



Beyond caregiver burnout: Reimagining care in social work research

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Introductions



Land Acknowledgements and Accessibility Considerations

Presenters: Brianna Urquhart (she/her) and Margaret F. (Meg) Gibson (she/her)

The Reimagining Care/Work Policies

- Principal Investigator: Andrea Doucet (Brock University)
 - bridget livingstone, Jenna Cooper, Karen Foster, Laura Fisher
- Partnership Grant from the Social Sciences and Humanities Research Council (SSHRC)



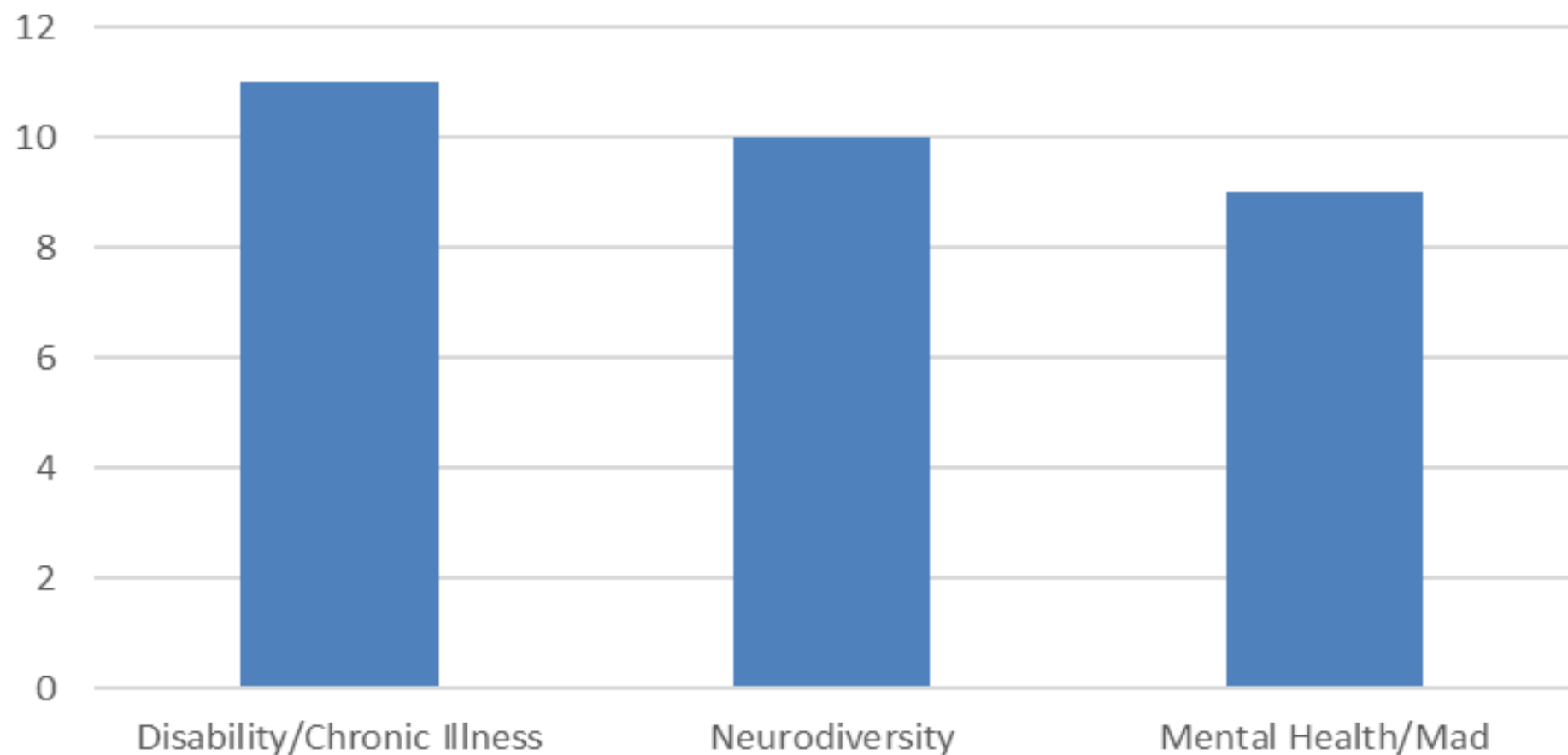
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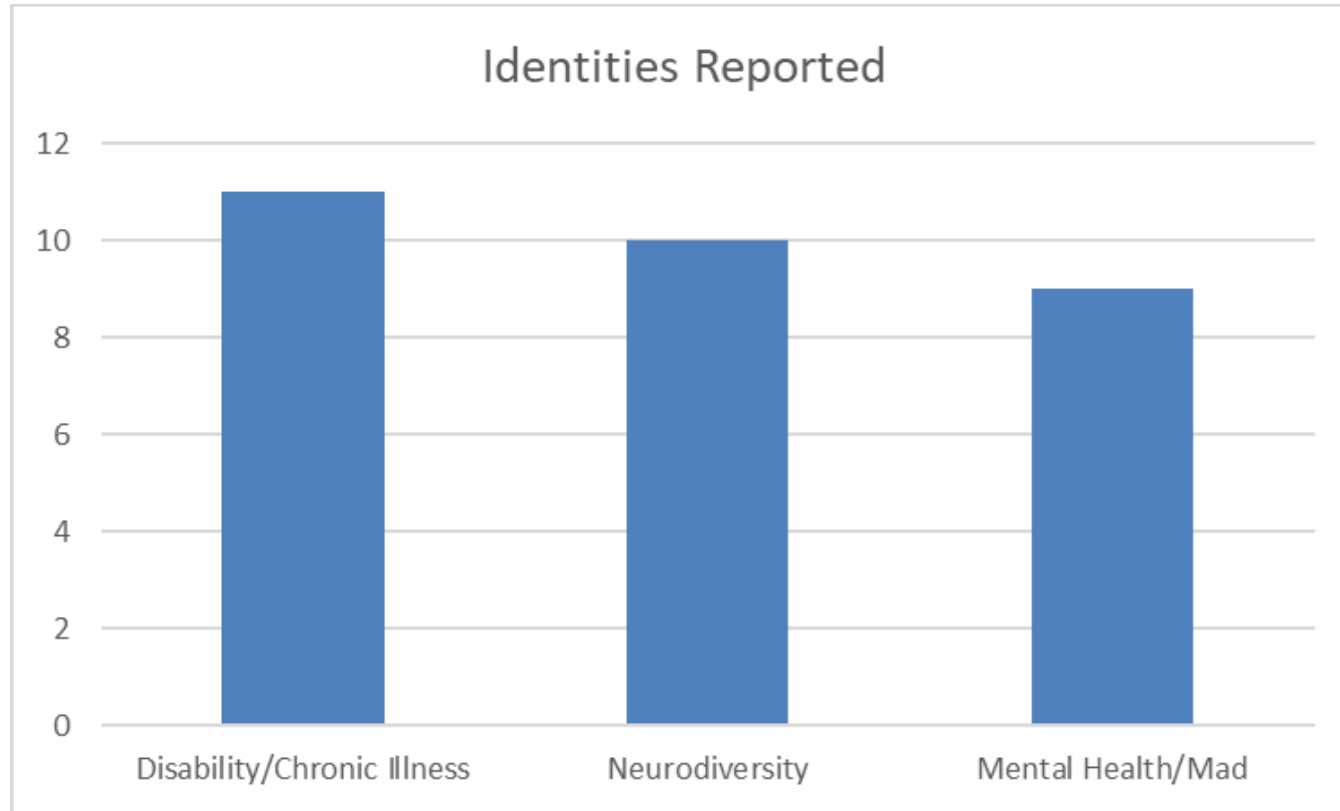
1. Conducting a literature review on families where someone/multiple people identify with disability or chronic illness.
2. Co-leading interviews on two sites: 2SLGBTQ+ parents and parents with disabilities.

Interviews from the Reimagining Care/Work Policies

- a. **Semi -structured** utilizing **The Care/Work Portrait** via Zoom across Canada
- b. 2SLGBTQ+ Site: 14 participants, conducted August 24, 2022 - November 7, 2022
- c. Disability Site: **17 families** - demographics
 - Conducted January 18, 2023 – March 22, 2023

Identities Reported





Note: there were overlapping identities reported by participants and amongst participants in the majority of interviews

How I come to this work

Registered Social Worker (RSW)

Family Caregiver

Chronic Warrior

MSW Student and Researcher



Research on Care

Who receives care?

- Elderly
- People with disabilities/disabled folks or chronic illness (e.g. cancer, MS, dementia)
- Children & Youth*
- People with mental health challenges/mental distress

Paid Caregivers

Family/Informal Caregivers

- Spouses
- Children and grandchildren (youth & adults)
- **“The Sandwich Generation”**
- Friends, neighbours, extended family

How researchers describe care

Negative impact on physical, emotional, mental, social, and financial wellbeing of care provider (Aldridge & Becker, 1996; Chinner et al., 2022; Fortinsky et al., 2013; Gerain & Zech, 2019; Hatton & Emerson, 2009; Kim & Schulz, 2008)

- “Family caregivers for cancer patients experience high levels of stress and burden and diminished quality of life.” (McMillan et al., 2005)
- “Significant personal sacrifices to provide appropriate care for their injured family member.” (Boschen et al., 2007, *as cited in* Chinner, Pauli, & Cruse, 2022, p. 1644)
- “Compared with their non-caregiving peers, caregivers suffer from poorer emotional health, including increased rates of clinical depression and anxiety disorders, and experience loss of personal control over their lives combined with a sense that everyday demands are overwhelming.” (Fortinsky et al., 2013, p. 552)

Increased risk of potential harmful behaviour (Beach et al., 2005; Gerain & Zech, 2022)

How researchers describe care, cont.

Positives:

- **Strengthened relationship** and bonding between provider and recipient (Howson & McKay, 2020)
- Sense of **purpose** and **accomplishment** (Chinner et al., 2022; Gerain & Zech, 2019; Howson & McKay, 2020)
- **“Integral”** to the daily lives of those needing care and the healthcare system (Pristavec & Luth, 2020)
- “Findings indicate that most parents appraised their **QOL positively and reported benefits, despite challenges** they had to negotiate daily.” (Howson & McKay, 2020, p. 306)

Disability Justice - *“Disabled mutual aid sees us as agents and as people who have skills and gifts to offer.”* - Leah Lakshmi Piepzna-Samirinha

Caregiver Burnout Framework

- Care as **unilateral** , **fixed** , and **consistent**
 - *“Research and policy development on ‘carers’ generally has assumed that this social issue concerns a relative where one party, the “carer”, takes responsibility for another, the “dependant.”* (Keith & Morris, 1995)
- Focus on **individual** , rather than structural and systemic factors
- “Caregiver” as an **identity**
 - **Resources**
 - Choice
 - Roles and Responsibilities
- Focus on **negative** implications of care work
- Exclusionary

BUT

What I was reading in the literature did not reflect my experience

For example, my family is a **multigenerational, multidirectional mutual care network that fluctuates** over time.

(Professional example - burnout from pressure/lack of support vs care itself)

This discrepancy between everyday experience and abstract, authoritative discourse can be considered a “**disjuncture**” (Smith, 2005)

This caregiver burnout framework did not fully capture what I was also hearing in interviews with parents.

What Are People Saying About Care Work and Disabilities?

- Care is sometimes described in terms of burnout or burden, but care is also presented as **neutral** or **positive** - *more on this in a bit!*
 - Partnership and collaborative exchanges
 - Negotiations (e.g., “I do this, so they do this.”)
 - Not a major consideration or factor
- Care as **multidirectional** and **fluid** throughout the lifespan
 - Care to children, care for illness/disability, care for caretaker



What people are saying, cont.

- Societal, institutional, and structural factors - *more on this in a bit!*
 - Navigating **healthcare** and **social systems**
 - **Socioeconomic status** and access to **resources**
 - Insurance, private services vs public services
 - Paid work arrangements
 - **Policies** and **funding** constraints
- Impact of the COVID-19 **pandemic** and lockdowns

Discussions about burnout were usually framed in terms of structural factors and inadequate resources



Care as Neutral

“For me, I’ve got a bunch of autoimmune disorders, but they’re all minor so nothing really affects my life much.” - parent with chronic illness and mental health (self and family)

“These are the choices I’ve had to make, because there’s no options for me.” - parent with chronic illness, who provides care for her live -in mother



Care Work as Positive

*S: “[mimicking others] ‘He’s so lucky to have found you guys.’ And we’re like, but **we feel lucky that we found him? Because he’s part of our family.** But a lot of people don’t get that.”*

*M: “So, yeah, a lot of **people are worried on our behalf.** Because of all of the amount of time and, you know, like, medical issues, and everything that comes with them. And we’re like, **that’s just part of who he is.**”*

-2SLGBTQ+ parents with a family where autism, mental health, and disability are present (selves and children), discussing their adopted adult son.



Care Work and Resources

Participant 1: *“You know, some things are more important than our bank account. **So we were willing to spend the money.**”*

Participant 2: *“We also have **very supportive family.**”*

Participant 1: *“Yeah, that helps.”*

- two parents with neurodiversity, chronic illness, and mental health (selves and children)

One participant, when asked how not having private insurance would have impacted his child's diagnosis process, answered that it *“**would have added years, I think.**”*



Lack of Services and Institutional Barriers

“There is literally nothing. You are pushed into the wild and hope for the best.”

-Participant whose spouse sustained a TBI during pandemic lockdowns and works as a nurse.

“We give you meds and we shove you out the door.”

-Parent with a chronic illness and care provider for their parent



Care Work and Neurodiversity

*“Okay, so I’ve got to find the location, and set up a time, and everything on my own? ... And that, **with the ADHD**, and looking back on it, and just, like, **all the extra steps** that ‘okay, here’s the requisition now **you go figure out yourself**’? That, **it takes me a lot longer to do that.** I know places now, I’m getting better at it, but yeah.”*

- Participant with neurodiversity and mental health concerns (self and children)



“What would help? What would make things better?”

Support with household tasks

- Cleaning
- Meal Prep

Many participants expressed a desire for expansion or strengthening

- **Healthcare** systems (particularly **mental health**)
- **Childcare** systems (cost, ratios, availability)
- **Employment** policies (ex: flexible work hours, shorter weeks)
- **Financial** - *“Dual income families should be by option, or by opportunity, but not by necessity.”*



Reimagining
care/work
Policies

Réinventer
les politiques
soins/travail



Key takeaways

Many of us occupy **multiple roles** and social locations that can **change over time**

- Care provider and care recipient
- Professional and personal

If we are explicitly choosing to study caregiver burnout, we are already **making a choice** as to the effects of care and what care is. Care can be positive, neutral, negative, or a blend.

Care can be seen instead as **complex, flexible, and directly impacted by other factors**, particularly structural and systemic constraints and inadequate resources.

If you think you are not currently supporting, teaching, interacting, or researching with disabled folks - think again!

Thank You

Thank you to the funders, participants, RCWP project, and research teams!

To learn more about or connect with us

- [Brianna Urquhart](mailto:brianna@simplysocialwork.ca) - brianna@simplysocialwork.ca | IG @simply_socialwork
- [Meg Gibson](mailto:margaret.gibson@uwaterloo.ca) - margaret.gibson@uwaterloo.ca
- [The Reimagining Care/Work Project](#)
 - To learn more about the Portrait: Doucet & Kloustermann (2023)

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