

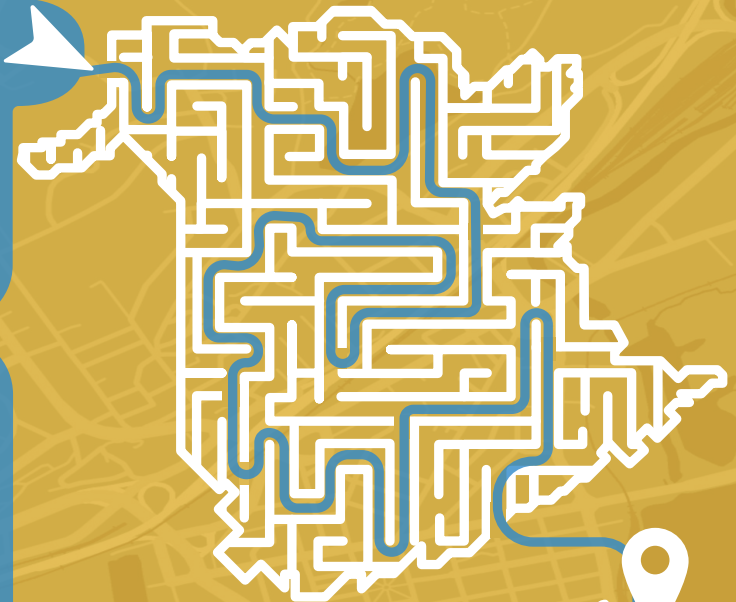
“What do I do? Where do I start? Who do I talk to?”

Challenges of information navigation among informal caregivers of older adults in New Brunswick

Introduction

Informal caregivers are the **spouses, adult children, family members and friends** who provide unpaid assistance that enables seniors to ‘age in place’ in the home. They provide the vast majority of the care work performed and the New Brunswick health system could not operate without them.

Informal caregivers often face **tremendous challenges** in occupying this **important role**, and we want to **understand their challenges and needs** in order to **better inform policy and practice in New Brunswick**.



Methods

We interviewed 28 informal caregivers from across NB with questions like:

“What are the challenges you face in providing care?”
“What helps you manage?”

Our goal was to identify the central challenges facing caregivers in NB.



Findings

Navigating the health care system was described as one of the biggest stressors participants faced, describing it as **opaque, disjointed** and **confusing**.

Without a clear point of entry into a coordinated system, caregivers felt **disoriented, confused, lost, and alone**.

“You really are on your own to find out what's out there.”

Solution 1 - Personalized and ongoing navigation support for caregivers:



Caregivers described needing personalized support from someone who is familiar with their ongoing situation, understands the system and can anticipate ‘next steps’ in their caregiving journey.



“Just navigating the whole process - navigating the social work departments, the financial aspects of it all. There is no one person that you can pick up the phone and say ‘This is where we are, what's my next step?’”

Solution 2 - System revision toward person-centred continuum of care:

Caregivers also described the need for a health care system grounded in the needs of older persons and their caregivers.



“We're a small province and I don't see why there isn't a continuum of administration under Health. If you're really serious about homecare, then, let's go beyond just having a bunch of somewhat approved homecare companies. But really have something that gives you the sense of ‘Ok, this is where my wife is, this is what she needs, and these are the kinds of people who are available.’”



You don't know what you don't know

Without a coordinated system of care, caregivers often have trouble knowing what questions to ask, what services are available, and how to get help.

“You don't know where to start.”

“In order to find something you have to know what you're looking for.”



Inconsistent information

Caregivers often receive different information from different service providers, deepening their confusion.

“One group tells you one thing, another group tells you something else. You go to four [care]homes and you get four different answers about how it's all paid. And then you're lost.”



Technology as a barrier

Several participants described automated phone services and websites as barriers to information navigation.

“My parents were in their late 70s and they couldn't negotiate [the phone system] ‘push one for this and two for that’. That was just absolutely ridiculous for them to try to do!”