

Caring for Carers: Exploring the Experiences of Health, Supports, and Services among Caregivers of Children with Disabilities living in Northwestern Ontario



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INTRODUCTION

Caregivers of children with a disability (CCWD) provide long-term unpaid physical, emotional, social, and financial support. High levels of stress, reduced mental and physical health, and a heightened risk for premature mortality are commonly experienced. Programs aimed at attenuating caregiver burden while improving health are lacking.

Disabilities are physical or mental conditions that profoundly limit an individual's ability to carry out normal and routine daily activities:

- **physical disabilities** restricts an individual's physical functioning, mobility, dexterity, and stamina (e.g., amputations, limb disfigurement, muscular dystrophy, acquired spinal injury, and spina bifida).
- **intellectual and developmental disabilities** are neurodevelopmental conditions characterized by significantly impaired intellectual and adaptive functioning, including conceptual, social, and practical skills (e.g., Autism Spectrum disorder, Cerebral Palsy, Down syndrome, Traumatic Brain Injury, and Dyslexia).

Physical limitations may be mitigated with the use of aids, devices, or adaptations, whereas restrictions due to complex conceptual limitations are generally more difficult to overcome due to their conceptual nature.

Caregivers (e.g., parents) assist with the basic tasks of everyday life including activities of daily living (e.g., eating, bathing, dressing, toileting, and transferring). Caregivers of children with disabilities have a heightened risk of developing adverse health conditions due to their dependents unique and chronic long-term care requirements when compared to caregivers of typically functioning children. Caregivers experience unusual levels of chronic stress and have reduced emotional and physical health.

Services available provide caregivers with financial means to enable children and youth to access community services while also providing caregivers with an avenue for respite services. Caregivers report a variety and vast number of overall health conditions suggesting a greater breadth of supports are needed

PURPOSE

The study purpose was to conduct an exploratory needs assessment among CCWDs to determine challenges faced and what is valued regarding supports, in order to develop a caregiver-focused intervention.



METHOD

Ten CCWDs (9 mothers, 1 father) participated in a semi-structured focus group or one-on-one interview. Each session was transcribed verbatim, removing personally identifying information.



Inductive content analysis was applied to the transcriptions identifying barriers and facilitators to caregiving practices and optimizing personal caregiver health while uncovering unmet needs as they relate to service provision.

Strategies used to enhance **trustworthiness** include member checking (e.g., paraphrasing and summarizing), session debriefs between researchers, and having two researchers complete independent analysis confirming qualitative coding.

RESULTS

3 x Focus Groups (N = 4, 2, 2 [N = 8])
2 x One-on-one Interviews (N = 2)

Participant demographic information was captured for nine participants:

	Min	Max	M	SD
Age (Years)	40	56	48.4	5.5
Number of Children	1	3	2.1	0.78
Length providing care (Years)	12	25	19.3	4.4
Health Ins - Caregiver (Y/N)			78%	0.44
Health Ins - Child (Y/N)			89%	0.33
Disability Severity Rating	1	3	2.2	0.33

Caregiving

Facilitators

- **Family & Natural Support Systems**
"What family we do have they are always willing to help out." (Participant 2)
"I have my [partner], which helps me a lot, because when I do become overwhelmed, I just tell him 'it's your turn to take over.'" (Participant 10)
- **Technology**
"The internet is a big thing now, lots of research to be done, lots of cat videos to be watched." (Participant 5)
"We go out, [she] has her hub, and she has her tablets. ... No matter where we go ... she's going to sit there, calmly, for as long as I want her to." (Participant 6)

Barriers

- **Social Isolation**
"You feel like you don't fit in with anybody." (Participant 4)
"Finding authentic connections when you do have a child with needs is just difficult." (Participant 5)
- **Challenging Expertise**
"They were like 'that's impossible because he seems so typical and high functioning'. ... even though I brought them the whole freaking report." (Participant 7)

Health

Facilitators

- **Positive Health Behaviours**
"Sometimes you [use] those respite hours just to have a nap." (Participant 5)
"We are trying to make a point of getting out a little more now. ... We need to get out, just together, my husband and I." (Participant 2)
- **Social Support System**
"I have some pretty funny friends, or if we have an opportunity to go out ... and share some good laughs, um, that's extremely helpful." (Participant 2)

Barriers

- **Prioritization & Feelings of Guilt**
"I felt so guilty because I had to take the time for myself." (Participant 4)
- **Severity of Disability**
"[Wife] never of other ... Whether it's five minutes, ten minutes ... my son can not be left alone ever. Like, he is a twenty-four seven." (Participant 1)

Services

Facilitators

- **Caregiver Support & Control**
"People want to go and feel like they belong and feel like their not being judged." (Participant 5)

Barriers

- **Ageing Out & Loss/Removal of Existing Services**
"They kept on asking you questions [like], 'So, typically, what would an 18-year-old be doing, and what would he have to do to be like that 18-year-old?' and I'm like 'how the hell do I know?', like, I don't have another 18-year-old." (Participant 1)
- **Paperwork & Case Management**
"For others I know [paperwork] is a bottle neck, because you get this stack of papers and then they just sit on top of your fridge, for like a good year and a half, two years, before you get to them because you're just so overwhelmed with everything." (Participant 7)
- **Lack of Communication**
"You're on this waitlist for infinity, until whenever they decide to like 'bloop', ... you have been granted the golden ticket and you get to move forward with your child's life." (Participant 8)

DISCUSSION & CONCLUSION

Overall, caregivers described their days as routine, combined with accepting the unknown.

Caregiving was explained by many as "it's just what we do" whereby the child's needs always come first; prioritizing personal health was equated with guilt.

A strongly developed support network was identified as important to alleviate caregiver burden. Yet, social isolation was discussed often due to the difficulty of maintaining friendships.

Personal health was characterized as poor to good, and experiences of debilitating and chronic physical and mental health conditions were shared.

Caregivers agreed that future programming for CCWDs (e.g., family centred case management) and individual supports (e.g., Co-Active life coaching) could increase caregiver effectiveness and help reduce chronic stress.

These findings highlight the unique challenges that CCWDs face along with specific recommendations for intervention. Future caregiver-focused research aimed at providing support while mitigating gaps in service should be developed.

Given that the health of children is inextricably linked to that of their caregivers', identifying avenues to foster health and wellness in this population is imperative.