Ability to Care

Understanding the role of care ethics in disability policy design in Canada

Maryam Mughal

Supervised by Dr. Michael Orsini

Submitted on April 19th, 2024

Major Research Paper

Graduate School of Public & International Affairs

University of Ottawa

Winter 2024

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Acknowledgements

I would like to thank Dr. Michael Orsini for providing me with invaluable expertise and supervision at every stage of this research project. I would also like to thank my friends from GSPIA – Corinne, Marie-Christine, and Maxine – from whom I have sought guidance not only for this Major Research Paper, but for everything under the sun over the past two years. Lastly, I would like to extend the highest gratitude to my parents, Musharaf and Sonia Mughal, without whose endless support none of this would have been possible.

Abstract

For decades, persons with disabilities have advocated for a leadership role in shaping the policies that affect them. While Canada, along with the international community, has moved toward a greater recognition of the rights of persons with disabilities, there remains a major gap between what is needed and what public policies currently provide. To ameliorate this, disability policy design in Canada should move toward a participatory model, in which critical decisions should come from within the disability community. However, in advancing this new model, decision-makers must ensure empathy in their approach, in order to subvert some of the risks that can be associated with participatory approaches to policy design. To do this, I argue for the use of feminist care ethics, which offers a conceptual framework by which participatory approaches to disability policy design can be constructed equitably, in order to meet the needs of both the disability community as well as their family/friend caregivers. I find that care ethics works to bolster and enhance existing scholarship in disability studies, and thus can act as a positive (and crucial) conduit to achieve justice for persons with disabilities in Canada.

Keywords: Policy design, participatory policy design, critical disability studies, disability policy, feminist policy, care ethics

Introduction

Nothing about us without us. This phrase echoes from and throughout disability advocacy groups, signalling a goal that has been expressed by a community existing within the political margins for decades: equal participation in decision-making and opportunities for persons with disabilities. The tenet of participation, and recognizing it as an integral piece of governance, is not new – democracy finds its roots in the Ancient Greek tradition, where participatory democracy described the very form of governance wherein citizens gained agency in decision making processes.[1] That being said, historic and ancient forms of participatory democracy have broadly failed to accurately represent non-dominant communities within the sociopolitical sphere. The point stands, however, that the democratic principles upon which Western societies and forms of governance are based are ultimately rooted in the spirit of participation. It is this absence of participation that breeds the disability community's calls for equality and a voice within the political sphere, particularly in relation to public policymaking.

In recognition of this gap, the international community has moved toward greater recognition of the rights of persons with disabilities. The 2006 introduction of the United Nations' *Convention on the Rights of Persons with Disabilities* (CRPD) signals this, with its acknowledgement of the need for reforms of disability policymaking that support participation and equality.[2] To offer a perspective toward addressing the gap, this research paper seeks to understand the role of an alternative method to create more just and equitable outcomes for persons with disabilities. Specifically, I consider participatory approaches to public policy

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[1] Shmuel Lederman, *Hannah Arendt and Participatory Democracy: A People's Utopia* (Cham: Springer International Publishing, 2019), https://doi.org/10.1007/978-3-030-11692-7.
[2] Isabel Baltzan, "Adopting Universal Design in Disability Policy: An Approach to Centering People with Disabilities", *International Human Rights Internship Program | Working Paper Series* 10, no. 1 (2021).

design. Looking to the history of disability policy in Canada allows us to understand the ways in which policy design have developed, and how they can evolve to meet the shifting social and temporal needs of citizens with disabilities. Additionally, adopting alternative lenses through which we view issues related to disability policy can help to broaden our scope of focus, and consider novel ways forward. In this vein, throughout this paper, I adopt the lens of feminist care ethics to discuss disability policy, to offer a perspective rooted in equality, justice, and care.

Specifically, this paper advocates for the implementation of disability policy that incorporates a feminist care ethic in its conception and delivery to better meet the needs of the disability community. This analysis focuses on persons with disabilities, and considers the integral perspective of their family/friend caregivers. Throughout this paper I will explain why it is necessary to consider both groups together and relationally, as well as each one in isolation. For consistency and clarity, I define “disability” in line with the federal *Accessible Canada Act*, which is as follows: ‘… any impairment, including a physical, mental, intellectual, cognitive, learning, communication or sensory impairment — or a functional limitation — whether permanent, temporary or episodic in nature, or evident or not, that, in interaction with a barrier, hinders a person’s full and equal participation in society”.[3] This definition is materially equal to the definition offered by the United Nations’ CRPD, which is: “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”.[4]

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[3] *Accessible Canada Act, Statutes of Canada* 2019, c. 10. https://laws-lois.justice.gc.ca/eng/acts/a-0.6/.

[4] “Article 1 – Purpose,” CRPD, United Nations, https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html#:~:text=Persons%20with%20disabilities%20include%20those,an%20equal%20basis%20with%20others.

In the following sections, I will offer a scoping literature review to situate both disability studies and care ethics in relation to each other, and as distinct domains that hold significance in public policymaking. After this, I will describe my method for this analysis. Next, I will more deeply engage with the history and models of disability policy, and the broad topic of care ethics. I will then bring these fields into a dialogue, describing the role care ethics can play in disability policymaking. Finally, I will discuss my analysis and point to potential limitations, and then offer concluding remarks.

Literature Review

Design thinking stems from the private sector, and is rooted in treating users' experiences as central to service design and delivery.[5] The use of design methods in the public sphere has been popularized over the last decade, seeking to address the lack of democratic participation, as well as the efficacy and longevity of public policy, in governing bodies.[6] There has been extensive discussion concerning different types of co-design and participatory approaches to design in the public sphere,[7] but this study is concerned broadly with the inclusion of citizens in the development and implementation of public policy – specifically, with the inclusion of persons with disabilities in disability policy.

The use of participatory approaches to design has been criticized for its potential to support a neoliberal political agenda and maintain oppressive power structures, acting in a

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[5] Emma Blomkamp, "The Promise of Co-Design for Public Policy," *Australian Journal of Public Administration* 77, no. 4 (2018): 729–43, https://doi.org/10.1111/1467-8500.12310; Elizabeth B.-N. Sanders and Pieter Jan Stappers, "Co-Creation and the New Landscapes of Design," *CoDesign* 4, no. 1 (March 1, 2008): 5–18, https://doi.org/10.1080/15710880701875068.

[6] Blomkamp, "The Promise of Co-Design for Public Policy"; Michelle Farr, "Citizens and the Co-Creation of Public Service Innovations," *Handbook of Innovation in Public Services*, March 29, 2013, https://www-elgaronline-com.proxy.bib.uottawa.ca/view/edcoll/9781849809740/9781849809740.00042.xml; Michael Mintrom and Joannah Luetjens, "Design Thinking in Policymaking Processes: Opportunities and Challenges," *Australian Journal of Public Administration* 75, no. 3 (2016): 391–402, https://doi.org/10.1111/1467-8500.12211.

[7] Blomkamp, "The Promise of Co-Design for Public Policy."

manner antithetical to its intended purpose.[8] However, and with respect to the case of disability policy design, scholars with a critical approach recognize that the measurement of success of disability programs and policies must have a greater focus on its theoretical underpinnings – especially as it relates to structures of governance and hierarchy – as opposed to mere cost-benefit analyses centred more around economic efficiency than empathetic social aims.[9] Additionally, and relatedly, the question of *who* is included in participatory policy design is crucial in assessing the epistemological hierarchy of those being considered in policy design.[10] In other words, to avoid its neoliberal potential as well as other risks, it is important to ensure that participation is cognizant of the various and intersecting factors that would affect different persons' experience with policy, and thus assess its success in ensuring various needs and aims are met, particularly for those who experience intersecting challenges and disadvantages in the public sphere.

Related to this is a more general criticism of participatory approaches to design: "the issue of the gap between the rhetoric or ideology and the practice".[11] This refers to the asymmetry between research and implementation, the former of which may recognize the need for improvement in co-design, and the latter of which being the reality that care bodies still do not prioritize individuals and their family/friend caregivers.[12] Janet Jull et al. refer to this as the

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[8] Blomkamp; Farr, "Citizens and the Co-Creation of Public Service Innovations"; Michael Kaethler, Seppe De Blust, and Tim Devos, "Ambiguity as Agency: Critical Opportunists in the Neoliberal City," *CoDesign* 13, no. 3 (July 3, 2017): 175–86, https://doi.org/10.1080/15710882.2017.1355002; Mintrom and Luetjens, "Design Thinking in Policymaking Processes"; Karl Palmås and Otto von Busch, "Quasi-Quisling: Co-Design and the Assembly of *Collaborateurs*," *CoDesign* 11, no. 3–4 (October 2, 2015): 236–49, https://doi.org/10.1080/15710882.2015.1081247.

[9] Michael J. Prince, "Canadian Disability Policy: Still a Hit-and-Miss Affair," *The Canadian Journal of Sociology / Cahiers Canadiens de Sociologie* 29, no. 1 (2004): 59–82, https://doi.org/10.2307/3341945.

[10] Blomkamp, "The Promise of Co-Design for Public Policy."

[11] Bate, Paul, and Glenn Robert. *Experience-Based Design: From Redesigning the System Around the Patient to Co-Designing Services with the Patient* (BMJ Quality & Safety, 2006).

[12] Ibid.

"know-do" gap, or the imbalance between what is known in research, and the care that is provided by health systems, and, in the case of this report, social policy systems as well.[13] Jull et al. suggest there is an "ethical imperative" to bridge the gap between what we know and the care that we provide.[14] I concur with this analysis, and posit that this gap in disability policy design (broadly, and as it relates to participatory approaches) is fuelled and reproduced by a deficit of care. By employing the theoretical perspective of care ethics, participatory approaches to disability policy design can work toward bridging this gap by prioritizing relationality, and centring the needs of actual people and their family/friend caregivers above all else.

In seeking to address the "democratic deficiency"[15] of participatory approaches in public policy, this study will analyze existing scholarship and theory using a feminist lens, which offers a theoretical framework to assess structures and oppressive power dynamics.[16] Specifically, this paper draws on care ethics, which considers power structures in the social-political sphere.[17] Academic work relating participatory design to care ethics has been produced primarily in a theoretical or philosophical domain,[18] with limited or less robust connections made directly to public policymaking, demonstrating a need for enhanced practical discussion within this realm.

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[13] Jull, Janet, Audrey Giles, and Ian D. Graham. *Community- Based Participatory Research and Integrated Knowledge Translation: Advancing the Co-Creation of Knowledge* (Implementation Science, 2017).

[14] Ibid.

[15] Palmås and von Busch, "Quasi-Quisling," 246.

[16] Andrea Doucet and Natasha S. Mauthner, "Feminist Methodologies and Epistemology," in *21st Century Sociology*, by Clifton Bryant and Dennis Peck (2455 Teller Road, Thousand Oaks California 91320 United States: SAGE Publications, Inc., 2007), II-36-II–42, https://doi.org/10.4135/9781412939645.n62.

[17] Daniel Engster, "Care Ethics and Political Theory: Daniel Engster and Maurice Hamington (Eds.) Oxford University Press, 2015, X+336pp., ISBN: 978-0198716341," *Contemporary Political Theory* 16, no. 3 (August 2017): 430–33, https://doi.org/10.1057/s41296-016-0068-9; Eva Feder Kittay, "Welfare, Dependency, And a Public Ethic of Care," *Social Justice* 25, no. 1 (71) (1998): 123–45.

[18] Sonia Bussu et al., "Engaging with Care: Ethical Issues in Participatory Research," *Qualitative Research* 21, no. 5 (October 1, 2021): 667–85, https://doi.org/10.1177/1468794120904883; B. C. Groot et al., "Ethics of Care in Participatory Health Research: Mutual Responsibility in Collaboration with Co-Researchers," *Educational Action Research* 27, no. 2 (March 15, 2019): 286–302, https://doi.org/10.1080/09650792.2018.1450771.

By using the theoretical tools offered by care ethics, primarily by focusing on its key tenets of relationality and empathy, this study will present a means by which policy developers might address the democratic deficiency of participatory approaches to disability policy design. The study will consider the involvement of persons with disabilities in participatory approaches to policy design as this is a vulnerable group who a) have long been marginalized in and through public policy, and b) have an expressed desire to actively participate in decisions affecting them.[19]

Method

In this paper, I examine disability policy in Canada through the lens of care ethics to understand how the theoretical or philosophical foundations of disability public policy impacts the aims and outcomes of its services and service provision. Ultimately, I am exploring the question: How can the integration of a feminist conceptual framework make participatory approaches to disability policy design more equitable? It is important to note that this is not a mono-disciplinary research paper; rather, to explore my research question, I engage with literature from a multitude of disciplines and sub-disciplines including, though not limited to: (critical) disability studies, health services, patient experience, public policy and public administration research, service design, implementation science, bioethics, feminist philosophy, and care ethics. However, within this space, care ethics is my primary lens. Overall, I have sought to focus my literature review on the last decade, so as to remain current and recognize

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[19] Debra Jackson and Calvin Moorley, "'Nothing about Us without Us': Embedding Participation in Peer Review Processes," *Journal of Advanced Nursing* n/a, no. n/a (2021), https://doi.org/10.1111/jan.15122; Sandra Moll et al., "Are You Really Doing 'Codesign'? Critical Reflections When Working with Vulnerable Populations," *BMJ Open* 10, no. 11 (November 2020): e038339, https://doi.org/10.1136/bmjopen-2020-038339.

that research into participatory design has grown in salience during this period. The body of work on “co-design” research (in the service perspective, and consequentially as it extends to participatory approaches to policy development) has been most prominent in Australia, as demonstrated by Emma Blomkamp’s extensive review[20], so this study will act as an addition to Canada’s comparatively limited body of work in the area. Since Canada and Australia (as well as many other Western states) are similar in their broad approaches to organizing their social spheres, such as social policy, academic and theoretical works from Australia can reasonably be used to understand the Canadian context in this way.

Within this analysis, I will situate care ethics as a feminist approach to philosophy; thus, the perspective that I employ and express throughout this paper is a critical, feminist one. The feminist motivations of my research can also be seen in the underlying goal that motivates my work, which is a sociopolitical restructuring of the current public and private spheres to become more caring, equitable, and inclusive. This research goal of disrupting or challenging unjust social frameworks in favour of positive, social change is a common feature of feminist approaches to research.[21] This study will also explore how a feminist ethic of care has been conceptualized in the political realm in an effort to understand how a feminist approach can inform the democratic deficiency of participatory design, drawing largely from the body of works of Eva Feder Kittay and Jane Addams (through Maurice Hamington). The integration of a feminist perspective with participatory design in public policymaking will be used to discuss how vulnerable populations – especially those with disabilities – can be integrated[22] into

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[20] Blomkamp, “The Promise of Co-Design for Public Policy.”

[21] Jull et al., *Community-Based Participatory Research,* 2.

[22] The use of “integrated”, here, was chosen in favour of the term “included”, in recognition of the idea that “inclusion” can often divert focus from the groups who have been historically disadvantaged, toward those doing the “including”, as a sort of performative or virtue-signalling approach to progressive policy. As such, beyond inclusion,

participatory design in policymaking in Canada in ways that move beyond approaches to inclusion that reproduce dominant systems of power.

Additionally, I recognize that my perspective as a researcher is not separable from my unique experiences and viewpoints, but rather these aspects of my identity serve to inform the work that I do.[23] As a woman of colour, I recognize and have experienced some of the challenges that accompany the navigation of Western society from a marginalized social location. A personal motivation to engage in this research stems from an early recognition of how caregivers – who tend to occupy marginalized social locations – exist in a space in which their needs may not be considered primary, in part due to their occupation, and in part due to their marginalized social location. Perhaps of greatest import to this research paper, I experience life with a disability that is not noticeable or visible upon interaction with me. My experience as someone with a disability informs my approach to this work, and my motivation for engaging in this research, having had to navigate certain systems and structures that were not designed with my particular (dis)abilities in mind. However, this experience does not allow me to fully understand how each person with a disability – of any degree or type – might interact with or feel about the world around them. My aim is to make space for centring the voices of those who have historically been silenced. My motivation for engaging in this research, then, is inextricable from my experiences and values.

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we should be more interested in ensuring an active, intentional, and central role for citizen participation (as per Sara Ahmed, *On being included: racism and diversity in institutional life* (2012)).

[23] Wigginton, Britta, and Michelle N. Lafrance. *Learning Critical Feminist Research: A Brief Introduction to Feminist Epistemologies and Methodologies* (Feminism & Psychology, 2019), 7.

Disability Policy

Medical and Social Models

When discussing issues related to disability or disability policy, it is important to understand the historical and spatiotemporal context within which the discussion is rooted. In the case of this paper, I am engaging with a discussion of disability policy in Canada, considering both past and present policies, but rooting my discussion in a forward-looking context. To understand the placement of this discussion, I wish to situate Canada as a Western state and society, in order to highlight any implicit or explicit facets of such a society in relation to this report. In particular, it is important to recognize that such societies, rooted in neoliberalism in their approach to health and social policies, represent a masculinized version of reality, thus systemically overlooking the experiences and perils of communities that have historically been marginalized – this includes women, people of colour, and, of course, persons with disabilities.[24] By adopting an atomistic understanding of what it means to *be*, Western societies essentialize the human experience to that of a person who does not face marginalization in any way – typically, this means equating a "person" to a white, cisgendered, able-bodied, straight man.[25] However, in the field of disability policy and otherwise, the experience of such individuals cannot be extrapolated and generalized. I wish to establish this idea as foundational to my report whilst I engage in the following discussion of key paradigms in disability studies.

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[24] Emma Tseris, "Biomedicine, Neoliberalism and the Pharmaceuticalisation of Society," in *Routledge International Handbook of Critical Mental Health* (Routledge, 2017).

[25] Lorraine B. Code, "Is the Sex of the Knower Epistemologically Significant?," *Metaphilosophy* 12, no. 3/4 (1981): 267–76.

One of the key models that has been the subject of intense critique and has given rise to the field of critical disability studies is the "medical model". The "medical" characterization refers to understanding disability as a medical ailment, requiring fixing or improvement through scientific means, whereas its categorization as a "model" refers to the various discourses and narratives – as well as the paradigm – through which disability is discussed, engaged with, and viewed in society.[26] To paraphrase Mander's (2022) description of disability models, a discourse, in a Foucauldian sense, reflects power relations from a macroscale onto a microscale. Thus, any model of disability can be understood as a microcosm of a society's power dynamics. The medical model, specifically, understands disability as a fault of an individual; it is not only a problem that requires fixing, but it is also the responsibility of that individual to be fixed.[27] Not only does this perspective problematize being disabled, it also produces negative stereotypes and stigma that can be internalized by persons with disabilities, and by broader society.[28] The socio-psychological harms of this are apparent – such as bullying and social ostracization – but other harms include discrimination in the labour market and, as is the case in Canada and other Western societies, inadequate public policies and services.[29]

The "social model", which stands in direct contrast to the individualism put forth by the medical model, understands ability as something that is socially constructed through social

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[26] Alice Mander, "The Stories That Cripple Us: The Consequences of the Medical Model of Disability in the Legal Sphere.," *Victoria University of Wellington Law Review* 53, no. 2 (August 1, 2022): 337–63.
[27] Ibid.
[28] Ibid.
[29] Angela Daley, Shelley Phipps, and Nyla R. Branscombe, "The Social Complexities of Disability: Discrimination, Belonging and Life Satisfaction among Canadian Youth," *SSM - Population Health* 5 (May 24, 2018): 55–63, https://doi.org/10.1016/j.ssmph.2018.05.003; Statistics Canada Government of Canada, "The Daily — Labour Market Characteristics of Persons with and without Disabilities in 2022: Results from the Labour Force Survey," August 30, 2023, https://www150.statcan.gc.ca/n1/daily-quotidien/230830/dq230830a-eng.htm; Derek Hum and Wayne Simpson, "Canadians with Disabilities and the Labour Market," *Canadian Public Policy / Analyse de Politiques* 22, no. 3 (1996): 285–99, https://doi.org/10.2307/3551506; Mander, "The Stories That Cripple Us"; Rameen Siddiqui, "The Social Ostracism of the Disabled: A Tale of Discrimination, Deprivation, and Disregard," Modern Diplomacy, May 14, 2023, https://moderndiplomacy.eu/2023/05/14/the-social-ostracism-of-the-disabled-a-tale-of-discrimination-deprivation-and-disregard/.

structures and environments.[30] Thus, the "social" aspect of the social model is its focus on society as the locus for putting forth barriers experienced by certain people and communities. The social model, then, is an approach to understanding disability that argues for greater accessibility and decreased discrimination for persons with disabilities in the public realm – removal of barriers is a matter of social justice.[31] Another key element of the social model is its democratic nature, which demands both leadership from persons with disabilities in the development of matters that directly impact them and their communities, as well as community organization in order to achieve these aims.[32] The slogan, "Nothing about us without us," mentioned as this paper's opening line, serves as a manifestation of this call for persons with disabilities to be able to play a leadership role in the decisions that affect them. This feature is key to this paper, as it is this focus on democracy and relationality that position care ethics as critical to pursuing equitable disability policies and programs.

The social model has, however, not been without critique. Particularly, and of greatest relevance to this paper, the social model has been criticized for its neglect of the intersectional roots of disability oppression.[33] Intersectionality is the notion and reality that an individual's experience in the world is impacted by the various components of their identity, as opposed to a singular characteristic or in conflation with others who share a certain characteristic.[34] This is an

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[30] Tania Burchardt, "Capabilities and Disability: The Capabilities Framework and the Social Model of Disability," *Disability & Society* 19, no. 7 (2004): 735–51, https://doi.org/10.1080/0968759042000284213.
[31] Oliver, M., and Barnes, C, "Social Policy and Disabled People: From Exclusion to Inclusion" *London: Longman* (1998).
[32] Burchardt, "Capabilities and Disability".
[33] Moya Bailey and Izetta Autumn Mobley, "WORK IN THE INTERSECTIONS: A Black Feminist Disability Framework A Black Feminist Disability Framework on JSTOR," February 2019, https://www-jstor-org.proxy.bib.uottawa.ca/stable/26597131?sid=primo; Patty Berne, "Disability Justice - a Working Draft by Patty Berne," Sins Invalid, June 10, 2015, https://www.sinsinvalid.org/blog/disability-justice-a-working-draft-by-patty-berne.
[34] Crenshaw, Kimberlé. *Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics* (u. Chi. Legal f., 1989).

important lens within which to view disability, since a person experiences disability in conjunction with and within (and not devoid of) their race, gender, social class, and other points of identity that are experienced differently in society. I will expand upon this idea and its import to this paper in following sections, as an extension of my discussion of care ethics.

In the context of disability issues, the idea of "Disability Justice" acts both as a response to the critique of the social model, and as a framework and movement toward a more inclusive and equitable reconstruction of how disability is acknowledged and legislated in social and political life.[35] Disability Justice is a reconstructive framework, in that it advocates for the dismantling of existing systems in an effort to build an environment that understands disability through an intersectional point of view.[36] Apart from a foundation rooted in intersectionality, other key tenets of Disability Justice include anti-capitalism and sustainability, as well as a recognition of collective identity and interdependence – the latter of these being critical tenets of care ethics, as well, which will be expanded upon throughout this paper.[37]

Policy Landscape in Canada

Disability policies are delivered both at the federal and provincial/territorial levels in Canada. This dual-pronged delivery illustrates the jurisdictional tension that exists across the Canadian public policy landscape. The question of federal and provincial/territorial jurisdiction for disability matters mirrors the delivery of healthcare in Canada. Though healthcare is not the only service whose provision is ensured federally yet managed provincially/territorially, the similarity in nature does reflect the long-held conflation of disability as a medical or health-

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[35] Berne, "Disability Justice - a Working Draft by Patty Berne."
[36] Ibid.
[37] Ibid.

related issue, as discussed in the previous section. As opposed to a single, comprehensive piece of legislation on disability, Canada has historically used a combination of policies, laws, and benefits to address the needs of persons with disabilities. This multifaceted approach is governed, largely, by the *Canadian Charter of Rights and Freedoms*, which explicitly prohibits discrimination on the grounds of mental or physical disability, making persons with disabilities a protected, equity-seeking group under the *Charter*.[38]

In response to the 1996 *Scott Report*, which signalled the need for a national, comprehensive disability policy, a multi-level and inter-governmental collaboration began. From this point onward, the federal government has implemented measures – largely financial in nature – intended to support persons with disabilities. The goals of such policies were related to economic autonomy as opposed to integration and a focus on social wellbeing, signposting Canada's historical priorities as it relates to persons with disabilities.[39] However, from 2010 onward, upon Canada's involvement in and ratification of the United Nations' CRPD, which encouraged the development of monitoring and adherence measurement methods, the federal government's approach to disability issues veered toward a more social direction.[40] Since the instalment of a Canadian Minister with a specific portfolio on disability issues – a position held by Kamal Khera, as of July 2023, and previously held by Carla Qualtrough – the federal government appears to be more interested in addressing the needs of persons with disabilities. The Minister's promise to Canadians is to strive for greater equity and inclusivity, through the *Disability and Inclusion Action Plan* – which the federal government claims to be rooted in the

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[38] Mary Mccoll et al., "A REVIEW OF DISABILITY POLICY IN CANADA," (December 1, 2017).
[39] Sherri Torjman, *Disability Policy Highlights*, Caledon Institute of Social Policy (2014).
[40] Mccoll et al., "A REVIEW."

tenets of intersectionality, human rights, and stakeholder involvement – and action items related to financial, labour, accessibility, and modernization concerns for persons with disabilities.[41] [42]

The *Accessible Canada Act*, a key feature of the *Action Plan*, has the intent of removing existing – and preventing new – barriers faced by persons with disabilities by the year 2040.[43] The development of a national, comprehensive strategy marks an advent in Canadian disability policy, as the federal government has never before unified its approach in this way.[44] Thus, in addition to its actual content, the *Act's* significance lies in its symbolism, as a landmark of federal, legislative protection for persons with disabilities. Of particular relevance to this paper is section 5e of the *Accessible Canada Act,* which cites "the design and delivery of programs and services" as a specific problem area requiring the removal and prevention of barriers.[45] Key elements of the *Act* include outlining the role and mandate of the Minister – which is to realize a "barrier-free" Canada by 2040 – as well as the establishment of the Canadian Accessibility Standards Development Organization, which is meant to conduct research and make recommendations as it relates to barriers for persons with disabilities.[46]

Outside of the more recent development that is the *Disability and Inclusion Action Plan* (whose material benefits have yet to be enjoyed due to its novelty), Canada does provide other, limited support to persons with disabilities. These include disability benefits through the Canada Pension Plan, a Registered Disability Savings Plan, and the Disability Tax Credit (DTC). Family/friend caregivers of persons with disabilities also have access to certain supports, such as

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[41] Employment and Social Development Canada, *Canada's Disability Inclusion Action Plan*, (2022).

[42] An extensive analysis of these pillars – financial, labour, accessibility, and modernization – would serve as a useful and beneficial case study through which someone might assess, using a critical theoretical perspective, how well newly proposed disability policy integrates and empowers persons with disabilities and their family/friend caregivers. A case study of this sort is, however, beyond the scope of this paper.

[43] *Accessible Canada Act* (2019).

[44] Mccoll et al., "A REVIEW."

[45] *Accessible Canada Act* (2019).

[46] Ibid.

limited Employment Insurance (EI) benefits, the Canada Caregiver Credit (CCC), as well as the DTC (which can be accessed both by persons with disabilities as well as their family/friend caregivers).

Notably, all of the aforementioned supports are economic benefits, and do not involve social or other mechanisms for support, illustrating the federal government's historic entrenchment in policies with an economic focus as it relates to disability. T.H. Marshall's concept of "social citizenship" does argue that citizens cannot exercise their social rights until they have satisfied their economic and material rights, which could be put forth to argue in favour of the continuation of economic policies.[47] I do not oppose this view; however, I do argue that the economic policies that are currently in place are not sufficient, and instead hinder the attainment of substantial material rights and, consequentially, social rights. To illustrate this point, persons with disabilities comprised 41% of the low-income population of Canada in 2017, and earned 79 cents to every dollar of a person without disabilities, resulting in a 21.4% pay gap in 2019.[48] The inadequacy of the economic benefits' ability to meet the needs of persons with disabilities and their family/friend caregivers – both financially and otherwise – highlights both the gap that the *Disability and Inclusion Action Plan* attempts to fill, as well as the reality that effective disability policies in Canada necessitate an environment of care.

A major critique of the efficacy, or lack thereof, of existing federal disability policies is that they essentially require an individual to be doing "worse" (according to normative social constructs) in order to do "better", in terms of how they benefit from economic policies and

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[47] Marc Hooghe and Jennifer Oser, "Social and Political Citizenship in European Public Opinion: An Empirical Analysis of T.H. Marshall's Concept of Social Rights," *Government and Opposition* 53, no. 4 (October 2018): 595–620, https://doi.org/10.1017/gov.2017.11.

[48] Statistics Canada Government of Canada, "Low Income among Persons with a Disability in Canada," August 11, 2017, https://www150.statcan.gc.ca/n1/pub/75-006-x/2017001/article/54854-eng.htm; Statistics Canada Government of Canada, "The Daily — What Is the Pay Gap between Persons with and without Disabilities?," June 27, 2023, https://www150.statcan.gc.ca/n1/daily-quotidien/230627/dq230627b-eng.htm.

programs.[49] This means that, for a person with a disability to be eligible for public programs, they must in some way prove that they meet the requirements or criteria to be deemed "disabled"; however, this risks the limitation of social acceptance or positive attitudes toward the person with a disability, hindering their ability to meaningfully participate in society, socially, economically, and otherwise.[50] In other words, a person with a disability's independence – or interdependence, a term that better encapsulates the relational aspect of disability and autonomy[51] – is in many ways dictated by their dependence on the state for the receipt of necessary social programs. Tangentially, and still related, the conditions and features of economic policies stem from an individualist framework and benefit persons on an individual level,[52] thus making it difficult to attain collective action toward more expansive policies.

This latter idea stems from the broad evolution of political structures, systems, and ideologies that define the development of public policy at specific points in time. In the case of disability policy, significant contexts include a point in time categorized largely by state paternalism. This period encompasses the 19th century and onward, with its direct impact on disability policy extending well into the mid-late 20th century. Examples of policies throughout this period include preventing persons with disabilities from entering or immigrating to Canada, involuntary and non-consensual sterilization in Alberta and British Columbia, and forced institutionalization.[53]

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[49] Torjman, *Disability Policy Highlights.*
[50] Ibid.
[51] Barbara Arneil, "Disability, Self Image, and Modern Political Theory," Political Theory 37, no. 2 (April 2009), https://www.jstor.org/stable/25655473
[52] Berne, "Disability Justice."
[53] Ena Chadha, "'Mentally Defectives' Not Welcome: Mental Disability in Canadian Immigration Law, 1859-1927," *Disability Studies Quarterly* 28, no. 1 (January 31, 2008), https://doi.org/10.18061/dsq.v28i1.67; Deborah C. Park and John P. Radford, "From the Case Files: Reconstructing a History of Involuntary Sterilisation," *Disability & Society* 13, no. 3 (1998): 317–42, https://doi.org/10.1080/09687599826669.

Through these and similarly unjust policies, the government of Canada's attitudes and actions toward persons with disabilities was paternalistic and ignorant of the rights of persons with disabilities. This era was also defined as representing the charitable model of disability, wherein persons with disabilities received aid largely from religious authorities, under the idea that their care depended on the mercy and beneficence of others. This reductive understanding of disability, rooted in paternalism, contributed to the dehumanization of persons with disabilities.[54]

Moving out of the charitable model and into the post-World-War-II and neoliberal eras, disability policy was conceived of largely within the frameworks of the medical and social models described in the previous section. Within these contexts, policies were rooted in individualism, such as the economic benefits mentioned earlier.[55] Presently, within Canada's current sociopolitical context characterized more so by globalism than a direct entrenchment in strictly neoliberal policies (though these are still prevalent), we are beginning to see shifts toward policies that are more inclusive, holistic, and socially adept. Examples include Canada's ratification of the United Nations' CRPD in the early-mid 2000s, and in the 2019 *Accessible Canada Act*, outlined above, which directly acknowledges the importance of disability communities' participation in matters directly impacting them.

However, despite the generally positive trajectory on which we are seeing disability policy develop in Canada, the original roots in state paternalism remain intact. From the charity model, where persons with disabilities were essentially treated as wards of the state, and into the modern day, where persons with disabilities are seeing enhanced empowerment and integration within public decision-making, what remains is the state's reluctance to support the autonomy

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[54] McColl, MaryAnn, *Definitions of disability*, Canadian Disability Policy Alliance (2020).

[55] Micki McGee, "Capitalism's Care Problem: Some Traces, Fixes, and Patches," *Social Text* 38, no. 1 (142) (March 1, 2020): 39–66, https://doi.org/10.1215/01642472-7971091.

and interdependence of persons with disabilities. If new policies continue to be developed within this paradigm, paternalism will be reproduced, despite attempts to the contrary. Thus, a novel perspective is needed to imagine a future of disability policy design rooted in participation and justice; I suggest in what will follow that feminist care ethics provides this necessary perspective.

Care Ethics

Following the discussion of the components and trajectory of disability policy in Canada, I will now move toward an exploration of care ethics – what I posit, in this paper, to be a necessary feature of more equitable and inclusive approaches to designing disability policy. I will begin by introducing care ethics as a concept, situating it within a broader feminist framework, before bringing care ethics and disability policy design into a deeper and more nuanced dialogue.

Care ethics, broadly defined, is a relational moral and political theory that acknowledges the importance of context, or particularity, and relationships in its ethical deliberation.[56] This means that, as opposed to applying universal ethical principles to all situations, care ethics recognizes that humans exist interconnectedly (or interdependently) and within social webs.[57] Thus, a caring response values how people's situations inform their unique experience in the world – "including their history, relative power, relationships" – and, thus, responses are "unique and individualized".[58] Care ethics also has the goal of bringing care into the public sphere.[59] This is advocated for in terms of realizing and dismantling systemic injustices facing care workers,

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[56] Engster, Daniel, and Maurice Hamington. *Introduction* (Oxford Scholarship Online, 2015); Verkerk, Marian A. *The Care Perspective and Autonomy* (Medicine, Health Care and Philosophy, 2001); Branch Jr, William T. *The Ethics of Caring and Medical Education* (Academic Medicine, 2000); Hamington, Maurice. *Jane Addams and a Politics of Embodied Care* (The Journal of Speculative Philosophy, 2001)

[57] Engster and Hamington, *Introduction.*

[58] Ibid, 4.

[59] Kittay, Eva Feder. *Women, Welfare, and a Public Ethic of Care*. (Philosophic Exchange, 1997); Hamington, *Jane Addams*; Engster and Hamington, *Introduction.*

creating more caring social policy – such as childcare policy, and universal education and health care[60] – and realizing more caring societies.[61] This goal, which challenges the division of the public and private spheres, is rooted in care ethics as a feminist tradition.[62]

Care ethics is said to have been first explored in 1980 with Sara Ruddick's publication of *Maternal Thinking*, which examines the moral significance of ways of thinking specific to the experience of motherhood, with the first actual mention of "care ethics" in 1982, in Carol Gilligan's *In a Different Voice: Psychological Theory and Women's Development.*[63] Engster and Hamington note that care ethics was "solidified" as an ethical theory upon Nel Nodding's 1984 publication of *Caring: A Feminine Approach to Ethics and Moral Education.*[64] Though the precise history of care ethics is not vital to this paper, what is notable is the continued gendered conception of an ethic of care, illustrated by each of the aforesaid titles' mention of feminine identities. It is this foundation in paying attention to the experiences of women – whose unique experiences in patriarchal society have been underrepresented in the Western philosophical tradition[65] – as well as the care-ethical goal of realizing care in the public sphere that define the feminist tradition within which care ethics is situated.[66]

Care ethics is broadly understood to be a feminist ethic; however, there have been criticisms levied against it being a truly feminist ethic, namely in its historic neglect of

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[60] Held, Virginia. *The Meshing of Care and Justice* (Hypatia, 1995).

[61] Kittay, *Women, Welfare*; Kittay, Eva Feder. *The Benefits and Burdens of Social Cooperation* (New York: Routledge, 1999); Weir, Allison. *The Global Universal Caregiver: Imagining Women's Liberation in the New Millennium* (Constellations, 2005); Tronto, Joan C. *The 'Nanny' in Question in Feminism* (Hypatia, 2002); Held, *The Meshing of Care*

[62] Engster and Hamington *Introduction.*

[63] Ibid, 5.

[64] Ibid.

[65] Grasswick, Heidi E. *Individuals-in-Communities: The Search for a Feminist Model of Epistemic Subjects* (Hypatia, 2004).

[66] Ibid.

intersectionality and its origins within a Western context.[67] Thus, in order to weigh my use of care ethics in this paper against such claims, I will adopt Allison Jagger's approach to classifying a feminist ethic. However, although I am using Jagger's (2001) criteria to classify care ethics as a feminist ethic, there are certain realities which make it difficult to navigate Jagger's criteria, the history of care ethics, and the history of feminism, more broadly. Feminism has not always been inclusive of women of non-dominant racial (and other social) identities, including disability; thus, it is important to emphasize Jagger's first criteria, outlined below, which acknowledges that different women experience society differently. Additionally, care ethics has been criticized for reproducing patriarchal conceptions of womanhood (by associating the feminine with care), ignoring or eradicating the nuance of gender identity, and for its connection to colonialism.[68] While it is beyond the scope of this paper to discuss these issues in greater depth, I acknowledge these tensions and explicate my intention to conceive of feminism through an intersectional lens throughout this paper.

With these caveats in mind, according to Jagger, to be considered "feminist", an ethical approach must fulfill the following criteria: first, it must recognize the ways in which a woman's experience in the world differs from a man's, and that different groups of women – such as those who belong to non-dominant racial groups or sexual orientations – experience the world differently. Within this condition, there is an understanding that a woman's intersectional identity affects the way she experiences power in society.[69] Additionally, it is crucial to note that the ignorance of this perspective is a feature of the ways in which white women and white feminists oppress women and feminists of colour. A woman's experience – or, more specifically,

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[67] Deniz Durmuş, "Care Ethics and Paternalism: A Beauvoirian Approach," *Philosophies* 7, no. 3 (June 2022): 53, https://doi.org/10.3390/philosophies7030053.

[68] Narayan. *Colonialism and Its Others: Considerations on Rights and Care Discourses* (1995).

[69] Crenshaw, *Demarginalizing the Intersection of Race and Sex*.

experience in marginalization – in the world is defined not only by sex or gender, but also by race, ethnicity, social class, and other factors of identity.[70] Second, a feminist ethic must acknowledge both a history of women's oppression, as well as the ways in which women have resisted oppressive structures; this approach must be "transitional and non-utopian".[71] Third, a feminist ethic must critically assess the distinction between the private and public domains. Fourth, and last, a feminist ethic must take seriously the moral experience of every woman, which implies taking a critical approach to empathy in understanding the experiences of women.[72]

From the description that I have provided, it is evident that care ethics can, indeed, be classified as a feminist ethic. The historical recognition of the difference in women's experiences (in comparison to men's) in care ethics satisfies Jagger's first condition. For the second condition, an ethic of care as a political philosophy acknowledges the history of oppression and (continued) resistance faced by women in the effort toward an equitable, caring society. [73] Similarly, care ethic's aspiration of reorganizing the public and private spheres in accordance with more caring, equitable, and just principles appeals to Jagger's third condition. Lastly, as is outlined later in this paper, an embodied ethic of care places great significance on active listening and fostering empathy for people's unique experiences.[74] Thus, care ethics and "its radical implications for our understanding of ourselves and our place in the world" can be classified as a feminist ethic.[75]

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[70] Ibid.
[71] Jagger, Allison M. *Feminist Ethics* (New York: Routledge, 2001), 532.
[72] Ibid*,* 532-533.
[73] Engster and Hamington, *Introduction.*
[74] Hamington, *Jane Addam.*
[75] Engster and Hamington, *Introduction*, 6.

In the context of disability – particularly with respect to the development of public policies pertaining to disability – care ethics is of great importance and relevance. I posit the integration of participatory approaches to disability policy design as the central argument of this paper because the ideal goal of such approaches is to meet the needs of *people* and improve the human experience, as opposed to strictly system or program improvement. Design, in this way, is concerned with the relational aspect of being human. [76] That is, in attending to the needs of individuals based on their specific circumstances and social environments – as participatory design does[77] – these such approaches acknowledge the importance of providing disability services within the context of care. The relational element is imperative when it comes to ensuring an ethic of care avoids the perversion of paternalism, in that care should be understood as an interaction and exchange between parties – not in a transactional sense, but in the sense that no one person is devoid of needing to give or receive some sort of care.[78]

Participatory approaches to design are caring also in their pursuit of democratization.[79] As noted earlier, much of the prominent care-ethical literature seeks to realize a social care ethic, or a presence of care within the public sphere both in the forms of social policy and in a cultural or societal mindset that recognizes the importance of care, care work, and social justice.[80] Participatory design's parallel goal – of creating systems that embrace and exhibit care for a world friendly to disability – is demonstrative of the pertinence that care ethics has to such forms of design. This is important to establish as, in this paper, I am concerned with the connection and

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[76] Jull et al., *Community-Based Participatory Research.*
[77] Donetto et al., *Experience-based Co-design*; Blomkamp, *The Promise of Co-Design*; Sanders and Stappers, *Co-Creation*; Jull et al., *Community-Based Participatory Research.*
[78] Jonathan Herring, "Ethics of Care and Disability Rights: Complementary or Contradictory?" In *Spaces of Care*, 165–82 (2020).
[79] Ibid.
[80] Kittay, *Women, Welfare*; Kittay, *The Benefits and Burdens*; Tronto, *The 'Nanny' in Question*; Weir, *The Global Universal Caregiver*; Hamington, *Jane Addams*; Engster and Hamington, *Introduction.*

dependence between developing disability policies and ensuring those policies are caring. Since participatory approaches to design are popularly supported as a means to improve disability policy, I hold them as central to the perspective advanced in this paper.

Since care ethics is not prescriptive, but rather encourages particularity, I am not advocating for an ethic of care to be applied as a bioethical, social, or other sort of decision-making tool in the realm of disability; instead, it can be used to influence the design of participatory frameworks for disability policy development and innovation. As we saw during the COVID-19 pandemic, which negatively impacted persons with disabilities to a concerningly high degree both in terms of health risks and financial insecurity – in large part due to the very nature of those systems and institutions – caring and person-focused systems are needed in our society.[81] It is not just within academic literature and papers such as this one where this sentiment is shared; since the pandemic, there has been a rise in the social phenomenon of care mongering to help individuals who cannot help themselves;[82] beyond this, through social demonstration for various issues – from Black Lives Matter protests which centre around police brutality and legal (in)justice, to Palestine solidarity protests which call for humanitarian aid and anti-Western imperialism – we have experienced a societal push toward social justice for issues concerning those beyond ourselves.[83] These demonstrations of relational caring demonstrate people's desire to be included and heard in the sociopolitical realm. In other words, these examples seem to indicate a desire to bolster the sense of autonomy, and especially interdependence, that people have over decisions that affect their lives, and the lives of those

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[81] Shelley Tremain, "COVID-19 and The Naturalization of Vulnerability," *Biopolitical Philosophy* (April 2020).
[82] Seow et al. *# Caremongering: A community-led social movement to address health and social needs during COVID-19*, 2021).
[83] Hoffman, Louis, et al. *An Existential–Humanistic Perspective on Black Lives Matter and Contemporary Protest Movements* (Journal of Humanistic Psychology, 2016)

around them. In the context of this paper, this is reflected in a desire for those who experience disabilities to be able to express increased autonomy in their care and receipt of services, which can take place in the process of policy design.

In the context of disability, it should come as little surprise to draw connections between the *care* of those with disabilities and *care* ethics. However, the body of literature on the moral orientation of care within disability policy remains rooted in theory and academia, and in a practical sense, is not nearly as expansive as the broader literature of health care, which discusses the ethical principles of beneficence, autonomy, and justice, known to be major pillars within the Western medical tradition (and have been criticized by disability activists and scholars).[84] It is important to note that, though I advocate for distancing disability policy from its historic roots in health policy within the public realm with respect to the medical model, I illustrate its connection here to underline the reality of practical discussions of disability being situated within the health sphere. This stems from the medical model of disability's aim of fixing or eradicating disability through medicine, which, despite the positive trajectory toward more social conceptions of disability, remains historically entrenched within neoliberal Canadian and Western politics and scholarship.

However, practically, there are indeed inextricable links between the two domains that require a close collaboration between the health and disability spheres. Within this context are specifically health-related disabilities, such as ailments or diseases that require medical procedures or medications to maintain life, as well as disabilities that, due to jurisdictional and political realities, are practically managed at the provincial level. For example, in Ontario, persons with disabilities related to old age, and who require assistance outside of family/friend

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[84] Branch, *The Ethics of Caring*; Beauchamp, Tom L., and James F. Childress. *Principles of Biomedical Ethics* (Oxford University Press, 2019).

caregivers, often access such support through long-term care, and this provision is managed by the provincial health care budget.[85] Thus, the provision of care for some persons with disabilities is linked to the health sphere, and by recognizing this reality I do not intend to advocate for a medicalized understanding of disability, or adoption of a medical model of conceptualizing disability. Instead, I move toward a justice-oriented approach to disability policy, whilst remaining cognizant of the socio-temporal medicalized context.

Additionally, even though many medical and other professionals, as individuals, practice care, there is a lack of critical recognition or understanding of an ethic of care in their work.[86] This epistemological gap is indicative of the need for an explicit positioning of care ethics within disability care, disability policy, and broadly within health care, as well. Realizing care within *all* spheres is an aspirational goal of this research paper; however, under the constraints of space, I will engage in discussing its realization within the development of disability policy in Canada.

Policy Design in the Context of Care

Now that I have discussed the policy landscape of disability in Canada, and have developed an understanding of care ethics as a specifically feminist ethic, I will begin to integrate participatory approaches to policy design into the social and philosophical framework of care ethics. As noted earlier, an ethic of care offers a perspective from which designers (or policymakers) and users (or citizens, or policy recipients) can create more equitable, caring, and effective approaches to disability policy through adopting a relational approach. As such, the design of disability policies needs to consider care ethics; however, care ethics in this context

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[85] "Ontario Health Sector: 2023 Budget Spending Plan Review", Financial Accountability Office of Ontario, last modified May 31, 2023, https://www.fao-on.org/en/Blog/Publications/health-update-2023.
[86] Branch, *The Ethics of Caring.*

must also consider the ways in which care has been and can be mobilized to deliver harm, both directly and indirectly. This caveat will be explored and expanded throughout the following section of this paper.

To begin this discussion, it is critical to note the importance of family/friend caregivers in the development, receipt, and discussion of disability policy. Of course, the primary consideration for expressing care within disability policy should be for persons with disabilities, and ensuring their involvement in developing policies and services that best meet their self-identified needs. Additionally, and in respect of the various degrees to which individuals struggle to navigate systems and structures not created with their disabilities in mind, care in many cases cannot be administered or actualized without the help of loved ones who provide care in its actionable sense. By this, I am referring to family/friend caregivers who may or may not live with a person with a disability, and provide any or all of the necessary physical, emotional, financial, and social support. Since this care work exists outside of the economic labour market, it is work that often goes unpaid and unnoticed.[87] Since, in some cases, the services and policies available to and for persons with disabilities are accessed by family/friend caregivers, their involvement and inclusion is critical within the context of care ethics. Given the importance of relationality – established within this report as key to an equitable care ethical foundation – family/friend caregivers cannot be ignored.

On a broad scale, and as discussed within the section *Policy Landscape in Canada*, one major problem is that disability policies in Canada lack adequate inclusion and consideration of family/friend caregivers and the role that they play in the lives of persons with disabilities. Conversely, it could be argued that the inadequate policies that are currently in place create a

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[87] Kittay, Eva Feder. *The Benefits and Burdens*.

situation in which family care and support is critical, in the sense that care has become the near-total responsibility of an individual family unit, as opposed to responsibility being borne by the state. In any case, and regardless of which of these arguments come to take greater shape within disability policy discourse, it stands that the federal government offers limited financial aid to family/friend caregivers to persons with disabilities. These financial supports include EI benefits, the DTC, and the CCC – which, as described earlier, are insufficient both in terms of content and intent. As opposed to being rooted in a framework of relational care, where family/friend caregivers might see more social supports or an environment more conducive to providing care labour, Canada's current policies and services are largely economically driven, thus reinforcing a complicated combination of individualism – as is the predominant perspective of the medical model – and financial dependence (on the state), as opposed to community-based autonomy or interdependence, which, in the public sphere, involves both persons with disabilities and their family/friend caregivers.

Before moving forward, I would like to acknowledge that absent from my analysis thus far is a discussion about the role of Personal Support Workers (PSWs) and other care work professions. The work done by PSWs and other care workers is undervalued in Canadian economic society. These individuals face insufficient pay, job insecurity, and discrimination, to highlight only a fraction of the issues. Thus, based on this lack of fair and equitable treatment, it is clear that the treatment of care workers who do operate as part of the labour market is not based on principles stemming from an ethic of care. An entire report can (and should) be written on this issue, as well as how employing principles of care ethics in the political realm could encourage the development of more caring practical directives to help ameliorate this injustice. Discussion beyond this intervention, however, surpasses the purview of this paper.

Participatory Approaches to Policy Design

Throughout this analysis, I have been using “participatory approaches to policy design” as an umbrella term to describe approaches to policy development that involve the participation of its recipients (i.e., persons with disabilities, as well as their family/friend caregivers) through the development and provision processes. The approaches to which I refer in this report are research-based, and I engage with them in a largely theoretical sense, in that I focus on their foundational and conceptual facets before and as part of consideration of their actual deployment. This is in part because, in the realm of disability policy in Canada, such innovation remains housed within the academic or theoretical sphere.

One approach that connects to the aims of participatory policy design through an equitable lens is Community Based Participatory Research (CBPR). CBPR connects researchers and users throughout the entirety of its process.[88] CBPR is a more established methodology in comparison to other participatory approaches to design, and works through a research-based method in marginalized communities in order to address injustices which have been identified specifically by those within the community.[89] In other words, CBPR addresses the inequities that community members themselves have identified, effectively including the voices and addressing the concerns of those who have historically gone unheard. According to the Kellogg Foundation, “CBPR begins with a research topic of importance to the community, has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities”.[90]

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[88] Jull et al., *Community-Based Participatory Research.*

[89] Ibid, 5.

[90] Kellogg Foundation. *Community-Based Public Health Initiative* (Kellogg Foundation,1992).

CBPR is influenced by equitable research methods, which are inclusive of community members from the very beginning to the end of the endeavour.[91] What I consider to be of particular importance as it relates to CBPR is the role of "participatory action research",[92] which involves advocacy for flat power structures, and for oppressed individuals to "examine their own oppression and then bring about social change".[93] In essence, this methodology seeks to empower those who have been oppressed in achieving their own liberation through equitable research. Jull et al. also cite feminist scholars as major influences of this research approach for their recognition of the importance of including marginalized voices – and particularly those of women – in research.[94]

Overall, CBPR is a research methodology, and thus can be used in conjunction with different theories such as feminist ethics, which, as I posit, includes an ethic of care. An integral component of CBPR is that the perceived dominance or superiority of researchers and their knowledge should be decentred, in favour of focusing on the knowledge of the oppressed and marginalized, whose experiences should guide the CBPR process.[95] The adoption of this lens ensures that knowledge is co-constructed, addressing "micro-level issues of power in research while challenging dominant systems of knowledge and power".[96] Care-ethical approaches have similar outcomes, such as centring the voices of the community, paying particular attention to making space for those occupying marginalized spaces.[97]

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[91] Jull et al., *Community-Based Participatory Research,* 5l.
[92] Freire, P. *Pedagogy of the Oppressed* (New York: Continuum, 2000).
[93] Jull et al., *Community-Based Participatory Research,* 5.
[94] Ibid, 3.
[95] Darroch, Francine, and Audrey Giles. *Decolonizing Health Research: Community-Based Participatory Research and Postcolonial Feminist Theory* (The Canadian Journal of Action Research, 2014); Jull et al., *Community-Based Participatory Research,* 3.
[96] Darroch and Giles, *Decolonizing Health Research,* 30.
[97] Hamington, *Jane Addams*, 116.

Another approach – which is perhaps most relevant to discussing disability policy – is universal design. Universal design creates spaces or systems catering to all people – regardless of race, gender, age, ability, or other characteristics.[98] Like the broad field of co-design or participatory design, universal design has roots in and implications for the private sphere, particularly as it relates to architecture and urban design.[99] Similarly, the tenets of universal design can be applied to the public sphere, as well, as it relates to disability policy. By its nature, universal design is tied to the social model of disability; by understanding spaces as being inaccessible to people, universal design agrees with the social model's claims that (dis)ability, in the way we have come to engage with it, is socially constructed. Thus, applying the principles of universal design to disability policy design allows for a critical engagement with relevant bodies of work – which, in the context of universal design, is already widely researched and studied. Additionally, by paying attention to the experiences of users and people accessing the designed space (physical or otherwise), universal design is also democratic.

The application of universal design to disability policy design acts, in many ways, as a direct response to the historic exclusion of persons with disabilities from physical spaces – through inaccessible architecture – by recognizing that this form of exclusion extends to the social realm. Thus, the application of universal design principles and associated recognition of the interrelation of the physical and social spheres can be used to achieve equitable outcomes for the disability community.[100] Engaging in this process is inherently caring, as in it is aligned with

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[98] "History of Universal Design", Centre for Excellence in Universal Design, accessed April 1, 2024, https://universaldesign.ie/about-universal-design/history-of-universal-design#:~:text=In%20the%20United%20States%20Ron,standards%20in%20the%20United%20States.

[99] Inger Marie Lid, "Universal Design and Disability: An Interdisciplinary Perspective," *Disability and Rehabilitation* 36, no. 16 (2014): 1344–49, https://doi.org/10.3109/09638288.2014.931472.

[100] Baltzan, "Adopting Universal Design in Disability Policy."

an ethic of care, in how it is rooted in pursuing just and equitable aims through participation and consideration of those most affected.

Now that the direct application and connection between universal design and disability has been established, it becomes possible to conceptualize a more tangible method for application in a real-world setting. In considering universal design's principles for realizing a person-centred approach to conceiving a built environment, policymakers and decision-makers can adapt these tenets for use in disability policy design. Over the course of the evolution of universal design, which occurred largely within the academic silo of architecture and physical design studies, eight goals have emerged to encourage critical assessment of *who* a space has been or will be designed for. These goals are as follows: body fit, comfort, awareness, understanding, wellness, social integration, personalization, and cultural appropriateness. Of these tenets, I will highlight the latter three – social integration, personalization, and cultural appropriateness – for their direct relevance to participatory disability policy design, through a care ethical lens.[101]

Social integration refers to the treatment of all groups with respect, equity, and dignity; similarly, care ethics, as has been outlined, necessitates a baseline recognition of the experience of all persons, in celebration and not despite their identity.[102] Personalization is the goal of universal design in that it allows each individual being able to uniquely define or achieve comfort, according to their own definition of it.[103] Feminist care ethics' acknowledgement of intersectionality aligns with this goal, in that both tenets support the idea that, even within a

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[101] "7 Principles of Universal Design," Universal Design Network of Canada, accessed April 1, 2024, https://universaldesign.ca/principles-and-goals/.

[102] "7 Principles of Universal Design," Universal Design Network of Canada; Grasswick, *Individuals-in-Communities*.

[103] "7 Principles of Universal Design," Universal Design Network of Canada.

broader community, an individual's particular experience in the world and in society is distinct, and thus cannot be conflated or reduced to a general conception.[104] Finally, cultural appropriateness refers to ensuring respect for and reinforcement of cultural values or ideals in design.[105] This goal is critical to any effort to apply universal design to disability policy, in that the disability community (the "culture", in this case) must be upheld and centred at any and all stages. This might include a recognition of the history of persons with disabilities in Canada and their struggles. The care ethical implication, in this case, is derived from the fact that these cultural needs exist relationally, in that they are inextricable from the broader community, and the plights of individuals or subgroups with disabilities contributes to the overall culture.

Thus, by employing an approach to public decision-making that centres the needs and voices of persons with disabilities, the integration of universal design can lead to more equitable and socially just outcomes. This theoretical result connects directly with the aims of care ethics, in that empathy – through active listening – is the key driver of both universal design and an ethic of care. A participatory approach to policy design that is founded in universal design aligns with care ethics by its nature, through active listening and democratic engagement, and is thus one means by which public policies can be designed in a way that is undergirded by caring principles.

Defending Participatory Design Through Care

Approaches to policy design that employ a participatory approach, such as universal design or CBPR, carry great democratic potential.[106] This means that allowing individuals with

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[104] Crenshaw, *Demarginalizing the Intersection of Race and Sex*.
[105] "7 Principles of Universal Design," Universal Design Network of Canada.
[106] Sanders and Stappers *Co-Creation*; Jull et al., *Community-Based Participatory Research*; Staniszewska S. *Patient and Public Involvement in Health Services and Health Research: A Brief Overview of Evidence, Policy and Activity*. (Journal of Research in Nursing, 2009); Blomkamp *The Promise of Co-Design*; Brett, J. O., et al. *A*

disabilities – and their family/friend caregivers, where relevant – to take an active role in the development of policies and services that impact them allows these individuals to exercise more agency in their lives, which have historically faced indiscriminate paternalism from the state and from the medical profession. Care ethics shares a similar focus on democracy with respect to considering the intersection between the individual and the public.[107] By this, I mean that, in the public policy realm, participatory policy design seeks ways to turn a social entity into something that caters to the needs of individuals by considering their self-identified needs and their relationships, such as family/friend caregivers. Care ethics can be said to bridge this divide in the equal and opposite direction, by seeking to understand care, often conceived of as a private entity, in the public realm, considering relationships to be foundational to our experience in the world.[108] With these parallel goals, it is not difficult to surmise the connections between care ethics and participatory approaches to policy design and how, in conceiving of public policy through a caring lens, participatory approaches might be able to focus more on relationships and relationality, and thus improve the overall experience of those engaging with such policies and services.

Expanding upon the use of participatory approaches to policy design, there are several ways in which they exemplify or embody facets of an ethic of care, especially an ethic of care conceived in the feminist tradition. First, these such approaches to public policy development seek to cater to the specific needs of an individual;[109] care ethics is a philosophy that differs from other theories in that, instead of prescribing a singular universal, normative framework to all

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Systematic Review of the Impact of Patient and Public Involvement on Service Users, Researchers and Communities (The Patient-Patient-Centered Outcomes Research, 2014).

[107] Engster and Hamington, *Introduction,* 7.

[108] Engster and Hamington, *Introduction*; Tronto, *The 'Nanny' in Question*; Kittay, *Women, Welfare*; Kittay, *The Benefits and Burdens.*

[109] Staniszewska, *Patient and Public Involvement.*

persons and situations, it offers a relational lens and urges us to consider the relationships, context, and environmental influences specific to a situation.[110] As understanding context is foundational to any ethic of care,[111] and context is similarly crucial to any participatory approach to design, it can be said that, perhaps inadvertently, participatory approaches are in themselves situated within an environment of care. Participatory approaches, such as universal design, place significance on relationality and questioning the immobility of traditional structures, whether these relationships are with family/friend caregivers, or with society at large [112]. This focus on relationships, experience, and the recognition that there is no one-size-fits-all approach, present both in care ethics and in participatory approaches to design, demonstrates the ways in which participatory design can be grounded in care.

Of particular importance is the idea of relational autonomy, or the idea that, in the context of care (both in the health sphere and in general) and decision making, an individual's environment and relationships impact their options and decisions.[113] This conception of autonomy stands in contrast to the traditional view, or rather the view prominent in Western society, which considers individuals to be independent, rational, and self-sufficient when it comes to care and decision making.[114] However, this understanding of autonomy is thought to ignore the importance of the social environment within which individuals make decisions which, in reality, are not entirely divorced from any sort of external influence, and may be tied to things

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[110] Engster and Hamington, *Introduction*, 2; Hamington, *Jane Addams*, 107.

[111] Hamington, *Jane Addams*, 107.

[112] Lid, "Universal Design and Disability."

[113] Oshana, Marina. *Personal Autonomy in Society* (Ashgate Publishing, Ltd., 2006), 98; Sherwin, Susan, and Meghan Winsby. *A Relational Perspective on Autonomy for Older Adults Residing in Nursing Homes* (Health Expectations, 2011), 184.

[114] Beauchamp and Childress, *Principles of Biomedical Ethics.*

like race, gender and ethnicity. [115] Care ethics rejects the notion that people are entirely and completely independent, especially many of those who have disabilities or unable to care for themselves,[116] and instead embraces an understanding of the human experience as one that is interdependent and relational, and thus autonomy should be thought of in terms of our relationships.[117]

The way that this idea relates to participatory approaches to design is twofold: first, participatory approaches, in themselves, support autonomy by empowering individuals to participate in their own care and experience within the public sphere; secondly, we might consider this autonomy to be relational when it ensures the inclusion of the voices of family/friend caregivers.[118] Thus, both care and participatory approaches to policy design embrace a conception of the human experience that acknowledges the social webs within which we are situated. Again, I reintroduce the concept of Disability Justice, here, which is founded in the idea that interdependence is central to advancing the rights of persons with disabilities [119]; thus, it is within this realm of interdependence that care ethics, participatory design, and disability rights intersect.

Additionally, participatory approaches to policy design put into practice some of the key tenets involved in the pursuit of a “political embodied ethic of care”, or rather a social conception or ethical stance that centres relational care.[120] Among these tenets are active listening, participation, connected leadership, and activism, as outlined by Maurice Hamington in

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[115] Ho, Anita. *The Individualist Model of Autonomy and the Challenge of Disability* (Journal of Bioethical Inquiry, 2008); Walter JK, Ross LF. *Relational Autonomy: Moving Beyond the Limits of Isolated Individualism* (Pediatrics, 2014).

[116] Kittay *The Benefits and Burdens*, 105.

[117] Verkerk, *The Care Perspective*, 292.

[118] Jull et al., *Community-Based Participatory Research,* 2; Donetto et al., *Experience-based Co-design.*

[119] Berne, “Disability Justice.”

[120] Hamington, *Jane Addams,* 111.

her examination of Jane Addams' embodied ethics of care.[121] Participatory approaches are centred around the notion of active listening, or rather the act of engaging with patients and their caregivers to understand their experiences.[122] To Addams, according to Hamington, active listening is a process that involves leaders engaging directly with community members, cognizant of power dynamics whilst dismantling them in the act of being available to *listen* as opposed to *speaking over*, effectively transforming leadership into a social and collaborative endeavour.[123] This stands in stark contrast to the way in which leadership is perceived in Western politics, health care, and social life, where leaders act as ultimate decision-makers and have, to varying extents, concentrated power.

Addam's conception of leadership recognizes that powerful people run the risk of listening selectively, especially when listening to women of colour.[124] However, by curating an environment with open and caring two-way dialogue, leaders can foster trust and, through it, develop psychological safety by acting upon the concerns of marginalized community members and exacting positive change.[125] There is much to consider with respect to the intersectional consideration of the voices of those who have historically been marginalized, even within the disability community; what is pertinent to this report, however, is the clear connection between the care-ethical practice of active listening to realize a social ethic of care and the premise of active listening that underscores the processes associated with participatory design. With participatory design, individuals' and communities' experiential knowledge is used to guide problem definition and problem ramification.[126] Though there is work to be done to realize the

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[121] Ibid.
[122] Jull et al., *Community-Based Participatory Research*; SE Research Centre, *PR2A*.
[123] Hamington, *Jane Addam,* 112.
[124] Ibid.
[125] Carel, Havi, and Ian James Kidd. *Epistemic Injustice in Healthcare: A Philosophical Analysis* (Medicine, Health Care and Philosophy, 2014).
[126] Sanders and Stappers, *Co-Creation*; Jull et al., *Community-Based Participatory Research.*

ideal of equitably, actively listening in existing and theorized participatory design frameworks, this foundational feature (or aspiration) is very much in tune with care ethics.

Aside from active listening, I mentioned three other aspects of embodied care from Hamington. The first of these is participation, an act that, in a political-social atmosphere, allows a greater volume of diverse voices to be heard which, in turn, fosters empathy for their unique individual and collective experiences, thereby motivating leaders to pursue change.[127] This connects to participatory design in terms of the inclusion of different voices to understand and improve the experience of those within the disability community.

The next aspect of embodied care is connected leadership, which refers to community leaders who are in power because of the effective (and affective) ways in which they serve their community, particularly through engaging in active listening and acting upon needs that have been outlined by their constituents.[128] Connected leaders are also physically present in their community, acting as a visible and approachable conduit for the community to have their needs met.[129] Within participatory approaches to policy design, this relates to leaders – who are likely policymakers at all levels of government, researchers, directors of service provision institutions, or others in a position of power – engaging in the co-creative process directly with participants, such as in to improve access to care and services for those with disabilities.[130] Additionally, on a macro scale, this applies to political leaders and governing parties, who tend to be disconnected from the day-to-day lives of members of their communities, in any context. Lastly, the tenet of activism acknowledges that gaining empathy for others' experiences – likely through the other

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[127] Hamington, *Jane Addams*, 116.
[128] Hamington, *Jane Addams*, 118.
[129] Ibid, 117.
[130] Jull et al., *Community-Based Participatory Research.*

three aspects of embodied care – will lead to the desire to improve their experiences.[131] This connects to participatory approaches to design, such as those discussed earlier, that carry the underlying goal of achieving social justice through research in combination with experiential knowledge.[132] Care ethics is concerned with creating a caring social sphere by focusing on human relations and interactions, bringing care to the forefront of the public domain.[133] Care ethics' methods of achieving this goal vary within the literature, but the ideals of social justice and centring the voices of marginalized communities are prominent, such as the notion of active listening outlined above. [134]

A point of concern with respect to participatory approaches to design more broadly is the fear that they can serve to maintain existing power structures as opposed to flattening them; however, I posit that employing care ethics as a foundation can offer tools by which power *can* be challenged.[135] CBPR, as an example, struggles with this criticism of the potential for maintaining imbalanced power, as well as being subject to external societal, political, or financial factors. [136] In response, some literature posits the incorporation of other feminist perspectives to challenge power dynamics in its approach. Specifically, Darroch and Giles propose the use of post-colonial feminist thought to centre marginalized voices and push back against dynamics that might place researchers in a position of power over community members.[137] This approach requires that power imbalances and effects of colonialism affecting the community be explicitly

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[131] Hamington, *Jane Addams*, 119.
[132] Jull et al., *Community-Based Participatory Research,* 3.
[133] Engster and Hamington *Introduction*, 2; Kittay, *Women, Welfare.*
[134] Hamington, *Jane Addams,* 119; Weir, *The Global Universal Caregiver,* 308; Tronto, *The 'Nannny' in Question*; Jull et al., *Community-Based Participatory Research*, 3.
[135] Staniszewka, *Patient and Public Involvement,* 206.
[136] Darroch and Giles, *Decolonizing Health Research*; Israel, Barbara A., et al. *Challenges and Facilitating Factors in Sustaining Community-Based Participatory Research Partnerships: Lessons Learned from the Detroit, New York City and Seattle Urban Research Centers* (Journal of Urban Health, 2006).
[137] Jull et al., *Community-Based Participatory Research,* 3.

acknowledged.[138] Additionally, the perceived dominance or superiority of researchers and their knowledge should be decentred, in favour of focusing on the knowledge of the oppressed and marginalized, whose experiences should guide the CBPR process.[139] The adoption of this lens ensures that knowledge is co-constructed, addressing "micro-level issues of power in research while challenging dominant systems of knowledge and power".[140] Care-ethical approaches have similar outcomes, such as active listening (outlined above), which centres the voices of the community, paying particular attention to making space for those occupying marginalized spaces.[141] Essentially, in this paper, I suggest that *care ethics* can be used to address power imbalance in co-design at large and Darroch and Giles use *post-colonial feminist theory* to acknowledge how CBPR might actively dismantle unjust power relations.[142] Both of these approaches, in tandem with one another, can serve as a way to improve the capacity of CBPR to address unjust power relations, using the targeted post-colonial feminist approach with a foundational desire to create caring co-design. I use this illustration to depict how care ethics can be used as a foundational device on its own and in concert with other critical theories to achieve more just outcomes.

Scholars of critical disability studies have put forth certain approaches to advance equity and justice that, in themselves, highlight the importance of relationality and interdependence in their foundation. For example, the framework of Disability Justice holds as one of its foundational pillars interdependence as a means by which to achieve self-determination.[143] The interdependence tenet understands the call for "independence" within the historic plight for

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[138] Darroch and Giles, *Decolonizing Health Research*, 30.
[139] Darroch and Giles, *Decolonizing Health Research,* 30; Jull et al., *Community-Based Participatory Research,* 3.
[140] Darroch and Giles, *Decolonizing Health Research,* 30.
[141] Hamington, *Jane Addams*, 116.
[142] Darroch and Giles, *Decolonizing Health Research,* 26.
[143] Berne, "Disability Justice."

improved disability policy as part of a Western or Eurocentric project that in effect reduced autonomy for persons with disabilities by limiting collective or community action.[144] Thus, the requirement of interdependence for just and equitable disability policy can be understood in terms of relationality, in how it recognizes liberation and self-determination as a collective effort. I put forth that this tenet of Disability Justice is entrenched, even if indirectly, in care ethics or care ethical principles, for the significance that both theoretical frameworks place on relationality. So, my contention that care ethics is critical to and inextricable from the advancement of disability rights does not stand in opposition to existing proposed disability rights frameworks; indeed, my argument supplements the existing body of theoretical and advocacy work.

Overall, developing public policy, related to disability or otherwise, is a values-laden process, especially when the object of pursuit is an equitable approach to design.[145] It is my assertion that one of the key values we should focus on, in this realm, is care, and participatory approaches to policy design are an effective mechanism to achieve this, with approaches like universal design having specific merit. One of the most significant areas in which this approach should be employed is in the inclusion of family/friend caregivers in efforts to improve services for persons with disabilities, both in terms of content and provision. In the following section of this paper, I will consider how another key gap that care ethics can fill – and should be made certain not to reinforce – is a democratic deficiency in disability policies and services.

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[144] Ibid.

[145] Jull et al., *Community-Based Participatory Research*, 7.

Democratic Deficiency and the Integration of Care

Participatory approaches to disability policy design are, as expressed in the previous section, deeply related to an ethic of care. These such approaches certainly have the propensity to integrate a higher degree of care into the health sphere, with democratic methods like universal design demonstrating particular promise; however, it is still important to discuss the specific ways in which care is lacking in many existing frameworks for improving disability policy design. In this section, I will present two facets of participatory approaches in which there is room for a stronger care ethic to be integrated. First, on a macro-level, I will briefly re-introduce the critique that such approaches can have the damaging effect of maintaining existing power structures. Next, I will discuss the more focused issue of the general lack of attention paid to family/friend caregivers.

To reiterate, a broad critique of participatory approaches to policy design is that they are thought to maintain existing power structures.[146] This critique applies largely to service-design-based approaches – for the risk they run of being conflated with neoliberal aims and ideology – though it also applies to approaches that are meant to be more participatory. [147] The challenge of struggling to reorganize power relations often arises in the context of political or public service environments that are occupied by persons with power, who are unwilling to redistribute or share their power.[148] Since participatory design is a co-creative process that builds new knowledge and, in some ways, "[embeds] … new knowledge, structures, and practices", individuals in governing or leadership positions may feel a threat to their personal power, and thus not wish to engage

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[146] Staniszewka, *Patient and Public Involvement,* 296.

[147] Blomkamp, "The Promise of Co-Design for Public Policy."

[148] O'Rafferty, Simon, Adam de Eyto, and Huw J. Lewis. *Open Practices: Lessons From Co-Design of Public Services for Behaviour Change* (Design Research Society, 2016).

with it. [149] It is here, within the culture and structures surrounding the implementation of participatory approaches to disability policy, where we need to see the most extensive and most fundamental integration of care ethics. As has been noted, a care-ethical perspective has the power to encourage processes that actively disassemble oppressive power structures. This is true both at the scale of implementation (i.e., service delivery) and also at the broader, societal scale. [150] Care ethics is rooted in the aspiration of creating a more caring society,[151] and it would be through a paradigmatic change in how our society values care work that individuals' mindsets might expand to become more relational, and embrace co-design for the good it can bring to individuals with disabilities and society in general, as opposed to fearing a loss of power. In this way, the motivation behind engaging in participatory disability policy design might shift away from system improvement and being outcome-focused, and move toward being rooted in the betterment of the human experience.

The second aspect of participatory approaches to design that I wish to highlight here is the systemic devaluing of family/friend caregivers in our society. I refer to this as a systemic issue because of the institutional barriers that have contributed to care workers, at large, being devalued in our social, health, and economic systems, which in turn have affected family/friend caregivers. An important note to delineate family/friend caregivers from other caregivers is that their work goes unpaid; that is, even though the work done by family/friend caregivers is valued at over twenty billion Canadian dollars each year,[152] these caregivers receive no compensation (save for the minimal tax credits and EI benefits discussed earlier in this report), and instead

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[149] Lenihan, Don, and Lynelle Briggs. *Co-Design: Toward a New Service Vision for Australia?* (Public Administration Today, 2011), 46.

[150] Darroch and Giles, *Decolonizing Health Research*, 30; Jull et al., *Community-Based Participatory Research*, 3.

[151] Kittay, *The Benefits and Burdens*; Engster and Hamington, *Introduction*; Hamington, *Jane Addams.*

[152] Hollander, Marcus J., Guiping Liu, and Neena L. Chappell. *"Who Cares and How Much.": The Imputed Economic Contribution to the Canadian Healthcare System of Middle-Aged and Older Unpaid Caregivers providing care to the elderly* (Healthcare Quarterly, 2009), 48.

experience loss in other aspects of their lives, such as social and mental wellbeing.[153] Though the work done by family/friend caregivers can be enriching and valuable, and promotes caring relations, the stressors experienced by these caregivers – or rather, the "caregiver's burden"[154] – hamper financial, emotional, and relational flourishing, as all cognitive attention is being paid to the dependent party, who in the case of this analysis would be the person with a disability requiring such care.[155] These challenges faced by family/friend caregivers are not new, yet their voices and perspectives continue to be excluded from conversations surrounding patient care in the context of participatory design, and more generally, as well.[156]

Additionally, the responsibilities of family/friend caregiving pose an added burden on those who occupy marginalized social locations – in other words, those who are not white or financially prosperous.[157] These people, most often women, fill unpaid caregiving positions that represent gaps left in the labour market as a result of neoliberal policies that devalue the relational importance of caregiving work.[158] A study conducted by Giesbrecht et al. examining the support received by family/friend caregivers in Canada found that caregivers of certain social identities receive less assistance.[159] Specifically, inequitable support was found for those whose cultural values differs from values of the Canadian healthcare system, women (and men) who are impacted by gender stereotypes that either direct them into or undermine their caregiving role,

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[153] Turcotte, Martin. *Family caregiving: What are the consequences?* (2013).

[154] Bialon, Laura Nelson, and Sallie Coke. *A study on Caregiver Burden: Stressors, Challenges, and Possible Solutions* (American Journal of Hospice and Palliative Medicine®, 2012).

[155] Giesbrecht, Melissa, et al. *Critically Examining Diversity in End-of-Life Family Caregiving: Implications for Equitable Caregiver Support and Canada's Compassionate Care Benefit* (International Journal for Equity in Health, 2012).

[156] Goldhar, Jodeme. *Co-Design and Co-Delivery: The Benefits of Integration From the Family Caregiver's Perspective* (International journal of integrated care, 2018).

[157] Giesbrecht et al., *Critically Examining Diversity*; Boris, Eileen, and Jennifer Klein. *Caring for America: Home health workers in the shadow of the welfare state* (Oxford University Press, 2015); Kittay, *The Benefits and Burdens*

[158] Giesbrecht et al. *Critically Examining Diversity*; Tronto, Joan. *There is an Alternative: Homines Curans and the Limits of Neoliberalism* (International Journal of Care and Caring, 2017), 28.

[159] Giesbrecht et al., *Critically Examining Diversity.*

those who are not geographically close to their care-providing services, younger families who struggle with job security and balancing responsibilities, and those lacking material resources (both monetary and caregiving equipment).[160] These disparities demonstrate the deep need for a societal reorganization of caregiving resources, and also of the support provisioned to family/friend caregivers.

This phenomenon is not limited to Canada, either. Lynne Baxter, a care ethics scholar, has discussed her experience acting as a caregiver to her aging father in the United Kingdom throughout the COVID-19 pandemic, noting the ways in which she was assumed to be primary caregiver due to her gender identification as a woman, as well as the lack of support, agency, and security her father experienced, which in turn affected the mental and emotional wellbeing of Baxter. [161] Additionally, Boris and Klein examine the timeline of the marginalization of care work in the United States, noting how paid care work has been subject to legislation that precludes these professions from job security and other protections.[162] Additionally, the constant reorganizing and redefining of different care work positions resulted in what was effectively the relegation of women of colour and immigrant women to caregiving work, or rather the jobs that no one else wished to do for their perceived lack of required skill and genuine lack of compensation.[163] Though these events refer to paid care workers, and not unpaid family/friend caregivers, what this demonstrates is an attempt by the state – which has not since been remedied in the US or other societies, such as in Canada, in which care workers are not fairly compensated or have job security[164] – at trying to divorce domestic work from the public sphere, maintaining

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[160] Ibid.

[161] Baxter, Lynne F. *A Hitchhiker's Guide to Caring for an Older Person Before and During Coronavirus-19* (Gender, Work & Organization, 2020), 768-769.

[162] Boris and Klein. *Caring for America*, 187.

[163] Ibid, 189.

[164] Zagrodney, Katherine, and Mike Saks. *Personal Support Workers in Canada: The New Precariat?* (Healthcare Policy, 2017)

the myth that these two realms are separate. However, from the lens of an ethic of care, the act of care should be present in and protected by the social sphere.[165]

Additionally, Eva Feder Kittay discusses the *doulia* principle, which essentially calls for a reciprocity of care for caregivers.[166] This principle would affect caregivers at a societal level, seeking to "[treat] the dependency worker equitably, [provide] care for dependents, and [respect] the dependency relations in which fundamental human attachments grow and thrive".[167] The caregiver would be supported by the broader society under the recognition that dependency is a facet of all of our lives (be it in sickness, or in old age, or in youth, or injury, or disability), and thus caring work is valuable work.[168] This element of caring reciprocity between people and the social-political sphere is mentioned in other care ethics literature, as well, and exemplifies the sort of structural change that I believe is needed to see a shift in mindset and practice surrounding co-design approaches to patient health. [169] Especially when considering the role that the social location of a family/friend caregiver plays in their social support and experienced burden, as outlined above, it is clear that, in order for participatory approaches to disability policy design to genuinely serve the needs of the individual and disability community (through the extension of their family/friend caregivers), then the approaches to participatory design must themselves be more caring, and must operate within a system that embraces an ethic of care.

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[165] Kittay, *The Benefits and Burdens*; Engster and Hamington, *Introduction.*

[166] Kittay, *The Benefits and Burdens*, 108.

[167] Ibid.

[168] Ibid.

[169] Hamington, *Jane Addams*, 118.

Discussion and Limitations

Given the scope of analysis I have put forth as it relates to disability policymaking in Canada and the integration of a care ethical framework, it serves to reason that there are certain limitations or points to consider consequentially. To begin, there is the underlying risk inherent to any discussion of care and caregiving wherein the reproduction or reorganization of power dynamics must be considered. As it relates to caregiving, particularly for those with limited capacity to mitigate or report violations, abuses of power are possible and, unfortunately, prominent. An ethic of care within caregiving and policymaking frameworks, both in efforts toward its adoption and in its implementation, are not absolved from such risks of power abuse. Though an ethic of care provides a framework within which we might achieve, and even necessitates, a societal orientation toward justice, equity, and empowerment, the reality stands that vulnerable persons can often be taken advantage of. Thus, in the integration of participatory approaches to disability policy design that centre care ethics, it would be critical to ensure that power dynamics and relationships are always measured and managed to limit the risk of harm. A specific method for achieving this lies beyond the scope of this paper; however, it is still important to point out that such efforts do need to be taken, in any and all contexts.

Additionally, as my argument centres largely around an ethic of care, it is important to recognize some of the arguments that can be levied against such an approach, specifically in the pursuit of disability policymaking. First, one might argue that in an effort to include persons with disabilities in the design of policies impacting them, the idea of "inclusion" can be considered paternalistic, thus contradicting the notion that an ethic of care is not paternalistic, and instead encourages self-determination through relational autonomy. In recognition of this risk, I have strayed away from the use of the term "inclusion" throughout this paper, opting instead to advocate for integration and leadership for persons with disabilities with respect to decisions impacting them and their community.

Next, an economic-centred perspective – which is useful to consider, within a Western, financially-motivated, capitalist society – might posit that an ethic of care does not fit within a neoliberal political context that prioritizes financial efficiency and growth. My response to this is twofold: first, an initial incorporation of care ethics as a lens through which we conceive of social policy does not stand in direct opposition to the state's financial aims; instead, adopting a care ethical approach to designing participatory disability policy would ensure that the actual needs of persons with disabilities are being met, mitigating redundancy and ineffective, costly policies, thus increasing overall efficiency. An example of this would be to improve economic benefits for persons with disabilities and their family/friend caregivers to expedite the rate at which persons with disabilities actualize their material needs, in pursuit of social needs, as per T.H. Marshall's conception of "social citizenship" [170]. Second, I would respond that the accusation of care ethic's incongruence with neoliberalism is its very strength, or rather the piece that underlines its necessity in transformative political practices; ultimately, adopting an ethic of care to create more equitable disability policy is one piece within a broader framework that understands the need to adopt an ethic of care as a holistic theoretical foundation for all Canadian policymaking, which centres empathy and the needs of people above all other, tangential aims.

I have begun to explore a non-exhaustive list of some of the limitations and considerations that should be addressed, not in opposition to, but as part of my paper and overall argument. Ultimately, I remain firm in my assertion that the adoption of a care ethical lens to conceptualize participatory approaches to disability policy design is critical to the advancement

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[170] Hooghe and Oser, "Social and Political Citizenship in European Public Opinion."

of equality and justice for persons with disabilities. In pursuing these aims, we move toward a more inclusive state and society. Ensuring a deep recognition of limitations to these aims ensures that such frameworks can be made stronger, and thus more effective.

Conclusion

In this research paper, I have sought to answer the question: How can the integration of a feminist conceptual framework make participatory approaches to disability policy design more equitable? To do this, I have presented a means by which decision-makers might better integrate the needs of persons with disabilities, which includes the needs of their family/friend caregivers, in order to achieve more just and equitable public policy, rooted in a commitment to participation. In this way, I outlined how participatory methods for disability policy design could be employed and enhanced through the incorporation of a feminist care ethical lens. Adopting this lens, in essence, would situate the necessity of integration – beyond inclusion – of the perspectives of those who are most affected by disability policy. Care ethics, when conceived of in the way I have presented it in this paper, ensures this in its foundation of intersectionality, justice, equity, and relationality; all of which are key components of progressive theories in disability studies and related areas, such as universal design and Disability Justice.

By engaging with relevant literature in the areas of disability policy in Canada as well as care ethics, and seeking to bring these fields together, I offered an engaged analysis of the role that feminist care ethics can play in equitable disability policy design. I also offered a discussion of the considerations and limitations that deserve credence in such an analysis, including a measured assessment of power structures, terminology, and theoretical paradigms that are implicated by my proposed approach. Ultimately, my argument has been that, by employing the theoretical perspective of care ethics, participatory approaches to disability policy design can work toward bridging the “know-do” gap in disability policy, which is caused by a deficit of care, by prioritizing relationality, and centring the needs of actual people and their family/friend caregivers above all else. In writing this paper, it is my hope to contribute to an ever-growing scholarship surrounding the necessity of participation in the political sphere for communities that have historically been oppressed and underrepresented, and recognize it a critical step toward achieving an overall more just and caring society.

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