Services-Among-Individuals-Dually-Eligible-for-Medicare-and-Medicaid-An-Environmental-Scan-of-the-Literature-May2022.pdf [perma.cc/UN4U-HDGN].

[50] Chong et al., *supra* note 46, at 2.

[51] *Id.*

[52] *Medicaid HCBS Waiver Waiting List Enrollment, by Target Population and Whether States Screen for Eligibility*, KFF, https://www.kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers [perma.cc/H32N-EPS7] [hereinafter *Medicaid HBCS Waiver Waiting List Enrollment*] (showing waitlist data for 2021); MaryBeth Musumeci, Priya Chidambaram & Molly O'Malley Watts, *Key Questions About Medicaid Home and Community-Based Services Waiver Waiting Lists*, KFF (Apr. 4, 2019), https://www.kff.org/medicaid/issue-brief/key-questions-about-medicaid-home-and-community-based-services-waiver-waiting-lists [perma.cc/AZ7U-U7CK].

[53] *Medicaid HCBS Waiver Waiting List Enrollment*, *supra* note 52; Alice Burns, Molly O'Malley Watts & Meghana Ammula, *A Look at Waiting Lists for Home and Community-Based Services from 2016 to 2021*, KFF (Nov. 28, 2022), https://www.kff.org/medicaid/issue-brief/a-look-at-waiting-lists-for-home-and-community-based-services-from-2016-to-2021 [perma.cc/9PG7-UC28].

[54] Antonisse, *supra* note 40, at 1805.

mains the sole insurer covering essential HCBS, such as personal assistance.[55] However, strict income and asset limits on Medicaid qualification mean disabled people who work or have savings can forfeit their eligibility for such services. These rules effectively coerce some people into staying unemployed and poor to maintain critical supports.[56] Medicaid buy-in programs also typically have rigid financial criteria that bar earnings above poverty-level wages.[57] Consequently, Medicaid's narrow eligibility standards erect barriers to essential HCBS for disabled people who need them.

Moreover, even if a state provides HCBS, disabled people often face challenges hiring caregivers. As legal scholar Samuel Bagenstos observes, "some state Medicaid policies . . . make it impossible in practice for individuals with disabilities to obtain adequate community-based services even if the state does not place those individuals on a waiting list."[58] Furthermore, home care worker availability dropped by almost 12% between 2013 and 2019 and is expected to deteriorate further as the general population ages and demand for home care rises.[59]

Alternatively, paying privately for care can be cost-prohibitive. Being disabled is expensive, and among the many out-of-pocket expenses associated with having a disability, the highest costs are for personal assistance services and healthcare. These expenses for disabled people are more than twice as high as expenses for those without disabilities.[60] In 2021, the median annual cost of in-home care was $61,776,[61] while the

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[55] Stephanie R. Hoffer, *Making the Law More ABLE: Reforming Medicaid for Disability*, 76 OHIO ST. L.J. 1255, 1260 (2015); *see also* Powell, *supra* note 24, at 416 (explaining that Medicaid is the only health insurer that pays for HCBS like personal assistant services).

[56] Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1, 32–34 (2004).

[57] *Medicaid Eligibility Through Buy-In Programs for Working People with Disabilities*, KFF, https://www.kff.org/other/state-indicator/medicaid-eligibility-through-buy-in-programs-for-working-people-with-disabilities [perma.cc/4LQ3-RC3T]. For example, Louisiana's monthly income limit is $1133. *Id.*

[58] Bagenstos, *supra* note 56, at 58.

[59] Amanda R. Kreider & Rachel M. Werner, *The Home Care Workforce Has Not Kept Pace with Growth in Home and Community-Based Services*, 42 HEALTH AFFS. 650, 650 (2023).

[60] NANETTE GOODMAN, MICHAEL MORRIS, ZACHARY MORRIS & STEPHEN MCGARITY, NAT'L DISABILITY INST., THE EXTRA COSTS OF LIVING WITH A DISABILITY IN THE U.S.—RESETTING THE POLICY TABLE 2 (2020), https://www.nationaldisabilityinstitute.org/wp-content/uploads/2020/10/extra-costs-living-with-disability-brief.pdf [perma.cc/9ZBL-Y8GE].

[61] Priya Chidambaram & Alice Burns, *10 Things About Long-Term Services and Supports (LTSS)*, KFF (Sept. 15, 2022), https://www.kff.org/medicaid/issue-brief/10-things-about-long-term-services-and-supports-ltss [perma.cc/5SLK-RN3D].

median yearly earnings for disabled people was only $45,314.[62] This significant disparity makes accessing essential support services even more difficult.

B. *Legal and Bureaucratic Impediments*

Additional legal and bureaucratic barriers complicate access to unpaid and paid care for people with disabilities and their families. Fink posits that ableism is "embedded in our gendered, neocolonial, racist care structures" (p. xvii). Legal scholar Yiran Zhang refers to the impediments imposed by laws and policies as "care bureaucracy."[63]

The rising demand for HCBS in the United States has led the government to assume more fiscal and managerial responsibility for providing long-term home care.[64] The expanding public care system is rapidly transforming, turning family caregivers into paid caregivers.[65] However, families and care workers dependent on this system face a highly regimented and bureaucratic framework that measures, monitors, and controls care.[66] This system imposes strict documentation requirements to substantiate the necessity and provision of care.[67] These requirements impose significant administrative, emotional, and financial strains on care recipients, their families, and caregivers by adding complexity, restricting flexibility, and prioritizing quantifiable tasks. They also often overlook the holistic aspects of caregiving relationships and hinder the delivery of personalized and compassionate care.

Further, these legal and bureaucratic impediments have sparked concerns among experts who worry publicly administered state care is an extension of the growing state surveillance and control apparatus.[68] This raises the potential for heightened policing and scrutiny within the

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[62] NAT'L INST. ON DISABILITY, INDEP. LIVING, & REHAB. RSCH., ANNUAL REPORT ON PEOPLE WITH DISABILITIES IN AMERICA: 2023 16 tbl.7 (2023), https://disabilitycompendium.org/sites/default/files/user-uploads/Accessible-Annual%20Report%20---%202023%20---%20Accessible.pdf [perma.cc/QN76-LGJ4].

[63] Yiran Zhang, *The Care Bureaucracy*, 99 IND. L.J. (forthcoming 2024), https://papers.ssrn.com/sol3/papers.cfm?abstract_id=4390066 [perma.cc/5JW5-9FEQ].

[64] *See* Naomi Cahn, Clare Huntington & Elizabeth Scott, *Family Law for the One-Hundred-Year Life*, 132 YALE L.J. 1691, 1695–1704 (2022) (describing the growth of the aging population and mounting care needs); *see also* LINA STEPICK & BROOKE ADA TRAN, FED. RSRV. BANK S.F., THE RAPIDLY GROWING HOME CARE SECTOR AND LABOR FORCE PARTICIPATION 12–13 (2022), https://www.frbsf.org/community-development/wp-content/uploads/sites/3/rapidly-growing-home-care-sector-and-labor-force-articipation-sffed-cdrb-2022-02.pdf [perma.cc/75D4-5KMV]; Vicki A. Freedman & Brenda C. Spillman, *Disability and Care Needs Among Older Americans*, 92 MILBANK Q. 509, 509 (2014).

[65] Zhang, *supra* note 63 (manuscript at 3).

[66] *Id.*

[67] *Id.*

[68] *Id.*

caregiving sphere and potentially compromises the autonomy and privacy of those involved in care relationships. As Zhang observes, "The coercive and punitive state, often activated in the name of family support, is ominously omnipresent in the life of poor Black families, poor pregnant women, poor mothers dealing with substance use, and poor individuals with disabilities."[69] Thus, care bureaucracy "imposes a[n] . . . omnipresent regulation of the users' family, workplace, and bodily autonomy by micro-managing and documenting their physical movements."[70] Our paternalistic welfare state has perpetuated a culture of suspicion and distrust through invasive monitoring, disproportionately impacting marginalized caregivers and recipients dependent on these services.[71] Such monitoring programs focus on fraud prevention rather than positive care outcomes.[72] And the separation between who pays for and receives care and the fragmented federalist funding structure creates numerous layers of conflicting interests and potential fraud in public care programs.[73] This structure drives accountability enforcement to prioritize procedural compliance over substantive harm prevention.[74] Moreover, categorizing care workers either as medical specialists or external to the public workforce brings about greater fragmentation and heightens the need for administrative oversight.[75]

An illustration of the intrusive nature of this bureaucracy is the implementation of Electronic Visit Verification (EVV) systems, mandated by Congress in 2016 for all Medicaid-funded care programs.[76] This system requires care workers to validate their GPS location regularly, log each care task performed, and in some circumstances even upload pictures of themselves with the care recipient for every visit.[77] The introduction of EVV exemplifies the evolving direction of the public care system, charac-

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[69] *Id.*

[70] *Id.*

[71] *See generally*, KHIARA M. BRIDGES, THE POVERTY OF PRIVACY RIGHTS (2017) (exploring the interconnected dynamics of poverty and privacy rights, examining how people experiencing poverty, especially people of color, often face infringements of their privacy and limited protection of their rights).

[72] *See* Zhang, *supra* note 63.

[73] *Id.*

[74] *Id.*

[75] *Id.*

[76] 21st Century Cures Act, Pub. L. No. 114-255 § 12006; *see also* Robyn Powell, *How a Little-Known Provision of an Existing Law Could Lead to Geo-Tracking of People With Disabilities*, REWIRE NEWS GRP. (June 23, 2017, 5:20 PM), https://rewirenewsgroup.com/2017/06/23/little-known-provision-existing-law-lead-geo-tracking-people-disabilities [perma.cc/6PTS-K7NE].

[77] Alexandra Mateescu, *Electronic Visit Verification: The Weight of Surveillance and the Fracturing of Care* 2, 5, 45, DATA & SOC'Y (2021), https://datasociety.net/wp-content/uploads/2021/11/EVV_REPORT_11162021.pdf [perma.cc/G88P-W2JC].

terized by intrusions on privacy and more stringent procedural requirements to access benefits. The implementation of EVV systems may also create additional barriers and complexities in the caregiver hiring process,[78] further exacerbating existing challenges disabled people face in accessing care.[79]

The expanding bureaucracy within care programs also poses a significant challenge to promoting person-centered care and enabling people with disabilities to live according to their own preferences.[80] The extensive bureaucratic framework impedes care services' effectiveness and adaptability.[81] Consequently, bureaucratic complexities and hierarchies compromise the autonomy and responsiveness central to care programs and the needs and goals of those receiving care.

C. *Caregiver Inequities*

Disabled people are not the only group impacted by the current care landscape. Unpaid and paid caregivers face enduring economic, social, and health inequities.[82] These caregivers encounter financial hardships, limited access to social support networks, and adverse health outcomes due to the nature of their roles.[83] Addressing these systemic inequities is paramount in fostering a more just and inclusive care system that recognizes and supports the well-being of all people involved in care relationships.

Most people in the United States who need care rely on unpaid care from family and friends.[84] Among the approximately 11 million noninstitutionalized people with care needs, 92% receive unpaid assistance, and

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[78] Naomi Gallopyn & Lisa I. Iezzoni, *Views of Electronic Visit Verification (EVV) Among Home-Based Personal Assistance Services Consumers and Workers*, 13 DISABILITY & HEALTH J. 1 (2020).

[79] There is no evidence of widespread abuse or inappropriate Medicaid spending on HCBS that would justify invasive oversight practices. *See* Alicia Hopkins, *How This 'Anti-Fraud' Device Violates the Rights of People with Disabilities*, THE MIGHTY (Aug. 20, 2023), https://themighty.com/topic/disability/electronic-visit-verification-violates-rights-people-disabilities [perma.cc/PTT2-GWMT].

[80] Kirstein Rummery, Julia Lawrence & Siabhainn Russell, *Partnership and Personalisation in Personal Care: Conflicts and Compromises*, 22 SOC. POL'Y & SOC'Y 187, 190, 199 (2023).

[81] Michelle Meyer, Michelle Donelly & Patricia Weerakoon, *'They're Taking the Place of my Hands': Perspectives of People Using Personal Care*, 22 DISABILITY & SOC'Y 595, 603 (2007).

[82] *See generally* AARP & NAT'L ALL. FOR CAREGIVING, 2020 REPORT: CAREGIVING IN THE U.S. (2020), https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf [perma.cc/EQ85-5EZS].

[83] *Id.*

[84] Puja Upadhyay & Janet Weiner, *Long-Term Care Financing in the United States*, LEONARD DAVIS INST. HEALTH ECON. UNIV. PENN. at 4 (Sept. 2019).

only 13% receive any form of paid assistance.[85] Nationally, there are approximately 53 million family caregivers.[86] The economic value of their unpaid care is estimated to be approximately $600 billion annually.[87] As Fink notes, for unpaid caregivers, "[t]he economic dimensions of care are profound," and the "[c]are needs of family members can cause a calamitous slide into poverty and underemployment" (p. 111).

Women, especially women of color, shoulder a disproportionate burden of care, which results in loss of time, income, and economic prospects.[88] As Fink writes, "To do care work is to be female. To be female is to do care work. Care work is what defines female gender as such" (p. 107). On average, mothers who engage in unpaid care for immediate family members face estimated employment-related costs of $295,000 throughout their lifetime.[89] Providing unpaid family caregiving results in a 15% reduction in a mother's lifetime earnings, impacting retirement income as well.[90] In addition to caring for family members, three-fifths of family caregivers are employed outside the home,[91] and often encounter work-related consequences.[92]

Furthermore, over three-quarters of family caregivers face out-of-pocket expenses related to caregiving. These expenses encompass household, medical, personal care, and other costs,[93] and average approximately one-quarter of the caregiver's annual income.[94] Black and Hispanic/Latinx families shoulder greater financial burdens, with costs

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[85] H. Stephen Kaye, Charlene Harrington & Mitchell P. LaPlante, *Long-Term Care: Who Gets It, Who Provides It, Who Pays, and How Much?*, 29 HEALTH AFFS. 11, 11 (2010).

[86] AARP & NAT'L ALL. FOR CAREGIVING, *supra* note 82, at 4.

[87] SUSAN C. REINHARD, SELENA CALDERA, ARI HOUSER & RITA B. CHOULA, *Insight on the Issues*, AARP, 1 (2023) https://www.aarp.org/content/dam/aarp/ppi/2023/3/valuing-the-invaluable-2023-update.doi.10.26419-2Fppi.00082.006.pdf [perma.cc/53EA-5SKK].

[88] *See* Valerie J. Edwards et al., *Characteristics and Health Status of Informal Unpaid Caregivers—44 States, District of Columbia, and Puerto Rico, 2015-2017*, 69 MORBIDITY & MORTALITY WKLY. REP. 183, 184–88 (2020); AARP & NAT'L ALL. FOR CAREGIVING, *supra* note 82, at 10.

[89] RICHARD W. JOHNSON, KAREN E. SMITH & BARBARA A. BUTRICA, URBAN INST., LIFETIME EMPLOYMENT-RELATED COSTS TO WOMEN OF PROVIDING FAMILY CARE, at v (2003), https://www.dol.gov/sites/dolgov/files/WB/Mothers-Families-Work/Lifetime-caregiving-costs_508.pdf [perma.cc/MBP7-39BK].

[90] *Id.*

[91] REINHARD ET AL., *supra* note 87, at 1.

[92] AARP & NAT'L ALL. FOR CAREGIVING, *supra* note 82, at 68.

[93] AARP, CAREGIVING OUT-OF-POCKET COSTS STUDY (2021), https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2021/family-caregivers-cost-survey-2021.doi.10.26419-2Fres.00473.001.pdf [perma.cc/K8DT-9D5H]; *see* Allison K. Hoffman, *Reimagining the Risk of Long-Term Care*, 16 YALE J. HEALTH POL'Y L. & ETHICS 147, 184 (2016).

[94] AARP, *supra* note 93.

representing 34% and 47% of the caregiver's average income, respectively.[95] Without affordable care, caregivers of color pay enormous sums to provide care, which exacerbates economic instability.

Similarly, the profound inequities experienced by paid caregivers, commonly known as "direct care workers," underscore the entrenched gendered and racialized division of care labor that persists within our society. Fink points out that the overrepresentation of women of color in the caregiving profession results from systemic racism—such as the Fair Labor Standard Act's notable exemption for domestic workers—that devalues this essential work and perpetuates the cycle of paying unlivable wages (pp. 108–09). Sixty-one percent of care workers are people of color, and 27% are immigrants.[96] Additionally, women constitute 87% of the caregiver workforce.[97] These disparities are striking.

What further compounds these inequities is the significant wage disparity care workers face.[98] In 2021, the median annual income for care workers was only $20,200.[99] In 2019, one in six care workers lived below the federal poverty line, while 45% resided in low-income households earning less than 200% of the federal poverty line.[100] The insufficiency of their wages places immense financial strain on care workers, forcing them to rely on government funded benefit programs like Medicaid to meet basic needs.[101]

III. REIMAGINING CARE

Given these realities, care demands a radical reimagining. Fortunately, the Appendix in *All Our Families*, titled "Recipes for a Revolution," is an invaluable compass, guiding our path forward with insights and strategies for transformative change (pp. 177–81). Building upon Fink's ideas, this Part puts forth a normative vision that challenges the existing care paradigms. By exploring transformative pathways, this Part seeks to

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[95] *Id.* at 15.

[96] *PHI Launches Institute to Address Inequities in the Direct Care Workforce*, PHI NAT'L (Feb. 8, 2022), https://www.phinational.org/news/phi-launches-institute-to-address-inequities-in-the-direct-care-workforce [perma.cc/247Q-PDWR].

[97] *Id.*

[98] Nicole Jorwic, *Let's Recognize That Care Work Is the Labor That Makes All Other Labor Possible*, TRUTHOUT (May 19, 2023), https://truthout.org/articles/lets-recognize-that-care-work-is-the-labor-that-makes-all-other-labor-possible [perma.cc/D974-HP24].

[99] PHI NAT'L, DIRECT CARE WORKERS IN THE UNITED STATES: KEY FACTS 1 (2021), https://www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-2 [perma.cc/2LCS-JYJ7].

[100] *Id.* at 10.

[101] NAT'L EMP. L. PROJECT, GIVING CAREGIVERS A RAISE: THE IMPACT OF A $15 WAGE FLOOR IN THE HOME CARE INDUSTRY 2 (2015), https://www.nelp.org/wp-content/uploads/2015/03/Giving-Caregivers-A-Raise.pdf [perma.cc/7GN9-MNYN] (noting that nearly half of workers receive government-funded assistance).

pave the way for a more compassionate and just future for care, addressing the needs of disabled people and caregivers while advancing inclusivity and dignity.

A. *Broadening Availability and Access*

As Fink argues, transforming care requires "large, scalable, systemic changes" in government policies (p. 137). Indeed, as this Review discusses, current care structures adversely affect all people in care relationships. Reimagining care necessitates broadening availability and access to paid care, particularly through HCBS and other publicly funded programs.

In April 2023, President Joe Biden issued an executive order instructing federal agencies to reduce the cost of child care and enhance the quality of care provided to older adults and people with disabilities.[102] The executive order responded to the Administration's inability to pass a $400 billion caregiving infrastructure package through Congress.[103] The Administration urged for increased transparency in the allocation of Medicaid funds by home care agencies, aiming to raise care worker pay without requiring an increase in Medicaid reimbursement rates.[104] The Administration has also pledged to increase HCBS funding through budget efforts.[105] Although these steps are crucial, greater attention is needed at both the federal and state levels.

National and state policymakers should allocate significantly more funding for HCBS. Notwithstanding *Olmstead*—which held that the unnecessary institutionalization of disabled people violates the ADA[106]—far too many disabled people, especially disabled people of color, are forced into institutions.[107] In addition to being legally mandated, HCBS tends to be more cost-effective for states than institutional settings.[108] Moreover, access to HCBS reduces disabled people's unmet healthcare needs, increases the possibility of continued employment for family members, and reduces racial disparities in care access.[109] Without sufficient funding,

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[102] Exec. Order No. 14,095, 88 Fed. Reg. 24669 (Apr. 18, 2023).

[103] Chabeli Carrazana & Sara Luterman, *Biden's New Executive Order Could Expand Access to Child Care and Long-Term Care*, THE 19TH (Apr. 18, 2023, 6:00 AM), https://19thnews.org/2023/04/biden-executive-action-child-care-long-term [perma.cc/VL8X-QXGK].

[104] *Id.*

[105] *Id.*

[106] Olmstead v. L.C. *ex rel.* Zimring, 527 U.S. 581 (1999).

[107] *See supra* Section II.A.

[108] Antonisse, *supra* note 40, at 1819–20.

[109] Kiley J. McLean, Allison M. Hoekstra & Lauren Bishop, *United States Medicaid Home and Community-Based Services for People with Intellectual and Developmental Disabilities: A Scoping Review*, 34 J. APPLIED RSCH. INTELL. DISABILITIES 684, 692 (2021).

however, HCBS will remain inaccessible for many people with disabilities.

Even in states without waitlists, HCBS are inaccessible due to strict eligibility rules, caps on hours of care, underfunding, and work disincentives.[110] Simply eliminating waitlists does not mean services are available for all who need them—significant policy changes are needed to provide adequate, comprehensive HCBS without bureaucratic red tape and rationing of care.

The current Medicare system does not cover HCBS.[111] Thus, even as we continue to see the urgent need for universal healthcare (often called "single-payer health plans") in the United States, it is important to recognize that expanding Medicare, as it currently exists, would not increase HCBS coverage. Policymakers should address this gap by updating Medicare to fund HCBS and explicitly including HCBS coverage in any universal healthcare proposals to ensure comprehensive and accessible healthcare that encompasses HCBS. Nevertheless, due to prevailing partisan divides and Congress's failure to enact universal healthcare, alternative avenues should be explored—like repealing Medicaid rules imposing stringent asset and income limitations or implementing a Medicaid buy-in program.

B. *Challenging Legal and Bureaucratic Impediments*

The complex legal and bureaucratic barriers that hinder access must be dismantled to expand access to care. The growth of HCBS has led to a more rigid and bureaucratic framework, placing significant burdens on people with disabilities, their families, and caregivers.[112] The complex eligibility criteria, cumbersome administrative procedures, pervasive surveillance, and limited flexibility in tailoring services have made accessing necessary care challenging.[113] While Medicaid care programs for disabled people in the United States have had the intent of empowering people through self-directed services since at least the 1990s, questions persist regarding the most effective methods to promote personal choice and autonomy within the constraints of the public funding framework.[114]

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[110] *See supra* Section II.A.

[111] Robyn Powell, *'Medicare for All' Must Truly Be for All—Including People with Disabilities*, REWIRE NEWS GRP. (Mar. 13, 2019, 1:15 PM), https://rewirenewsgroup.com/2019/03/13/medicare-for-all-must-truly-be-for-all-including-people-with-disabilities [perma.cc/G3JF-TB8J].

[112] *See supra* Section II.B.

[113] *Id.*

[114] NAT'L COUNCIL ON DISABILITY, THE CASE FOR MEDICAID SELF-DIRECTION: A WHITE PAPER ON RESEARCH, PRACTICE, AND POLICY OPPORTUNITIES 7, 9, 17–20 (2013), https://www.ncd.gov/assets/uploads/reports/2013/ncd_medicaid-self-direction.pdf [perma.cc/H92L-W3EB].

To ensure that disabled people, their families, and caregivers can live with dignity, we must reduce excessive recordkeeping and oversight. For example, self-directed programs could provide personalized budgets to disabled people based on assessments of their unique requirements and empower them to use the funds flexibly to meet their needs, as permitted under Medicaid law in Sections 1915(c), 1915(i), 1915(j), and 1915(k).[115] It is also crucial that we reevaluate how needs are assessed by focusing on the perspectives of disabled people and allowing for greater transparency and flexibility. Programs should embrace a more individualized approach and prioritize the identified needs of people with disabilities and their families. Ultimately, equity and flexibility will lead to streamlined programs and likely reduce costs.

Addressing privacy concerns is another vital aspect.[116] The implementation of EVV, mandated by the 21st Century Cures Act in 2016, has compromised privacy in the name of fraud prevention.[117] EVV and similar policies should be repealed. By working together, policymakers, disabled people, and caregivers can ensure accountability and privacy protections coexist through open communication and further a shared commitment to strengthen the supports many disabled people rely on.

C. *Confronting Caregiver Inequities*

Recognizing and confronting the pervasive inequities that paid and unpaid caregivers face is vital to transforming the care landscape. Disability rights and justice activists must understand that "caring relationships are multi-directional"[118] and require fairness, recognition, and support. Activists can empower caregivers by advocating for fair wages, working conditions, and support systems and creating a more equitable and just care system. Prioritizing the needs and well-being of caregivers is essential to reimagining care and fostering a society that values and supports all those involved in caring relationships.

Research and policy regarding disability and family life have historically focused on families with disabled members, documenting their caregiving challenges and emphasizing the coping abilities of nondisabled family members.[119] This approach has overlooked the diverse experiences and perspectives of disabled people within these family dynamics

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[115] *Id.* at 29–34; *see Self-Directed Services*, CTRS. FOR MEDICARE & MEDICAID SERVS., https://www.medicaid.gov/medicaid/long-term-services-supports/self-directed-services/index.html [perma.cc/Q3PT-RNLH] (describing self-direction options available under Medicaid law).

[116] *See supra* Section II.B.

[117] *Id.*

[118] Jonathan Herring, *Disability and Care*, 12 J. INDIAN L. & SOC'Y no. 1, 2021, at 43.

[119] McLaughlin, *supra* note 34, at 402; *see* Laurin E. Bixby, *Disability Is Not a Burden: The Relationship Between Early Childhood Disability and Maternal Health Depends on Family Socioeconomic Status*, 64 J. HEALTH & SOC. BEHAV. 354, 365 (2023).

and perpetuates ableist assumptions and stereotypes.[120] Instead, "[s]cholars and policymakers should focus their attention on how policies have failed to support the basic needs of disabled [people] and their families, particularly families with fewer socioeconomic resources."[121]

Policies should prioritize the development of care systems based on interdependence. This entails implementing measures supporting family members in managing work and family responsibilities. To that end, paid leave for family caregivers is urgently needed. The Family and Medical Leave Act (FMLA)[122] is the sole federal policy that guarantees eligible workers access to *unpaid* leave to care for family members, allowing up to twelve weeks of leave within twelve months.[123] However, eligibility for FMLA leave is contingent upon factors such as the number of hours worked in the past year and the employer's size, which creates varying levels of access to leave for caregiving responsibilities.[124] Indeed, an estimated 40% of employees do not have access to FMLA.[125] And even with the Act, many family caregivers struggle to meet their leave needs.[126] Two key factors drive this persisting challenge: some caregivers do not qualify for FMLA leave due to specific eligibility criteria—others cannot afford unpaid leave due to financial constraints, even if eligible.[127] In recent years, Congress has considered legislation that would establish a framework for paid leave, such as the Family and Medical Insurance Leave (FAMILY) Act, a version passed by the House of Representatives as part of the Build Back Better Act.[128] Congress should finally enact paid leave for caregivers.

Likewise, states should adopt their own paid leave policies. Eleven states and the District of Columbia have implemented paid family and medical leave laws.[129] Two states have enacted laws allowing private-

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[120] *See* McLaughlin, *supra* note 34, at 402.

[121] Bixby, *supra* note 119, at 365.

[122] Family and Medical Leave Act of 1993, Pub. L. No. 103-3, 107 Stat. 6 (codified as amended in scattered sections of 5 & 29 U.S.C.).

[123] *Id.* § 2612(1). Family member includes the spouse, son, daughter, or parent of the employee. *Id.* §§ 2611(7), (12), (13).

[124] JOELLE SAAD-LESSLER & KATE BAHN, CTR. FOR AM. PROGRESS, THE IMPORTANCE OF PAID LEAVE FOR CAREGIVERS 3 (2017), https://www.americanprogress.org/wp-content/uploads/sites/2/2017/09/BahnPaidLeaveLaborForce-report.pdf [perma.cc/TH2R-KNYP].

[125] *Id.*

[126] *Id.* at 4, 6.

[127] *Id.* at 5–6.

[128] Molly Weston Williamson, *The State of Paid Family and Medical Leave in the U.S. in 2023*, CTR. FOR AM. PROGRESS (2023), https://www.americanprogress.org/article/the-state-of-paid-family-and-medical-leave-in-the-u-s-in-2023 [perma.cc/2KP8-XH6Q].

[129] *Id.*

sector employers and employees to opt in for coverage while guaranteeing coverage for state employees.[130] Other states should quickly follow suit.

Importantly, paid leave should adopt the broadest possible definition of family to promote equity and ensure that marginalized groups, including women, can fully benefit from such a program. Disabled people often rely on friends, partners, and non-biological relationships for essential care and support (p. 145). To that end, laws should incorporate inclusive definitions to include people's "chosen family."[131] Several states have already done so in their paid family and medical leave programs.[132] Additionally, other states and localities have integrated chosen families into their paid sick leave laws, recognizing the importance of these relationships in providing care and support to employees.[133] Legal recognition of these chosen family relationships can guarantee disabled people access to necessary resources and assistance and ensure their chosen family members can provide vital care without encountering discrimination or legal obstacles.[134] This inclusive approach empowers disabled people and fosters a supportive environment that respects and values the diverse networks of care and support they have established.

Implementing caregiver-friendly workplace policies ensures family caregivers can effectively fulfill their caregiving responsibilities and safeguard their financial security and career advancement. These policies should include flexible working arrangements and hours, enhanced family leave benefits, and comprehensive employee assistance programs that offer counseling, support groups, and skills workshops.[135]

Congress should also enact legislation recognizing and compensating caregivers through Social Security or tax credits. One option is a Social

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[130] *Id.*

[131] KATHERINE GALLAGHER ROBBINS, LAURA E. DURSO, FRANK J. BEWKES & ELIZA SCHULTZ, CTR. FOR AM. PROGRESS, PEOPLE NEED PAID LEAVE POLICIES THAT COVER CHOSEN FAMILY 1 (2017), https://www.americanprogress.org/article/people-need-paid-leave-policies-that-cover-chosen-family [perma.cc/8JQ7-7GL8]. "Chosen family" is a concept commonly connected with LGBTQ+ communities and is formed of "nonbiological kinship bonds, whether legally recognized or not, deliberately chosen for the purpose of mutual support and love." Trevor G. Gates, *Chosen Families*, *in* THE SAGE ENCYCLOPEDIA OF MARRIAGE, FAMILY, AND COUPLES COUNSELING 239, 239 (Jon Carlson & Shannon B. Dermer eds., 2017).

[132] Caroline Medina & Molly Weston Williamson, *Paid Leave Policies Must Include Chosen Family*, CTR. FOR AM. PROGRESS (Mar. 1, 2023), https://www.americanprogress.org/article/paid-leave-policies-must-include-chosen-family [perma.cc/R4SQ-VZJC].

[133] *Id.*

[134] *See* ROBBINS ET AL., *supra* note 131.

[135] ADMIN. FOR CMTY. LIVING, U.S. DEP'T OF HEALTH & HUM. SERVS., 2022 NATIONAL STRATEGY TO SUPPORT FAMILY CAREGIVERS 54, 73 (2022), https://acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyToSupportFamilyCaregivers.pdf [perma.cc/4CZZ-RMTS].

Security credit in a caregiver's overall career earnings.[136] This credit could be used to calculate future Social Security benefits for caregivers who spend at least 80 hours per month caregiving.[137] Congress has also considered a $3,000 tax credit specifically for family caregivers.[138] Enacting these proposals would be an important step toward compensating unpaid but crucial care work.

In addition, amending regulations to enable family caregivers to receive direct compensation from publicly funded care programs like HCBS would be a vital step towards recognizing their invaluable contributions and promoting a more equitable caregiving system.[139] By directly compensating family caregivers, we would acknowledge their dedicated efforts, support their well-being, and alleviate the financial burdens that often accompany caregiving responsibilities. Compensation could help address gender- and race-based disparities in caregiving and ensure a fair distribution of responsibilities within families. Additionally, providing financial support to family caregivers would enable them to access necessary resources and services more effectively, enhancing the quality of care delivered.

Policymakers must also dramatically increase wages to ensure equity and fairness. Experts estimate that a living wage for paid caregivers would reduce turnover, improve financial well-being, and lower reliance on public assistance programs, resulting in potential annual savings of $912 million to $1.6 billion.[140] Disabled people must join caregivers and labor organizations in the fight for fair wages. As legal scholar Jenny Breen observes, "Coalitional organizing is especially viable in this policy arena, as many different constituencies are harmed by the poor working conditions of care workers."[141] All stakeholders, including disabled people and caregivers, must lead these efforts together.

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[136] Bryce Covert, *One Small Fix to Help People Who Leave Their Jobs to Care for Loved Ones*, THINK PROGRESS (Mar. 18, 2016, 1:11 PM), https://thinkprogress.org/one-small-fix-to-help-people-who-leave-their-jobs-to-care-for-loved-ones-bf5c1ef066c2 [perma.cc/UCZ9-S52E]; Andy Jones, *Social Security Caregiver Credit Act Reintroduced*, ROOTED IN RTS. (Apr. 7, 2016), https://web.archive.org/web/20180329225607/http://www.rootedinrights.org/social-security-caregiver-credit-act-reintroduced [perma.cc/Z7CW-V5TT].

[137] *See* Covert, *supra* note 136.

[138] *See* Dena Bunis, *Bill Would Give Some Family Caregivers Financial Relief*, AARP (May 14, 2019), https://www.aarp.org/caregiving/financial-legal/info-2019/tax-credit-for-caring-act.html [perma.cc/Z78L-2FGT].

[139] *See* Carol Levine, *Putting the Spotlight on Invisible Family Caregivers*, 176 JAMA INTERNAL MED. 380, 380 (2016).

[140] CHRISTIAN WELLER, BETH ALMEIDA, MARC COHEN & ROBYN STONE, MAKING CARE WORK PAY: HOW PAYING AT LEAST A LIVING WAGE TO DIRECT CARE WORKERS COULD BENEFIT CARE RECIPIENTS, WORKERS, AND COMMUNITIES, LEADING AGE LTSS CTR. (2020), https://www.ltsscenter.org/wp-content/uploads/2020/09/Making-Care-Work-Pay-Report-FINAL.pdf [perma.cc/MVW6-7KSN].

[141] Jenny Breen, *Caring Work, Women's Work, Essential Work: Reconsidering Comparable Worth as an Approach to Pay Equity for Care Workers*, 43 BERKELEY J. EMP. & LAB. L.

Advocacy to increase caregiver wages presents an opportunity to unite disability rights and justice, caregiver, and labor groups at the federal and state levels. Federally, the minimum wage remains just $7.25 per hour, unchanged since 2009.[142] Activists must also keep pushing for federal legislation that substantially invest in caregivers, like the Better Care Better Jobs Act[143] and the Home- and Community-Based Services Access Act.[144]

While advocates should persist in backing robust federal investments, political hurdles[145] mean state and local efforts are also essential to lift caregiver compensation. Indeed, efforts at the state level have led to a majority of states establishing minimum wages higher than the federal floor.[146] Dual federal and state strategies can help make progress through targeted advocacy, as each approach builds momentum to properly value care work.

D. *Supporting Mutual Aid*

Finally, support for mutual aid work is vital, as mutual aid builds supportive networks and communities that offer assistance, resources, and solidarity to empower disabled people and create a more inclusive and equitable care paradigm. Mutual aid involves communities coordinating collectively to meet each other's needs.[147] This "radical" care builds supportive relationships while envisioning new political possibilities.[148] Though often dismissed as idealistic, mutual aid pragmatically enacts change through solidarity. By aiding each other directly, community members gain the expertise and power necessary to catalyze larger systems transformations. Inherent in the name, the mutuality of mutual aid means those needing and providing care unite rather than remain divided as givers and takers (pp. 130–31).

311, 356 (2022). In California, disability activists and other stakeholders joined the labor movement to increase care worker wages. *Id.*

[142] *The Impact of Raising the Minimum Wage to $15 by 2025, by Congressional District*, ECON. POL'Y INST. (Jan. 28, 2021), https://www.epi.org/publication/minimum-wage-to-15-by-2025-by-congressional-district [perma.cc/UZ58-ACM3].

[143] Better Care Better Jobs Act, S.100, 118th Cong. (2023).

[144] HCBS Access Act, S.762, 118th Cong. (2023).

[145] *E.g.*, Leigh Ann Caldwell, *Democrats Want Billions to Pay for Elder Care. Republicans Say the Price Tag is too High.*, NBC NEWS (Aug. 21, 2021, 4:30 AM), https://www.nbcnews.com/politics/congress/democrats-want-billions-pay-elder-care-republicans-say-price-tag-n1277210 [perma.cc/VJR4-NV2P].

[146] *Minimum Wage Tracker*, ECON. POL'Y INST., https://www.epi.org/minimum-wage-tracker/ - /min_wage [perma.cc/XHG3-NFTG].

[147] DEAN SPADE, MUTUAL AID: BUILDING SOLIDARITY DURING THIS CRISIS (AND THE NEXT) 7 (2020).

[148] Dean Spade, *Solidarity not Charity: Mutual Aid for Mobilization and Survival*, 38 SOC. TEXT, Mar. 1, 2020, at 131.

Mutual aid is vital to disability justice because it enables disabled people to lead the reimagining of care. As Fink writes, the disability community holds invaluable expertise about care that stems from often unrecognized lived experience (p. 117). Still, despite this lack of recognition, "[d]isability justice activists, care workers, families, cultural workers, and self-advocates are reimagining paradigms of care with unprecedented energy and imagination" (p. 129). Through mutual aid and collective care, disabled people can "take charge of their own care and care work in a more humane, equitable, communal fashion" (p. 129). These cooperative networks thus help disability communities build expertise and capacity from within, by reimagining care as reciprocal and interdependent. They enable democratic participation and empowerment rather than hierarchical power.

Drawing from disability justice, writer and activist Leah Lakshmi Piepzna-Samarasinha envisions interconnected communal support systems prioritizing the well-being of people who live at the intersection of disability and other marginalized identities or statuses.[149] These "care webs" operate without rigid hierarchies and foster inclusivity.[150] Throughout the height of the COVID-19 pandemic, disability justice communities and organizations leveraged their expertise and assumed leadership roles in establishing mutual aid networks—the mutual aid work of the Disability Justice Culture Club in Oakland, California is one of many examples.[151]

Piepzna-Samarasinha's care webs emphasize the transformative power of collective care and envision a world where care is seen as a shared responsibility and source of community strength, not an individual burden.[152] These networks can include informal arrangements among friends, families, neighbors, and organized community initiatives and support structures.[153] Importantly, mutual aid confronts formalized care structures' limitations, such as caregiver shortages, rigid eligibility rules, and the ongoing precarity of funding.[154] It also allows disabled people to decide who helps them.[155]

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[149] LEAH LAKSHMI PIEPZNA-SAMARASINHA, CARE WORK: DREAMING DISABILITY JUSTICE 41 (2018).

[150] *Id.*

[151] Brooke Anderson, *How Disabled Activists Are Fighting Isolation, Collectively*, IN THESE TIMES (Apr. 1, 2020), https://inthesetimes.com/article/disabled-queer-activists-isolation-mutual-aid-bay-area-covid-19 [perma.cc/HV4L-HGMW].

[152] PIEPZNA-SAMARASINHA, *supra* note 149, at 21–42.

[153] *Id.* at 41–47.

[154] *Id.* at 40–47.

[155] *Id.* at 41.

At the same time, Piepzna-Samarasinha acknowledges the challenges and limitations of establishing sustainable care that operates independently of state support.[156] Participation in a mutual aid network to receive care requires connection to a community involved in such endeavors.[157] Moreover, disabled people should not have to rely on being liked or loved by others to access necessary care.[158]

This observation highlights the potential for mutual aid initiatives and state supports to complement each other. While mutual aid networks can provide vital care and support within communities, there may be instances where additional assistance from the state becomes necessary. The two can work together synergistically, with mutual aid efforts filling gaps left by the state and state services reinforcing and expanding the reach of community-based care. Recognizing the potential for collaboration between these two spheres can lead to more comprehensive and sustainable care systems.

CONCLUSION

In *All Our Families*, Fink issues an urgent call to action by exposing how ableism drives the devaluation of care, arguing "[c]are work is the hidden twin of disability" (p. xv). She compels readers to confront the oppressive biases ingrained in care structures that simultaneously embrace disability as core to understanding family dynamics. Fink contends we can only catalyze radical legal and societal transformation to actively combat ableism and truly center care relationships by unmasking the ableism woven into care discourse. The time for incremental change has passed; this demands immediate, bold action to swiftly reimagine anti-ableist systems that honor our shared humanity. Transforming care systems would dismantle the oppressive biases that have inflicted deep harm, so families will celebrate the diversity of their members rather than agonize over "keeping" a disabled child. Robust support for care can alleviate the fear of disability and honor the beauty of interdependence by recognizing disability as integral to each family and our shared humanity. This inclusive approach calls us to uplift the richness of life rather than marginalize differences. Caring for family members with dignity will unlock joy and possibilities for all.

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[156] *Id.* at 63–64.

[157] *Id.*

[158] *Id.*