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THE MEANING OF CARE AND CARE WORK IN NUNAVUT

A CROSS-TERRITORY EXPLORATION OF HOW NUNAVUMMIUT CARE
FOR EACH OTHER AND WHAT THE FUTURE OF CARE COULD BE

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EXECUTIVE SUMMARY

Nunavummi Disabilities Makinnasuaqtiit Society (NDMS) is the only Inuit cross-disability organization in Nunavut. We have undertaken a comprehensive study to assess the state of caregiving practices and support services for individuals with disabilities in Nunavut. This report synthesizes insights from community members, examines current challenges, and proposes recommendations for improving care and support systems in the territory.

About Disability

In Nunavut, the definition of disability includes a broad spectrum of physical and mental conditions, such as mobility impairments, sensory impairments, mental health disorders, substance use disorders, and developmental disabilities like Fetal Alcohol Spectrum Disorder (FASD). The prevalence of disabilities is increasing due to demographic shifts, expanded legal definitions, and improved diagnostic capabilities. Statistics Canada and McGill University suggest that disability rates, particularly among Indigenous populations, are higher than the national average. The aging population further contributes to this increase, as disability prevalence tends to rise with age. The Nunavut Human Rights Act recognizes these diverse conditions, including dependencies on alcohol or drugs and trauma. Consequently, we often estimate that approximately 80 to 90% of the population faces some form of disability or barrier.

It's important to note that the concept of disability, as defined in Western contexts, does not fully align with the Inuit worldview. Traditionally, Inuit society did not classify individuals as disabled; instead, everyone contributed to the community according to their abilities. Modern definitions and services often impose Western frameworks, leading to cultural dissonance and the assimilation of Inuit into Western practices. This misalignment can erode the strengths of traditional interdependency within Inuit communities and significantly impacts the understanding and practice of care and caregiving for people with disabilities.

The Meaning of Care

The essence of care and caregiving in the Inuit context is deeply intertwined with traditional values and practices, as reflected in the concept of Inuit Qaujimajatuqangit (IQ). Inuit Qaujimajatuqangit, translating roughly to “what Inuit have always known to be true,” is a broad term encompassing the complex cultural values, societal norms, and technologies of the Inuit.¹ Inuit caregiving traditions emphasize transmitting knowledge and wisdom across generations, embodying a holistic approach to nurturing individuals within the community. While specific research on caregiving for Nunavummiut with disabilities may be limited, insights from Shirley Tagalik's work on caring for children the Inuit way, sheds light on the profound significance of

¹ *Inuit Qaujimajatuqangit*. Government of Nunavut. (n.d.). <https://www.gov.nu.ca/en/culture-language-heritage-and-art/inuit-qaujimajatuqangit>

care within Inuit cultural frameworks. Tagalik's (2009)² exploration underscores the pivotal role of grandparents and Elders in imparting essential social and cultural teachings to children, viewing this process as not merely a temporary duty but a lifelong commitment crucial for survival and cultural identity. Central to this perspective is the belief that children carry the essence of their namesakes, emphasizing the importance of honouring and preserving their inherent qualities. As such, the dynamic between caregivers and recipients of care can be characterized by a reciprocal relationship grounded in mutual respect and shared learning, a stark departure from Western paradigms of dependency that may undermine the traditional Inuit values of interdependency.

Drawing from Tagalik's (2009) insights on Inuit caregiving practices, applying these principles to care for individuals with disabilities offers profound implications for enhancing support and fostering well-being. By embracing the values of individuality, cultural sensitivity, interdependency, and collaborative learning partnerships within the context of caregiving, the Inuit approach to care transcends mere assistance to embody a profound connection to heritage, community, and identity. This holistic understanding of care underscores the importance of nurturing the whole person and acknowledging their unique strengths, needs, and cultural background. By upholding these values in caregiving practices, individuals with disabilities are supported in a manner that respects their autonomy and dignity and is also enveloped in a web of relationships that promote belonging, empowerment, and cultural continuity. The Inuit perspective on care challenges conventional notions of dependency by emphasizing the strength of interconnectedness and mutual support within the community, fostering a sense of collective responsibility and shared well-being. Through the lens of learning, partnerships and reciprocal respect, the Inuit approach to caregiving embodies a profound philosophy that transcends mere assistance to encompass a holistic, culturally grounded expression of compassion, respect, and interconnectedness.

Conclusion

While traditional Inuit values provide a strong foundation for caregiving in Nunavut, there is a pressing need for systemic changes to enhance support services and promote the well-being of individuals with disabilities and their families. By prioritizing community engagement, cultural relevance, and intergenerational knowledge sharing, Nunavut can work towards building a more inclusive and resilient caregiving ecosystem. This approach honours the region's rich cultural heritage while addressing the evolving needs of its residents, ensuring that care practices are both effective and culturally respectful.

² Tagalik, S. (2009). Inunnguiniq: Caring for children the Inuit way. Child & Youth Health, National Collaborating Centre for Aboriginal Health.

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We would like to specifically acknowledge **The Canadian Centre for Caregiving Excellence** for their support and collaboration on this report. Their commitment to supporting quality care in Canada and ensuring that caregiving is valued has provided a supportive framework for this study and future advocacy that will come from it.

THE MEANING OF CARE AND CARE WORK IN NUNAVUT

The dynamics of care and caregiving in Nunavut represent a complex interplay of Inuit societal values, socio-economic pressures, and the challenges faced by remote communities. Understanding the meaning of care in Nunavut requires a deep recognition of Inuit culture and the role of family, community, and leadership. This report will explore the insights on care offered by more than 540 individuals from across the territory who participated in a study from 2021 to 2024. Through interviews and focus groups, Nunavummiut shared what care means to them, what they want to see to create a more care-friendly Nunavut, and how Inuit culture is central to understanding care in families and communities in the north.

ABOUT NUNAVUT

Nunavut is a remote arctic territory comprised of 25 fly-in communities. Despite its vast geographical expanse, Nunavut sustains a relatively small population, with over 36,000 Nunavummiut (residents of Nunavut) inhabiting the region. Of this population, 84% identify as Inuk (Inuit).

According to Statistics Canada's most recent survey on disability (released in 2024), 4,640 Nunavummiut over the age of 15 identify as having a disability.³ However, due to the stigma around disability and the hesitancy of people to identify with that term, it is speculated that the actual number of Nunavummiut experiencing disability is likely much higher. The Nunavut Bureau of Statistics compiles the number of people receiving disability benefits or credits in any given year. In 2005, there were 450 people in Nunavut receiving disability credits or benefits from the Government of Nunavut; by 2018, this number had increased to 670 people.⁴

There are an estimated 1,645 seniors aged 65 and over in Nunavut⁵. The territory currently has three long-term care homes, with 28 beds providing high-level care to seniors and individuals with disabilities.⁶ Waiting lists for these facilities are long, and many Nunavummiut opt to leave the territory to access care facilities in Ontario or Manitoba.

³ Statistics Canada. [Table 13-10-0375-01 Severity of disability for persons with disabilities aged 15 years and over, by age group and gender](#)

⁴ Nunavut Bureau of Statistics. 2020. Number of Persons Receiving Disability Benefits 1999-2018 [Excel File]. Retrieved from: <https://www.gov.nu.ca/en/nunavut-statistics>

⁵ Statistics Canada. 2024. (table). *Special Interest Profile*. 2021 Census of Population. Statistics Canada Catalogue no. 98-26-00092021001. Ottawa. Released March 20, 2024. <https://www12.statcan.gc.ca/census-recensement/2021/dp-pd/sip/index.cfm?Lang=E> (accessed April 29, 2024).

⁶ Grant, K. (2022, January 21). No place to grow old. *www.Theglobeandmail.Com*. Retrieved April 29, 2024, from <https://www.theglobeandmail.com/canada/article-how-elders-from-nunavut-end-up-in-long-term-care-thousands-of/>.

ABOUT THIS STUDY

The insights explored in this report emerged from a larger, cross-territorial study exploring the experiences of Nunavummiut living with disabilities and their family members. Through community-based data collection, care emerged as one of the most important topics for Nunavummiut.

A bit about our study:

- Over three years, we visited all 25 communities and spoke to **543** Nunavummiut about accessibility, services, and care
- Conversations occurred in groups (group interviews) and one-on-one interviews
- We spoke to Nunavummiut aged 18-88, of all genders
- 88% of our participants identified as Inuk (Inuit)

Care was a topic of concern in **182** out of 247 group interviews and individual interviews, representing **74%** of the total discussions. Care is one of the most pressing areas of concern for participants, comparable to transportation (81%) and community-based programs and services for people with disabilities (79%).

This report will explore what care means to Nunavummiut - to those who receive and provide care. We will discuss how care is understood through the lens of Inuit Qaujimajatuqangit (IQ), which roughly translates to “what the Inuit have always known to be true.”⁷ IQ is a broad term encompassing the complex and varied cultural values, societal norms, and technologies of the Inuit. Inuit Qaujimajatuqangit is central to understanding the importance and meaning of care in Nunavut. It is the cultural underpinning of families and communities. It shapes how community members view the meaning of care and what resources, supports, and programming they wish to see in their communities.

As this study seeks to amplify the voices of Nunavummiut, this report will feature many quotations from the over 500 Nunavummiut who took the time to share their insights and wisdom.

METHOD

This study is grounded in community-based research methodology. All research activities were undertaken by Nunavummi Disabilities Makinnasuaqtiit Society (NDMS), a community-based organization in Nunavut, with a board of directors made up of representatives from the Inuit

⁷ *Inuit Qaujimajatuqangit*. Government of Nunavut. (n.d.). <https://www.gov.nu.ca/en/culture-language-heritage-and-art/inuit-qaujimajatuqangit>

organizations.⁸ The project also utilizes the Piliriqatigiinni research model⁹, a research framework developed in Nunavut that centers Inuit knowledge and values in responsive, participatory research. Central to this model is the integration of Inuit Qaujimagatuqangit (IQ), which includes traditional Inuit knowledge and cultural practices, ensuring that research respects and incorporates Inuit ways of knowing and being. The Piliriqatigiinni model promotes a collaborative approach where researchers and community members work together as equal partners, making decisions collectively and maintaining transparency and inclusivity throughout the research process (Healey & Tagak, 2014). This project seeks to centre the voices and concerns of Nunavummiut as they relate to care and caregiving in the north. At all stages, this research project has sought to be informed by community members and be responsive to feedback from communities on how to best engage and be informed by Nunavummiut on the topic of care.

This project was authorized by the Nunavut Research Institute (NRI)¹⁰, which provides ethical oversight to research in health, social sciences and the physical/natural sciences in Nunavut¹¹. An advisory committee of 20 members representing all three regions of Nunavut also oversaw project activities.

The project included participants from all 25 Nunavut communities, from ages 18 to 88. We spoke with respondents living with a disability and receiving care, and those who provide care. Participants were invited to join the research team for a group interview (group discussions of 4-25 people) or one-on-one interviews. Participants were recruited through a variety of methods appropriate for the remote context. Postings on social media, including Facebook and Instagram, were important in getting the word out. Radio was also utilized to inform community members about the project and how they could participate. Interviews were held both virtually and in person. Transcripts were transcribed, and all identifying information was removed. Transcripts were then coded for themes relating to care and Inuit Societal values.

The following paper discusses the general themes explored in our conversations with Nunavummiut about what care means to them, what they need in their communities to provide good care, and how culture impacts the importance and centrality of care in their lives.

⁸ *About NTI*. Nunavut Tunngavik Inc. (2017, June 7). <https://www.tunngavik.com/about/>

⁹ Healy, G., & Tagak Sr., A. (2014). PILIRIQATIGIINNIQ 'Working in a collaborative way for the common good': A perspective on the space where health research methodology and Inuit epistemology come together. *International Journal of Critical Indigenous Studies*, 7(1), 1-14.

¹⁰ *Nunavut Research Institute (NRI)*. Nunavut Research Institute. (n.d.). <https://www.nri.nu.ca/>

¹¹ *Nunavut Research Institute (NRI)*. Nunavut Research Institute. (n.d.). <https://www.nri.nu.ca/>

WHAT CARE MEANS TO NUNAVUMMIUT

CARE IS HELP... AND RESPECT

The most common word in discussions of care was “help.” Care is gentle assistance for those who need a bit of support. Care rarely came up as an identity or ideology - it was simply providing help in instances of daily life where help was needed. Household tasks like cooking, cleaning, and bathing were commonly discussed.

“Oh, it means a lot of help to me since they can help me, that I cannot do. Caring is helping other people because they are your neighbours or because they just need help.”

“Like helping with cleaning around the house or help the person with disability with medications and something like that.”

In addition, care was viewed as help that was provided because it was needed. There was an expectation that one might anticipate the support required by another and provide it simply because it is needed. It is important to note that for many participants in this study, the terms caregiver and care recipient were not rigid identities but more reflected states of being. Anyone can give and receive care, and participants in this study spoke about their experiences from both vantage points.

Many respondents avoided all-encompassing perspectives on care. Few spoke about care requiring extensive time and energy (although some respondents did experience this) instead, care was often regarded as simply helping out in small ways.

“Caregiving just simply means that you're not holding their hand, but you are listening to them and recognizing that they can't get to the store very easily. So we can provide transportation.”

“It really depends how that individual is handling things. Right? Because at the end of the day, anybody with a mental illness, it's their struggle and we're just there to support them. But we are only playing this much of a role in their life. They're the one doing the mean struggle. So how it feels for us, I think it's very secondary because it's basically how they're doing with their medication.”

“When I used to help my parents, my hubby. I just let them know. I'm just being an extra arm.”

Participants valued maintaining autonomy and identity. Caregivers are invested in ensuring that loved ones know they have value and are in charge of their own lives.

“I have a daughter who has disability. She gets so focused now with our support and love that she can make it, make things like clothes, winter clothing and through the learning programs and so forth she was successful. She's able to create something that is for her own, for herself and her own family and even also, you know, gifts to some of her siblings and so forth. So that makes her who she is, our heart is happy and her heart for sure.”

“That happened with my grandfather too when he had cancer. He knew how his body was failing, and he did everything he could to walk around the house and do stuff. Put popcorn in the microwave for the kids. Ask for help, but he wants to do it himself.

“But what I’m basically saying, is, we do it for ourselves and this community, we do it for an Elder or someone who is sick, we always make sure that they’re happy. And it’s kind of another accessibility issue where we’re just like, no it’s not what we want, (it)’s what you want.

Recipients of care are also concerned with autonomy and independence. They spoke about finding ways to contribute to their households and care for themselves within their capacities. This is closely linked to the concept of *Qanuqtuurniq* (being innovative and resourceful)¹², an Inuit societal value that is many participants demonstrated. *Qanuqtuurniq* reflects the idea of providing practical assistance and support to others in ways that are responsive to their needs and circumstances. This value encourages individuals to find creative solutions to challenges and to offer help in whatever ways are most beneficial and appropriate. Just as caregivers in the quote provide gentle assistance with household tasks and daily activities, they demonstrate the value of *Qanuqtuurniq* by finding practical ways to support those in need within their communities.

A few respondents also spoke about refusing care and stressed their abilities and self-sufficiency. By expressing a strong inclination towards self-sufficiency, these individuals underscore the significance of autonomy and independence in their perception of care. Their refusal of offered assistance highlights a deep-seated desire to maintain control over their lives and daily activities despite potential challenges or limitations. This insistence on managing tasks independently reflects a broader cultural value placed on individual agency and resilience. Thus, the narratives of participants who refuse care offer valuable insights into the nuanced dynamics of caregiving, emphasizing the importance of understanding and respecting individual preferences and values providing care within the community.

Interpreter: “But because she’s active, so that’s why she declined (homecare).”

Researcher: “How about homecare? Do you get any homecare support?”

Participant: “Nope.”

Researcher: “Would you like that?”

Participant: “No.”

Researcher: “No? Okay. What about things like a meal service or anything like that?”

Participant: “No.”

Researcher: “You prefer to be independent? Okay.”

Participant: “I do it myself so I need to exercise more.”

Researcher: “Okay, So you would prefer maybe more like, financial support so you can take care of yourself? But a little easier?”

Participant: “That’s the problem for me.”

Researcher: “Yeah?”

Participant: “Big time.”

¹² *Inuit societal values*. Government of Nunavut. (n.d.-b). <https://www.gov.nu.ca/en/culture-language-heritage-and-art/inuit-societal-values>

For some, accepting care, especially from professionals, is wrapped up in cultural changes resulting from colonization. Several elderly respondents spoke about disability not existing in communities before permanent settlements. Although we cannot be certain from these exchanges alone, we might assume that disability was present but may not have been viewed in the same way. Communities would focus on ways individuals contribute to community life, so the concept of disability may not have been as salient. Also, when considering substance use and addiction as a category of disability, these impacts would be seen exclusively as a result of colonial contact.

“Back then they didn't have a helper or caregiver. They mostly did themselves, those who have disabilities because they were part of the community. Right now, we have a helper or there's a caregiver. Right now, is much easier but we also need it because this life now is different. Now, nowadays it's much easier those who have a disabilities because there is some things to help them but they also have disability because they are addicted to bad things now that we didn't have before.”

As a result, current ideas about disability, care, and assistance may be more closely tied to contemporary life in Nunavut, particularly for Elders.

Importantly, care is not confined to rigid roles but reflects a fluid exchange between caregivers and care recipients, emphasizing the reciprocal nature of assistance within the community. Participants prioritize maintaining autonomy and identity, ensuring loved ones are empowered to lead fulfilling lives despite challenges. This sentiment aligns with the Inuit societal value of Qanuqtuurniq, emphasizing resourcefulness and adaptability in caregiving practices. Further, the reluctance of some individuals to accept professional care reflects broader cultural shifts resulting from colonization, highlighting the evolving perceptions of disability and assistance within Nunavut communities. Overall, care in Nunavut encompasses practical support and a profound sense of respect for individual autonomy and resilience in the face of adversity.

CARE IS LOVE

Unsurprisingly, care was also most closely associated with the word “love.” For many respondents, care is an expression of love. In this respect, care is offered thoughtfully and gently. It is responsive and doesn't necessarily follow schedules or regimes. Care, as an expression of love and centers the care recipient. It is thoughtful and patient. It understands that the recipient is deeply affected by the act of caring and seeks to preserve dignity and autonomy.

“Caregiving means providing support and assistance to those who need it, whether it's at work or with family members at home. It involves understanding their needs and helping them at their own pace. It's about love in every way.”

“Like, care and caregiving is different. Care is like, deeper. It's love and it includes everything, and caregiving might be like, actively doing something like feeding someone or bringing them somewhere. In our family care is about everyday life. It's the same as loving someone, and the community, and our neighbours.”

Care is also an act of love that is reciprocal, not unidirectional. It strengthens bonds between family, between generations, and within communities.

“The caregiver, it's mean to me, they help Elders and take care of Elders at their place. It's how we show love and respect. Elders teach us their wisdom, and we look after them as they age. Parents raise the next generation, and neighbors help like extended family. It's about being together and making sure no one is left behind. And help others if they need a hand, like they go to the Elders and help with their hands and heart. It's about family and community coming together. It's taking care of our Elders, our children, and each other. We share food, stories, and help with daily life. It's not just a duty it's a bond that keeps us strong.”

Care can also be conceptualized as an act of cultural expression and resilience. It can be expressed through sharing food or stories, spending time with one another and passing on traditional knowledge.

“Caregiver means someone who helps and cares for family and community. It's like a warm, strong bond, like family and friends coming together, together, for each other. Caregiver means taking care of Elders, children, and each other, and it can mean passing down traditions, sharing food, and stories. It's not just work; it's love and respect, a way of life that makes us so strong and connected.”

“Yeah, like it's very cultural. Yeah, people go out on the land for some funeral and give out traditional food and what not. That's what we've been doing too. Yeah. We just help and love our family. Caring is helping and love.”

“We need knowledge passed down from our Elders and our families, knowing the ways to help. And we do, we need resources, like warm shelter and healthy food. We have to have the support from family and neighbors, like a strong community group. Also, our language and culture, they guide us in providing care with heart and respect. So, it's about knowing, resources, support, and our culture, all together to give good care.”

Participants were often very proud of the care that they saw being provided by their families and community. Providing and watching out for one another was a sign of how strong communities are and the deep connections that people have with one another.

The narratives shared by participants underscore the intimate relationship between care and love within Inuit communities. Care isn't perceived as just a duty but as a profound expression of affection and empathy. Participants describe care as a manifestation of love, characterized by thoughtful consideration and responsiveness to the recipient's needs, transcending simple assistance to embody a deeply felt connection. This understanding extends beyond immediate family circles to include broader community bonds, illustrating caregiving's reciprocal nature and communal support networks' centrality. Further, care is recognized as a cultural expression and act of resilience, including the sharing of traditional knowledge, stories, and resources within the community. The sense of pride expressed by participants in the care provided by their families and communities speaks to the strength of these connections, affirming the fundamental role of caregiving in fostering and preserving the fabric of Inuit life.

ENSURING ELDERS FEEL SPECIAL

Care as it relates to Elders is about demonstrating respect for the important role that Elders hold in their families and communities. They are the bearers of traditional knowledge and connect young people with their history and culture. Many respondents spoke about the importance of these relationships. Maintaining connections between Elders and youth was stressed by many as critical.

"As you can see, caregiving is a big part of our lives here. We take care of each other, especially our Elders, as it's something we've always done. It's about showing respect and gratitude for their knowledge and guidance. Our Elders hold a wealth of knowledge about our traditions, language, and ways of living that we want to preserve and pass on to the next generation. Caregiving is not just a duty to us, it's an expression of our cultural values and our connections to each other, even as a community."

Many respondents expressed that what was most important to them in the delivery of care was that Elders felt special. Caregivers wanted to ensure that Elders understand their place of importance in their families and communities and that the care they receive reflects that importance.

"Elders need to feel special."

"Taking care of others is really important because it's all about showing respect and making them feel special and it's like, it means helping them with whatever they need to be happy and comfortable. We spend time with them and show them love, and make sure they know they're valued to us and the community too."

"Oh, it, it, whenever I take care of someone, it feels like the, I'm making them proud for taking care of them or what, something like that... make them feel that they're safe, and... they don't need to worry about anything."

In Inuit culture, Elders are highly revered not only for their wisdom and experience but also as the keepers of traditional knowledge, language, and cultural practices. They play a crucial role in teaching and guiding younger generations, ensuring the survival and continuity of Inuit heritage. This deep respect for Elders is woven into the fabric of daily life, influencing how care is provided and received.

As an extension, many respondents wanted to see improved programs and services for Elders, including transportation, comfortable gathering spaces, and activities created specifically for their needs. In addition, participants wanted to see more opportunities for Elders to be spotlighted, and for their stories to be heard.

CARE AND THE LAND

For Nunavummiut, discussions about care also include the importance of caring for the land. Caring for the land is about showing respect and gratitude for all that the environment provides. It is not only about caring for the land as a living being but also about preserving the environment for future generations. This perspective is tightly linked to the cultural emphasis

on respect and love for one another. As values, care for the person and care for the environment are interchangeable.

"It's not just about helping Elders with their stuff or spending time with them. It's also like respecting their knowledge and experience. And this, also caregiving isn't just about people it's about the land too if that makes sense. Because the land is important for healing. It's like a way of caregiving too, because like we're making sure it stays healthy for the future so everyone can use it. It's like we're giving back to the land for what it gives to us you know? And when we take care of the land we're also taking care of each other because we all rely on it for like, food and stuff. So yeah caregiving is like everywhere. It's all about looking out for each other like, it's our Elders and the environment. We need to show love and respect in everything we do, you know what I mean?"

"Caregiving is really, it's about showing love and respect to people we love and even to the land."

Respect and care for the land are represented by the Inuit societal value of *Avatittinnik Kamatsiarniq*, "respect and care for the land, animals and environment."¹³ The predisposition to express love as respect also instills a deep respect for the land. Participants expressed an appreciation and respect for the land's harsh conditions and its ability to provide for them. As such, Inuit caregiving practices reflect a holistic understanding of care that encompasses not only individuals but also the environment. The care provided to Elders, for instance, is intertwined with the respect and knowledge of the land. Elders, as bearers of traditional knowledge, often teach younger generations about sustainable practices, emphasizing the importance of *Avatittinnik Kamatsiarniq*. This transmission of knowledge is a form of caregiving that preserves cultural heritage and ensures that communities remain resilient and self-sufficient.

IT IS WHAT WE DO

For many Nunavummiut, care is simply what communities do. It is integral to who we are, represented by the value of *Inuuqatigiitsiarniq*, "respecting others, relationships, and caring for people."¹⁴ It does not need to be prescribed or ordered. It is part of how communities naturally function.

"Care is normal, we care for everyone and our family. We care for everything around us and the land, like being on the land. It is all connected."

"Caregiving is like, kind of expressing that compassion too, like putting their needs above your own sometimes. It's almost like just a natural thing we don't really know we are doing it, I think."

In many interviews, care is described as a normal outcome of daily life rather than a set of tasks that need to be accomplished. Several participants connect this to Inuit culture and how Inuit

¹³ *Inuit societal values*. Government of Nunavut. (n.d.-b). <https://www.gov.nu.ca/en/culture-language-heritage-and-art/inuit-societal-values>

¹⁴ *Inuit societal values*. Government of Nunavut. (n.d.-b). <https://www.gov.nu.ca/en/culture-language-heritage-and-art/inuit-societal-values>

communities inherently make sacrifices for each other and watch out for each other's well-being.

"It, it is normal everyday. We care for everyone and everything."

"Taking care of my family is my responsibility, that's how I see it. Like it was my dad before he died and before him my granddad. I think we all do caregiving to ourself and the family and like (name redacted), said the land and animals too. We have to be very dedicated to their well-being, especially those who need extra help and to care for everything but it sounds like work and sometimes it's work and hard but the caregiving in our way it's like it flows back and forth and between us almost like it's a way of just living here. But we get that confused with caregiving as a job or something that's hard or physical but it's not always that."

"Well here families will do anything for each other. Like a lot of, a lot of out there, a lot of things out there. They will say I will do anything for you and but when when push comes to shove, they're not. It's kind of felt everytime. But in Inuit, when an Inuk says that they mean it, they live it to a fault. They will risk their lives trying to protect you, trying to save you, trying to do something you need done. We do take a little more serious than the average Joe. You say I'll do anything for you and then a day later, hey I need this and he's like hmm, I can't help you right now. It's just weird to a lot of people."

Care is a responsibility, and it is not to be taken lightly. As mentioned previously, many participants spoke about care as the force that builds communities and keeps them strong.

"It's important because it helps us build stronger relationships and makes our community a nicer place to be when we help other people. Taking care of each people is what makes us a community you know?"

For many, care is integral to community cohesion and resilience. This might explain why some participants seemed resistant to care support that originates from outside of the community. Homecare or health services delivered by non-Nunavummiut (often on short-term contracts) may be seen as eroding the networks of care that keep communities strong.

This deep sense of responsibility and interconnectedness in caregiving reflects the broader values of Inuit culture, where community well-being and collective care are paramount. These services must align with and support the existing community structures rather than replace or undermine them. Caregiving in Nunavut is not just about attending to immediate needs; it is about preserving the fabric of the community, maintaining cultural integrity, and ensuring that care remains a natural and respected part of daily life.

CARE AND THE FAMILY

ALL MEMBERS PARTICIPATE

Most Nunavummiut spoke about care as it takes place within the family. For many participants in this study, care is often the family's responsibility. Care is what family does - we care for each other and prioritize each other's needs and comforts. Several participants eschewed

professional support, like homecare, stating that this type of support was not required because these tasks should fall to family.

"We are nine people. My kids and I have a daughter-in-law. They all help me clean up my house. They are my helpers in my home. They are my caregiving. We don't need any institution for caregiving only when we need help with healthcare or more medical."

"I have a lot of kids. They help."

Interpreter: "That's where she used to get help from the home care workers, but she's the one who asked them to stop because she's active and because she's got adult children that can do the house chores for them to keep busy."

"Sometimes it gets pretty hard just to watch that person needs the help and these days they do have to pay in order to be helped. And I don't like that because they got family and grandchildren, great grandchildren that are able to help but nowadays they have to pay."

Respondents described providing many kinds of care for family members, including cleaning, cooking, bringing groceries and supplies, managing appointments, administering medications, and providing company.

"Uh, actually, no, um, yeah, that would, you know, just to check up on my mom. But I do a lot of cooking, I do a lot of cooking at home for her, so. The kids and, ready for me to go home so I can, you know, help her with my meals, I cook, so. I like cooking. I'm good at it."

"And so, when I'm home, I help her out. I do the dishes or do the floors, and whatnot. And I have a little brother that's staying with them right now. So, when I get home, he's gonna have free time, so."

Family tends to balance care responsibilities across siblings or generations when possible, and surprisingly, men and women appeared to participate in care work equally. Men were no less likely to participate in care activities, and many participants described receiving care from male relatives.

"But we take turns going over there."

"Yes. Even though they're all males. But they're taking their part looking after Anaana (mother) well enough."

Children also actively participate in caregiving, and many respondents described learning about care at a young age.

"I started babysitting her when I was ten... When she finally started coming back and my mom would leave me with her, a good half an hour to see if I'm a good babysitter or not. Like, I had to start at a young age because she was my sister, and I couldn't just watch my mother do it all alone."

"Oh, boy. Well, I started very young age, taking care of people with disabilities. And now two of my children have mental disabilities. And I've worked at the (place) from before, with mental disabilities."

And, of course, not all people have family they can depend on. Several respondents cited concerns for community members without family in a position to provide care. In these instances, a call for more community support was seen as the solution.

"In some ways that will be up to each individual family members if the person who disability have family members. But at the same time, there are the ones, some of the ones that I know who don't seem to get the support that they need from their own family members, though. So they have to end up reaching out to extended family members. I think for this one, I think the whole community somehow needs to come together about this one and then make improvements where improvement is needed. That's one thing that I could think of right now to respond to that."

Participants acknowledge that families are sometimes under pressure and living with limited resources themselves. They may not always be able to meet their family member's needs.

"Well, that's very important, they care, uhm people volunteer to take care of your family is very good. Uhm that doesn't always happen, but is, is sometimes happens. Uhh, when you have to take care of a family member sometimes you have to deny, sometimes you don't. Sometimes the reason why you deny not wanting to take care of your family member is because you know the person or something like that. Or, you know, we say yes or no. So it really, depending on the uhm what situation is, you know, uhm there may be a very urgent matter why you need to take care of your family, maybe losing a family member or anything like that. Um there may be urgent matter because your family member is in trouble with the law or anything like that. Well, I was in trouble so sometimes it's really hard for family members not to say no, or to say no when they're asked to take care of their family because there are few reasons, one lack of, lack of space in the house, shortage of housing within the community. So there is sometimes you have no choice to say no because you are living in the three bedroom with a 12 people in the family who is living with you."

Indeed, many participants noted that improved infrastructure in areas such as housing, transportation, mental health, and medical services would significantly improve the ability of families to support themselves. Participants also emphasized the need for culturally relevant support services that align with Inuit values and traditions. Access to resources that understand and respect their way of life would ease the burden on families and reinforce the community's resilience and interconnectedness.

CARE IS ABOUT GOOD MENTAL HEALTH, FOR EVERYONE

Participants acknowledge that providing care for a family member(s) is a lot of work and can be physically and emotionally demanding. Many respondents spoke about the dichotomy between care being physically and mentally taxing while also being deeply rewarding.

"A lot of responsibility and I don't know. Yeah, just a lot."

"Like, caregiving is like, it's beautiful at the same time, it's also tiring. But it's spiritual and spiritually fulfilling."

"It makes me feel like, it makes me happy. And I feel useful for something."

Participants highlighted that providing good care was just as much about mental health and well-being as it is about physical care. The need for emotional support extends to everyone, to care recipients and caregivers alike. As respondents shared, care is about creating safe, comfortable spaces for everyone.

"It means taking care of the person not only physically, but mentally as well. And at the same time if you are doing that, you also have to seek uh, therapy because you do need that help to release emotions you will get and mental strains you will associate with caregiver."

"Caregiving isn't just about one person though it's about helping anyone who needs it. It's a part of our everyday lives, you know? We don't just focus on what the person needs like physical stuff because we also care about how they feel and making sure they're okay emotionally too. It's like creating a safe environment for people."

Care recipients acknowledge the importance of emotional support in building their own resilience. Being cared for gives people strength. Care tells them that they are valued and that those around them empathize with them and care about how they are feeling.

"For me, disability is a big part of who I am and my story. It made me who I am. I had trouble thinking and a brain tumor when I was young. But I'm lucky because my family loves me a lot and took care of me the whole way. My family always loved and helped me a lot, which made it easier to deal with my disability."

"Um, actions, I guess, would be one way. Um, you know, like I just mentioned, they're willing to help me out when I need physical supports. Um, emotional, there's a lot of emotional support, just not being afraid of, you know, "oh, how are you doing (name redacted)? So but like, "hey, what's up?" Tell me your deepest, darkest secrets and, like, just being, um, yeah. And just people see what needs to, how I need help, and they just do it without asking any other questions."

Participants also spoke about complex feelings and complex family dynamics. The severe stress that many are facing can strain relationships.

"I became close to my family but to a certain stages I was going through it myself, was going through a lot of mixed emotion and anger, I burned the bridge to my family that I was helping me because I'm dealing with this acceptance of the the cane and the hunting I used to do the cooking and the working, I think it got the best of me or I push every body away."

For many caregivers, meeting people where they are at, respecting their autonomy and letting them set the pace was critical to providing care that also supported mental health and resilience. As mentioned above, autonomy is very important for Nunavummiut's feelings of self-worth. As such, an approach to care that values and centres autonomy is crucial to cultivating good mental health in a care environment.

"Oh, I mean, workwise. I mean, we work with more people with mental health issues, right? On a personal level, yeah. I do provide care to somebody in my family who have disabilities. So it means like going at their pace, working with them how they need to be. And some days are a little bit I guess some days you feel very helpless because you can't do much for them. But just working with them on their pace, on their sensitivity level is important."

“Because they need to feel that they're making their own decisions. Like, you know? They want to do something. I am there to help them feel comfortable with whatever they want to do.”

Unfortunately, limited resources and poor infrastructure can lead to burnout and many respondents described feeling stretched thin. Participants juggle caring for children and parents, work responsibilities and home responsibilities with limited options for respite and recreation.

“Yes I care for my grandmother. She can't really move around much and she uses a walker but it doesn't help much. But like, we don't have any help and not many resources and support here, so it's mostly up to me to help her every day. It can be so hard too because I also have my own things to do, like taking care of my children and helping with other things. But family is important to us, so I do my best to make sure she is always comfortable and cared for. I make sure she has everything she needs to be happy but I just think it would be helpful to have more support and like resources like help with getting her to a doctor's appointment.”

“It is draining like, our family goes through, our family can go through more burnout, if we don't carefully manage our time and like, if we don't share that responsibility, somebody will get a burnout or like, exhausted. Like, you'll get sick from caring for somebody, or like, it can be so stressful. Like, you don't really look after yourself because you're constantly like, looking after someone.”

Many participants spoke about the need for improved infrastructure to offset these pressures. Respite care, improved homeware services, community institutions, and recreational spaces and programs were all cited as resources that are needed to improve well-being.

“Interpreter: He's just talking about specifically his wife and his home situation as to how it is now, looking after the wife continuously. It takes a toll on the caregivers. (names redacted, speaker and his daughter) who live with her. It takes a toll over days, over weeks. It changes your body. It does affect everyone else other than that person. If there was a center in the community, that would be really good a center for, to care for such people who need continuous care, 24 hour care. It is very tiring to mind and soul and the person is not sleeping and the caregiver can't sleep. So it's like a cycle of of no one really resting and that type of thing. And it's just using his situation as a, as a case here.”

CARE AND WORK

CONFLICTING RESPONSIBILITIES

Participants spoke about challenges managing paid work and care work. Nunavut currently has a very high cost of living, with food costs being notoriously high. Store-bought foods can be up to 4 times as high as the equivalent food in other areas of Canada, and according to federal data, as many as half of Nunavummiut deal with food insecurity¹⁵. Nunavummiut also face high

¹⁵ Tranter, E. (n.d.). New statcan data shows food insecurity worst among nunavut single mothers. *Nunatsiaq News*. Retrieved from <https://nunatsiaq.com/stories/article/new-statcan-data-shows-food-insecurity-worst-among-nunavut-single-mothers/#:~:text=New%20data%20from%20Statistics%20Canada%20shows%20that%2057%20per%20cent,average%20of%2012.7%20per%20cent>.

costs and long wait times to access goods and services, often have to travel south for medical appointments or leisure and experience high costs for internet and phone service. Many respondents are employed (full-time or part-time) to support themselves and their families. For Nunavummiut who also care for a family member, the tension between employment and care can be very stressful.

Many participants spoke about feeling pressure and worry when leaving family members alone to go to their place of employment. They expressed concern and fear that something might happen while they are away, but had limited options for care and supervision. Participants spoke of anxiety and concern that their loved one was spending hours alone during the day while they were at work.

"Since I just go to work and nobody to care for my ten year old. So I have to say no sometimes because it will be too hard for my ten year old to be alone by himself here. Yeah. And he will be on the streets too much."

"Taking care of my sister. I have a hard time to help them up, when she needs to get up from the bathtub or bed, if I am not there due to work. She needs to eat in the evening. Before I go out, I give her something to eat. If she has not eaten all day, I give her food when I arrive."

"I was thinking of whether my sister was okay or needed anything, hungry, thirsty and if she had enough supplies, that's it."

"That would be a family issue partly, cause whenever I'm working, I'm thinking that my family needs help too and I need to help them and stuff."

Anxiety about the safety and well-being of family members while home alone without support was a common theme found in interviews. Several respondents spoke about leaving or considering leaving their jobs in order to provide care.

"Um, it was basically just my parents because there is no, what is called, home, home care. Yeah. And there was no (inaudible) services, nothing of that sort. So my parents would do most of the care and my mom had to leave a job basically to take care of me."

Nunavummiut who travel with family members for medical appointments also felt pressure. With medical travel often occurring with short notice and requiring days, if not weeks, out of the community, many found it difficult to manage employer expectations and demands. The unpredictable nature of these trips can lead to conflicts with work schedules and create additional stress for caregivers who are already worried about the well-being of their family members. Participants emphasized the need for better communication and advance notice for medical appointments, especially as short-notice travel may disrupt their ability to provide consistent care and support to their family members. The lack of predictability can also strain relationships with employers, who may not fully understand the challenges faced by caregivers. Improving the scheduling and communication of medical travel could help alleviate some of this pressure, allowing caregivers to better balance their responsibilities and reduce the anxiety associated with leaving their loved ones alone.

“Well, if it will be better if like, for instance, for my brother or anybody else who is less disabled, if they would let people know ahead of time, not short notice that way if it's a short notice, then you have to go to work and you won't be able to help him out or help anybody else.”

One respondent, an employer themselves, expressed concern at seeing caregivers struggle with balancing responsibilities. In their words, a lack of infrastructure creates an untenable situation that impacts the whole community.

“But I would say that other people's issues around disability affect my life as a manager. And I think that if we are caring for and don't have infrastructure in place to help our employees, it affects me because then it affects our ability to do our job and then it affects the community and then it affects the territory, you know? All of those effects are very compounding.”

Supporting family members on medical travel also means time away from family members. This displacement can be particularly challenging, as it disrupts caregivers' and their families' daily lives and routines. Participants expressed a desire for more services to be available within the community to reduce the amount of time spent seeking medical care down south. This extended absence can create a cascade of difficulties. Caregivers may worry about the well-being of the family members they leave behind, particularly young children or other dependents who may not receive the same level of care in their absence. The prolonged separation from their support network and the familiar environment of their home community can also lead to feelings of isolation and increased stress.

Respondent: “We were down for four months.”

Researcher: “Four months!?”

Respondent: “Yeah.”

Researcher: “And you have all your family here, and you're down there?”

Respondent: “Good thing my, good thing I got two daughters.”

With so many tensions between work and home, it is perhaps not surprising that many participants reported leaving paid employment in order to provide care at home, full-time.

STRESS AND STRAIN

Participants spoke about the mental load and resulting stress of care work. This stress was described by both caregivers and care recipients, and was a great concern for everyone. Care recipients feared contributing to the stress of their family, and recognized the pressures they were under.

“My family has so much going on for them, I don't want to have to create or add a stress. Because they're working people.”

“Like, I understand they don't want to let them too much, because they got to feed their kids. They got to take care of themselves, they got to pay for their power bills and fuel bill. Cause I have two of them that are private owned, so I don't want to put them too much. But when they offer me country meat, I'll definitely take.”

A majority of the respondents expressed concern about financial strain. In addition to the high costs of living in the north, those experiencing disability also have additional expenses necessary for their safe care. Many participants did not feel that the required financial support was in place, or if they were, it was too difficult to access.

“That's another tough question because when we found out my daughter had a big challenge, a year old and I wanted to work. I had to take some time off until we decided how we were going to go about it. Until she went to high school and everything got easier. So financially it can be pretty tough because there's not much help. Family will help you, but they can only do so much too physically. But financially you have to buy extra. So I have also a niece who has a daughter who has a congenital liver disease and she has to often buy her band-aid, special band-aids because of her feeding stuff and over time, it can be stressful because first five years she didn't work too because her baby needed so much care and she was delicate.”

“That's also a necessity because that person's usually not going to work so that they can stay home and look after that person. And most of the time that can't happen because they can't afford it, especially if they're looking after their husband or wife because they still have to pay the bills. So that is something that I know they've talked about for a long time and employment insurance kind of touches on that for like briefly. But there's nothing that really covers you for if something like that happens.”

Financial strains and concerns were at odds with how many participants saw their role as caregivers. Caregiving is natural and inherent to being part of a family. Many participants were uncomfortable equating caring acts with paid work or discussing forms of financial compensation for care work. However, up against the pressures of high living costs, many conceded that financial compensation was necessary to sustain themselves.

“And no, money is not an issue for caregiving... however, if you're losing work trying to take care of someone, and it, and it's live without pay. Kinda becomes an issue. And then, if you run out of your vacation time and you're trying to look after someone. Yeah. And it's live without pay and that.”

“I went through that I was feeling guilty because it was my grandfather I looked after and I end up getting paid for it. I feel bad for that because it was my grandfather. And I end up being a homecare worker for him. Because the people that were looking after they needed their own time to do things. But later on I got paid for it and I didn't like that because it is my own grandfather. But at the same time it helped me in order to help my parents to get what they want. So it was kind of back for me, but afterwards it helped me a bit.”

It is also important to note that not all participants experienced this same disconnect between care work and compensation. Many participants were very open to the idea of benefits and compensation for caregivers as a means to meet financial needs and cover expenses. Many saw financial compensation for care work as an important way of building infrastructure and supporting community systems under immense pressure.

Caught between the pressures of working within and outside of the home, balancing expenses and costs, balancing the needs of family members (both those with disabilities and those without), and the constant irregularity of medical travel, many respondents described having to make impossible choices for themselves and their families.

“Many of us have to juggle multiple responsibilities, like, I have to work so I can pay for food and other things, and I was going to school at the same time, I had to do both because I need money but I need school to get a better job. And even then you have to give, to do caregiving for your family like your kids, or your parents, which can be overwhelming at times. I was so tired and depressed. It's about needing to find a balance between our cultural things and changing to the realities of what we have to do today.”

For many, choosing between safety and well-being, as well as income and poverty, is an impossible position that leads to stress and burnout.

HOW FAMILIES ARE COPING

Considering the substantial stress and strain families are under, there is a question of how they are coping. Respondents indicated that for them, their ability to manage hinged on the support of their family networks. Maintaining paid employment was entirely dependent on families' ability to secure backup care from family members or care providers.

“For me. Like I have my son here that helps me out with him. I can see that he's a really big help. And it's easy for me to go to my workplace and then my granddaughter and my youngest son, they're in the same class, they go to school.”

“And they take care of. Well, one of them, one of my boys take care of my younger one as we work.”

Researcher: “Do you face specific barriers to participate in work?”

Participant: “Like I said, it depends. If I find a sitter or if he can go to his grandparents.”

Participants spoke about a need for improved access to childcare, eldercare and homecare to ensure they could continue to work.

“But if I don't have the daycare, if I don't have the school, I cannot work.”

“But for me it's babysitters so I can work... And a particular babysitter I want. Not daycare.”

Respondents, reasonably, also want options for care. Not everyone held the same preferences with some preferring in-home care, daycare, or family members to meet their care needs. The ability to rely on such services would provide much-needed relief and stability, allowing caregivers to balance their professional and personal lives more effectively. The availability of diverse caregiving options is essential to meet the varied needs and preferences within the community. This diversity in care options would support individual caregivers and reinforce the communal values of mutual support and interconnectedness, which are integral to the well-being and resilience of Nunavummiut families.

This diversity in preferences underscores the importance of flexibility in caregiving solutions. In-home care allows for a personalized and familiar environment, which can be vital for both emotional and physical well-being, especially for Elders and individuals with disabilities. Daycare services provide structured care and social interaction, benefiting young children and working parents who need reliable care during working hours. Further, care provided by family

members aligns with the cultural values of Inuit communities, emphasizing the importance of familial bonds and the traditional ways of caring for one another.

The need for multiple care options reflects the varying circumstances and resources available to families. Some may have extended family nearby who can assist, while others may rely on professional services due to the absence of immediate family support. By ensuring a range of caregiving options, communities can better accommodate the members' diverse needs and situations, thereby enhancing overall community resilience and well-being. The desire for varied care solutions also points to a broader recognition that caregiving is not a one-size-fits-all scenario; it requires tailored approaches to effectively support the unique dynamics of each family and individual.

SERVICES AND SUPPORTS THAT ARE WANTED

Nunavummiut described many different support and services they wish to see in their community to support improved care for everyone. Although diverse, most requests pointed towards addressing the high living costs in the north, and the gaps in infrastructure that occur.

FINANCIAL SUPPORTS

One of the areas discussed was financial support and benefits. While some respondents struggled with the idea of pairing care work with compensation, others acknowledged that the demands on time and resources needed to be offset by increased funding.

“Right? Is, it can be about giving shelter, being respectful, cleaning the land, but we need money or help to do this. It's expensive to live and there's no houses. How can we give care if we don't have these things? We have to choose now about basic needs and our cultural roots.”

“But caregiving can be hard, like for physical caregiving I mean and it's hard sometimes if you don't have money to care for someone. So we need more funding for programs in (community name redacted) that can help with this I think.”

As discussed above, financial benefits would greatly mitigate pressures on families to balance caregiving and employment. Ideally, improved benefit packages for those on disability and compensation for care work occurring within families would balance financial strain.

CULTURAL PROGRAMS

When discussing desired programs and services, most respondents pointed towards offerings that had a cultural component, either in content or method of delivery (or both). Participants wanted to see recreational activities such as beading, sewing, hunting, and going out on the land. And they wanted to see these activities be more accessible for people with disabilities and their families. Centering culture was often cited as the best way of ensuring a healthy, caring community.

“We need knowledge passed down from our Elders and our families, knowing the ways to help. And we do, we need resources, like warm shelter and healthy food. We have to have the support from family and neighbors, like a strong community group. Also, our language and culture, they guide us in providing care with heart and respect. So, it's about knowing, resources, support, and our culture, all together to give good care.”

Several respondents also spoke about the importance of providing opportunities for youth and Elders to connect.

“Have the family and young people help and learn about how to help people with disabilities.”

This is important for a multitude of reasons. Children would learn about their role in their community by caring for Elders. By learning to anticipate and meet the needs of Elders, young people would learn about the cultural meaning of care in Inuit society.

Respondents, both young and old, spoke about feeling the loss of this connection in their daily lives. Many participants, including community health professionals, saw the reinvigoration of the relationships between generations as central to building caring communities. Cultural programming that facilitates connections between community members, particularly between Elders and youth, helps build communities' capacity to manage care.

GATHERING SPACES

Several communities cited the lack of comfortable, accessible spaces for gathering. Many participants said that a gathering place and opportunities for social interaction would benefit their community and provide opportunities for relaxation for caregivers and care receivers. While some described a space akin to a community centre, with comfortable and accessible seating, a kitchen, etc., others described more institutional spaces, but ones that were open to family and facilitated continued connections between individuals and their community.

“Well, they can play a role in providing important care for some people who may require more help like, some families may not have the resources or even capacity to provide the proper level of care for someone. Sometimes facilities can give a structured environment with trained staff who can help with things like medical needs or daily activities. But they shouldn't be out of Nunavut. Like, we need them to be local so people don't lose their family or culture, or, like their language. I see them as gathering spaces, more like, a gathering space with people that is like a home.”

Participant 1: “Yeah, I agree. Like more of a home in the community, not a facility.”

Participant 2: “Yeah, yea.”

Participant 3: “I like that. The way they are now doesn't really align with our needs and expectations in Nunavut. We need these places but the way they do things is not good and does even include our values and expectations.”

Nunavummiut don't want to separate family from care work. They want more support, but professional support should also allow Nunavummiut to provide direct care for their families.

“And it would also be good to have more Elders places, like Elders home and they should be in the community with space in there for family to visit and help care for them. Family support is always important and we still need to care for them.”

Again, the link between care, community cohesion, and cultural resilience should be maintained. Nunavummiut want to keep the role of family and community from being replaced by professional systems or institutions. Instead, Nunavummiut would like to be better supported in delivering on their roles as caregivers through improved infrastructure.

The concept of gathering spaces deeply resonates with core Inuit societal values, reflecting the importance of community, connection, and care. These spaces serve as more than just physical locations; they embody the essence of Inuit culture, providing settings where traditions are upheld, stories are shared, and support is offered. By advocating for gathering spaces that prioritize inclusivity, accessibility, and cultural relevance, participants underscored the significance of maintaining familial and communal bonds in caregiving practices. Inuit values such as Inuuqatigiitsiarniq (respecting others, relationships, and caring for people) and Avatittinnik Kamatsiarniq (respect and care for the land, animals, and environment) are interwoven into the fabric of these spaces, reinforcing the interconnectedness of care, community cohesion, and cultural resilience.

CARE INSTITUTIONS

A surprising number of participants wanted live-in Institutions in their community, either for themselves or their family. Many were familiar with the Continuing Care Centres in Nunavut (currently 3) and wanted to see a facility like that in their home community. A major concern for many was that they acknowledged a need for high-level care but did not want to leave their community to access it. Several participants spoke about the pain of being separated from their loved ones who moved out of the community to seek care.

“I see a lot of out of towners but then you've seen this facility, but in my opinion, my thought was that we could do this here and not send people out. This type of facility could be established throughout the north, or throughout Nunavut and then more and we can perhaps do a little bit more within our region and within our community. Unfortunately, the government is not all that supportive and fast, but, you know, through everything, all we got, we got each other. But again, if we had it more, you know, people, communities such as this, if we had more facilities like this throughout Nunavut, I'm sure they can engage in a lot of our programs that are all in here. Yeah.”

“And about like the disability, because my uncle had a cerebral palsy. He was sent back to Ottawa and then he was sent to Edmonton. He's been there for eight years now. But it would be nice, even though we are a small community. Like even the small like it would be nice if there was like a place for people with disability disabilities to live in in our small community so they could stay close to like their family. That's one of the things that I like because I miss my uncle a lot and I wish I could see him but we can't.”

Several participants spoke about wanting to be admitted to a long-term care facility but not knowing how to access a spot or being on waiting lists. Many expressed concern for the lack of available spaces in care facilities in the north, and hesitancy about care facilities down south.

RESPITE SERVICES

Family members providing full-time care often spoke about burnout. Access to respite care so they could get a break, rest, and recover was cited as very desirable. Many spoke about having limited time for hobbies or activities, which could lead to feeling drained and depleted. Others mentioned that having access to professional care support only during weekdays, 9 am-5 pm, limited their ability to participate in many community activities or volunteer opportunities in the evenings or weekends. Participants also spoke about how hard it is to socialize or maintain friendships without access to respite care.

"Equipment for that building and like care for people who need more support. Like if someone needs a break they can bring them to the new place. Just like respite center."

"something like respite help so we can take a break here and there and recharge."

"That's why we need more breaks and mental health support for caregivers like respite or somewhere that people can go to get a break."

INCREASED AND IMPROVED HOME CARE SERVICES

Nunavut currently has homecare services in the territory, which provide things like, cleaning, cooking, and light nursing duties. Participants who received home care found it to be helpful.

"His wife is bedridden and he's getting a lot of help through the health center and the Elder or the home care. And he wouldn't have done it if he lived out on the land himself. He has to look after his family, feed them and then his wife. He cannot do it alone. He's very grateful for the support that home care is doing."

However, a significant number of participants either were not aware that homecare might be available to them, or were not aware that home care services were even offered in their community.

Participant: "Um, I think I'm doing good, but sometimes I need help."

Researcher: "Yeah, of course."

Participant: "Yeah, sometimes."

Researcher: "What kind of help would you like?"

Participant: "Like, anything, helpful with who has a disability. Yeah. I don't know what kind of help."

Researcher: "I mean, it could be even like, even like, more financial support. You know, like from benefits. Or it could be something like home care, like help with cleaning, help with meals or things like that."

Participant: "They really need a home care for disability."

Researcher: "Yeah. So have you ever had any home care help here?"

Participant: "Not here."

Home care services were clearly beneficial for many, but the capacity could be expanded to meet the needs of community members.

Families receiving professional support, either via homecare, through their local health centre, or outside of the territory, spoke about improvements to service that could be made. Further, more transparent and consistent communication was something that many discussed. A lack of follow-up, or having to chase down healthcare providers, was discussed as a source of stress

and increased mental load for caregivers. Difficulty locating information or navigating complex and non-transparent bureaucracies was also discussed. Respondents often felt in the dark about their loved one's care, or alternatively, felt like the only one who had a handle on that care.

"For example, myself, I'm having a hard time getting help on questions of my granddaughter. Like, why isn't there anyone telling me any updates about what her plan is? What happens to the father if we even going to the biological mother, like who is helping them and I don't get updates from the social worker about it."

"They're not checking on their patients. They're not doing home visits. They're not being on top of our health."

"Home care could do a lot more. Um, I know they're always saying they're short staffed, but sometimes I just want someone to come and stay with my mom for any hour or two... Yeah. And they always, they're always asking if I need help or not. But then they don't follow up on it... I'm constantly having to call them to remind them, "hey it's Wednesday, it's bath day", uh, she needs more diapers or she's running low on meds. I have to keep on top of them."

Participants also spoke about needing a more accessible mechanism to address concerns and provide feedback. Several respondents also talked about feeling like their concerns were not taken seriously.

"I wanted to complain, but where, where am I going to complain? So I never, I just brought it."

"So, she started complaining of her breathing, which I've been telling the health centre here. I started demanding. I said, No. If she's not getting the help she needs. I'm reporting them. So, that led me to email law, patient relations in Iqaluit."

IMPROVED TRAINING

Many felt that updated training could improve services. Some spoke about more patient-centred training, which provided the client with more autonomy. Others spoke about a need for cultural sensitivity training to mitigate racism and discrimination. Overall, people wanted to see more professional behaviour that aligns with transparent policy.

"I agree with her, like being empathetic is very important. And just like giving them training, some form of training of how to be a caregiver. To make it more about the client themselves. Like just having that clear boundary is very important."

Researcher: "What resources and supports are needed to provide good care? What do you think would be helpful for those that are providing care?"

Participant: "If they can come here regularly, be on time and follow company policy."

MENTAL HEALTH SUPPORT

In the majority of Nunavut communities, mental health support is limited. Most communities have a mental health nurse or counsellor on staff, but these roles can be subject to high turnover rates and are sometimes vacant or staffed via short-term contracts. Community

members would like more access to mental health support and a variety of other support services available to them. Specifically, many spoke about wishing to have access to Inuit counsellors - ideally, counsellors who are Inuit, but from a different community from their own (for privacy).

"Yeah, um. If there was any funding for that, I think like there should be more Inuit counselors who can travel to Inuit communities and have meetings throughout couple of weeks."

"And we shouldn't forget about mental health. Taking care of someone can be really hard on your mind, so having someone to talk to would be great. If we had Inuit counsellors or therapists, it could really help people who are feeling overwhelmed."

Access to Inuit staff in health care settings was also cited. This can mitigate language and translation issues, making clients more comfortable. Integrating Inuit mental health professionals can also help preserve and incorporate traditional Inuit healing practices, which are often more culturally appropriate and effective for community members. These professionals can bridge the gap between modern mental health practices and traditional Inuit knowledge, offering a holistic approach to mental well-being that respects and reinforces cultural values.

"Home care if they go to Elders, when they go to Elder's home. Well, I'm not complaining about their assistant. Their assistant is always Inuk."

Participant 2: "The whole time they went to my house since the fourth. It would be always a different person. Different person."

"To know, health names or, you know, big words or whatever to Inuktitut. Not to us 'cause my husband and I know, we understand what she say, but to unilingual Elder. If there's something wrong, I, I don't know. Just trying to help the home care workers. There's not many that are unilingual nowadays saying like they're going (Ila) and to understand, like words, difficult words or names or something...medication."

In line with more mental health support, Nunavummiut also want more opportunities to connect. In addition to the types of homecare services already provided, many would like more human connection, including visits, and sharing meals.

Participant: "And he sometimes doesn't eat much because he doesn't like, well, he likes cooking, but it's his mobility that limits him."

Researcher: "Hmm. Limits him to prepare food or to actually physically eat the food?"

Participant: "To prepare and eat."

Researcher: "Okay."

Participant: "But he sometimes prefers to eat with somebody."

Researcher: "Yeah, of course."

Participant: "And he waits for days."

"It would be good if they'd like would do home visits. Like, not the nurse or the worker. It's just like, have someone there to, like, come and visit. And like chit chat... Or have tea, coffee and just socialize... Because that's something we are not a part of in the community."

Inuit societal values prioritize collective well-being, interconnectedness, and the sharing of responsibilities among family members and the wider community. By integrating culturally appropriate and readily accessible mental health supports, caregivers can be alleviated of their mental and emotional burdens, allowing them to continue providing care.

Further, providing more opportunities for connection through social visits and shared meals aligns with Inuit values of *Inuuqatigiitsiarniq*—respecting others, relationships, and caring for people. These interactions support the mental health of caregivers and care receivers and strengthen community ties and resilience. The presence of Inuit counsellors and healthcare providers who understand and embody these cultural values ensures that the care provided is holistic, inclusive, and respectful of the unique needs and strengths of Inuit communities.

CARE AS LEADERSHIP

When asking study participants what care means to them, the research team was surprised that several respondents, particularly Elders, often spoke about leadership. It became clear that for Nunavummiut, the provision of community direction and guidance is also a form of care.

“They need communication and more discussions with everyone. Caregiving is everyone, not just one person making a decision. It is about all of us as one and beating together.”

Elders spoke about the role that community leadership played in communities before colonization. Leaders were responsible for community survival and wellbeing, and as a result were in charge of the care of the community. The transition to permanent settlements and western models of governance changed the dynamics of leadership, and thereby of care, in Inuit society.

“One of the things that we lost when we moved into (community name redacted) with the community leader like (names redacted). They were the ones running the camps and everything was pretty well set out, the people in the community were supposed to act. And the leadership, the Elders, and all the adults in the camps, were not challenges at all. Whereas when we moved to (community name redacted), they were no longer the bosses. It was people in (community name redacted), RCMP, they are the ones who were running the whole show in (community name redacted). So we had to go everything in their way, and sort of had to leave our way out there. Which was really what worked for us. Going to something totally different. We were sort of lost and our Elders no longer had the authority that they used to have out there, in making sure that we were going the right direction and, and looking after each other in our community.”

New governance systems in northern communities eroded the authority of Elders and diminished their ability to oversee the care of community members. Calls to reestablish Elders as community leaders and guides are also calls to reassert culturally relevant models of care.

Participants wanted to see several improvements to community leadership, to improve care for community members and engage people, particularly Elders, in community decision-making. This aligns with the Inuit societal values, *Ajiiqatigiinniq* (decision-making through discussion

and consensus) and *Piliriqatigiinniq/Ikajuqtigiinniq* (working together for a common cause)¹⁶. A desire for improved communication and awareness was also seen as important to ensure that programs services stemmed from community input, and that community members were fully aware of what is available to them and how to access it.

“I think care starts with having good programs and activities in the community. Like, organizing public meetings and discussion meetings to get input from the community and our Elders about their caregiving needs and challenges. I think, like, one significant thing we face here is lack of communication at all levels, like about the available resources or who has to do what. And even when there is something here, many caregivers may not be aware of those programs and services because they can’t be accessed anywhere, which is not good for their ability to provide the care someone needs.”

Increased awareness and open communication could help improve services and reduce stigma around disabilities. In light of the changes to structures of care resulting from colonization, disarming stigma can be a form of cultural resistance.

“Oh yea and I also think another barrier no understanding and awareness about disabilities at all, but like, in our own way not in the way other parts of Canada see it and because not everyone knows how to support people with disabilities now because things have changed so much it's confusing, which also leads to misunderstandings or even discrimination against people. And sometimes people might not even realize that they are doing this, like, that their actions or attitudes are creating barriers for someone with a disability which makes it really hard for people with disabilities and even their family to feel accepted and included in their communities. Isn't this crazy? Like, we support our families and neighbours, we care about them and we used to do everything for them and now they don't feel accepted.”

Communities want to see more representation of people with disabilities in decision-making and more transparency around how decisions are made. Many expressed feeling like people living with disabilities and those who provide care were excluded from decision-making. This was also attributed to stigma and discrimination. The importance of community consultation and guidance was stressed. Nunavummiut want to see services designed to address their unique needs and barriers. Participants are frustrated with models that are imported from the south and don't take into account cultural and geographical differences.

“Yeah, that's a really important thing to bring up and another one, another big problem is that people aren't included in making decisions that affect them like especially if it impacts them. It's like they're left out of the conversation when it comes to stuff that's going to have a big impact on their lives. And that just makes it even harder for them to get the stuff they need or be part of things but if it doesn't include people and people with disabilities, then they might not work for them at all. And that's not fair because everyone deserves to have a say in stuff that affects them. It's like they're being shut out on purpose, and that just adds to all the other barriers they're already facing. We really need to change that and make sure everyone's voice is heard equally.”

“Well, from what I've seen, decisions about accessibility are usually made at higher levels, like some include everyone and some don't. I don't know how these decisions are made though or how people are included. Sometimes people do come together to talk about the barriers they face and what needs to be

¹⁶ *Inuit societal values*. Government of Nunavut. (n.d.-b). <https://www.gov.nu.ca/en/culture-language-heritage-and-art/inuit-societal-values>

done to address them but I really don't see this often really. It's important for everyone to have a voice though so that decisions can be made that benefit the whole community. We need more input and collaboration here."

Respondents wanted to see communities have more autonomy and authority over how funding was utilized and what programs and services were funded. Many respondents also spoke about wanting to see more interdepartmental communication so that different services were better coordinated and informed.

"Yeah, I agree, it, like, decides where money goes, what gets funded here and stuff. So we should be included in that and we need the funding for way longer because programs don't really last that long. And sometimes, it's like, you know, the government doesn't really care about our, what they are doing with the money and most times it doesn't give us what we need, especially, um, when it comes to, like, accessibility and support services for people who need it."

In summary, Nunavummiut want improvements and changes to services that are driven by community needs and culturally informed.

CONCLUSION

In conclusion, care in Nunavut is deeply rooted in cultural values of love and respect. It is integral to family and community life and keeps communities strong and resilient. Nunavummiut want improvements to services and supports to address limited resources and reduce stress, but they want improvements that are culturally relevant and allow relationships of care to remain intact. Creating ideal environments for care in Nunavut means recognizing the inherent value and autonomy of all Nunavummiut and ensuring that infrastructure is informed by Inuit Qaujimagat and Inuit societal values.

The cultural significance of caregiving underscores the importance of preserving familial and communal bonds amidst the evolving landscape of care. From the outset, it is evident that caregiving in Nunavut transcends mere practical assistance; it embodies a profound sense of duty, respect, and reciprocity within families and communities. However, this intrinsic role of caregiving is compared against the harsh realities of financial strain, limited access to essential services, and the perpetual juggling of multiple responsibilities faced by caregivers. Participants' narratives highlight the delicate balance between cultural traditions and the pragmatic demands of contemporary life, underscoring the need for nuanced and context-specific approaches to caregiving support.

Central to the discourse is the theme of resilience as caregivers navigate the complexities of caregiving amidst adversity. The discussion surrounding stress, strain, and burnout underscores the urgent need for enhanced support mechanisms, including financial assistance, respite care, and mental health services. Moreover, the call for improved training and cultural sensitivity reflects a desire for more inclusive and patient-centred care practices rooted in the principles of respect, empathy, and autonomy. At the heart of the conversation lies the notion of

community, where gathering spaces serve as vital hubs for social interaction, cultural preservation, and mutual support. Participants express a collective yearning for accessible and inclusive spaces that foster a sense of belonging and connection—a sentiment deeply intertwined with Inuit values of communal solidarity and collective well-being.

The caregiving journey in Nunavut is characterized by resilience, resourcefulness, and a steadfast commitment to cultural continuity. As caregivers navigate the complexities of their roles, they seek tangible support and recognition of their invaluable contributions to the fabric of Inuit society. Addressing the multifaceted challenges of caregiving demands a collaborative and culturally responsive approach that honours the rich tapestry of Inuit culture while striving for equity, accessibility, and inclusivity in caregiving services and support systems. Through concerted efforts to amplify voices, bridge gaps, and foster community resilience, Nunavut can chart a path toward a more compassionate, equitable, and sustainable future for all its caregivers and care recipients.