# Caregiver profile: A sign for advocacy

# by Ana Merkureva

Photo: Shirley Hodder (left) with her mom, Tracey Gibson

Timer goes off in an empty kitchen. The smell of cooked – and now slightly burning – food rises up, as baby feet tap across the floor. Shirley Hodder searches for her Deaf parents, who are in another room, unaware it's time to turn off the stove.

Since she was a little girl, Hodder has been a caregiver for her parents. She started advocating for them in a doctor's office and in front of the Labour Board. Today, she advocates for entire communities as the African Nova Scotian Health Services Consultant.

## **Early caregiving**

Hodder grew up in Gibson Woods – a small historic community of Black Loyalists in rural Annapolis Valley. As a child of the only two Deaf people in the community, she quickly became the link between her parents and the larger world.

At first, it was simple. "I'd leave with my mom wherever she went and start interpreting as she signed," Hodder shared. As her vocabulary grew, she entered new spaces: by the time she was "7 or 8", she joined her parents at the bank and dove into the world of chequing accounts, savings, overdrafts and ATMs. A few years later, when her parents' contracts were cut short, she'd rush home from school to make resumes, arrange and interpret at the interviews.

#### **Facing barriers**

Interpreting was easy. Dealing with how some people responded – wasn't.

"There were a lot of things I heard that I didn't tell my parents," Hodder said. "I was softening the tone of voice, phrasing things nicer — a lot of people were very rude." She was also the one who had to deliver painful news: "I'd need to explain why they can't get a job – many times I was told they were a liability and weren't a good fit. I would interpret it to them and see their disappointment."

As Hodder advocated for her parents in front of the Labour Board, she faced another challenge: a school system that misjudged her abilities and needs.

In middle school, without her parents' knowledge or consent, she was placed on an Individual Program Plan (IPP) – a path usually meant for students who needed extra help to get through school.

"I didn't know I was on IPP until Grade 11," Hodder shared. "I assume, they tried to help me this way, but I didn't need it. I was an Honours student, I took Chemistry 12, Biology 12, the only thing I didn't have was math." By the time Hodder found out, nursing, the career she once dreamed of, was no longer on the table. So, she picked Health Promotion.

### **Unplanned path**

In hindsight, it was a perfect choice. "I found my passion," she said. "Health promotion is advocacy work, community work, identifying issues with social determinants of health: if you are Black, if you have a disability, if you are in a rural area – how do all of these factors combined affect your wellbeing? How do we come together to address that?"

As a caregiver, she looked from the side at her life, the barriers she spent her life navigating. In class, she gave many examples, trying to let people think what they would do in a similar situation, how they can improve it.

"For example, I'm trying to communicate a very serious health issue to the mother, who is the patient, but there's no interpreter there, so the young daughter is interpreting my words. How do I phrase it to her, making it age-appropriate? Should the family book the interpreter? There can be an emergency, when that's not an option."

#### **Driving change**

Over the years, Hodder kept sharing her story to spark change.

One of her first victories came when the Labour, Skills and Immigration Department created an Equity Committee, inspired by her advocacy. Their goal: to identify barriers faced by disabled workers and to improve legislation.

Today, at Nova Scotia Health, Hodder keeps pushing for change. Her calendar is full - back-to-back meetings, evenings, weekends – but she shows up wherever the momentum is strongest: where there are people, resources, funding and the will to act.

"In order to fix a systemic issue," she said, "you need to have a system."

And you need voices willing to speak.

"If I don't say anything, if I don't show up in the spaces I have the privilege to access, nothing is going to change. We advocate, we share, because you never know who's going to be in that room, listening. They could be monumental for that change."

