

Reflections on Being Seen

By Dr. Yona Lunsky

I am trying to figure out what made the [Canadian Caregiving Summit](#), hosted by the [Canadian Centre for Caregiving Excellence](#) this November, feel different for me. I have attended many conferences throughout my academic life. I have also been a caregiver much of my life, to different people in my family, sometimes for physical health concerns and sometimes for mental health concerns. Caregiving, for me, is not just a skill that I have, but also a significant part of who I am.

So, why is it that even a week after attending the Caregiving Summit, I am still thinking about it? Why has the experience stayed with me? One reason is that, for the first time, the focus was all about caregiving, surrounded by like-minded people who care. But, it was more than that.

The magic of this Summit started the evening before the conference. There I was, sitting in a room with fellow siblings, telling jokes, and sharing pizza. I am 51 years old and I have never done that before. And these were no ordinary siblings. Each one of them has a brother or sister with some



sort of disability. We were all part of [Siblings Canada](#), converging in Ottawa to take part in a national summit on caregiving.

At one point in the evening, one of the individuals casually asked another, “What high school did you go to? I think I recognize you”. As it turned out, they had spent several critical adolescent years together in the same school, unaware that they shared the same experiences as siblings caring for a family member. A few days after the conference, I learned that this had happened again; two other siblings, from a different community discovered they attended the same high school without realizing it. Sitting together that Sunday evening, it felt like I was at home with a group of friends that I didn’t know I had. The connection I felt highlighted the powerful bond that can exist among siblings who share similar caregiving experiences.

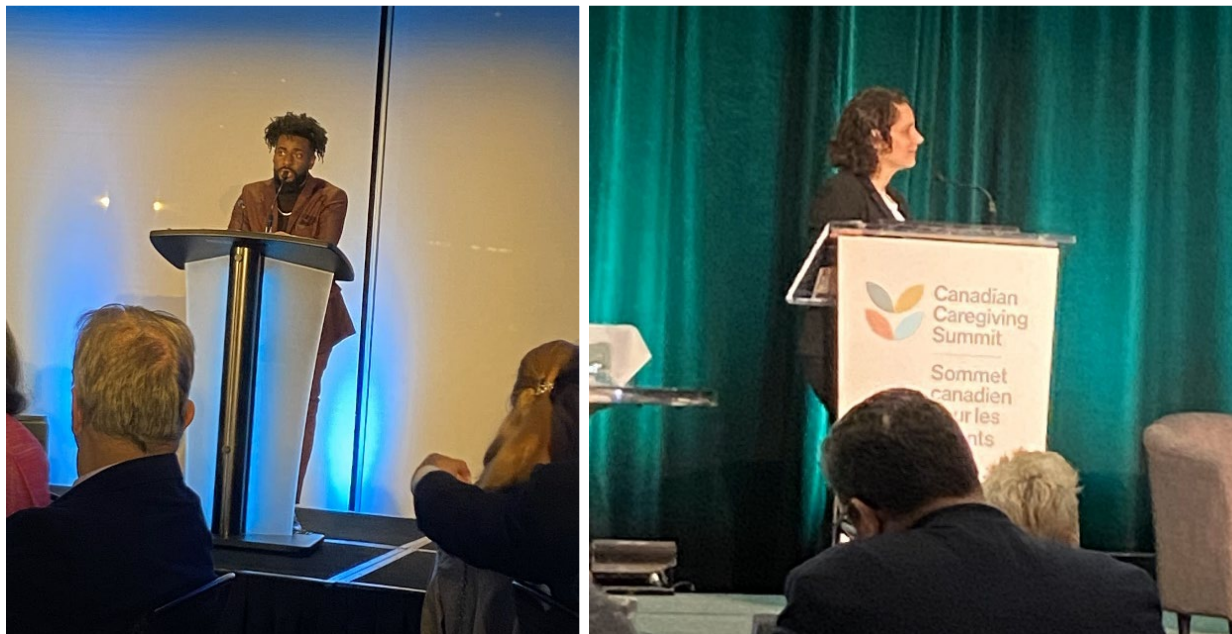
On Being Seen

If you look carefully, you will see that siblings are everywhere and they need all kinds of supports. However, they receive little attention and can get overlooked in the broader caregiving community. This is a huge loss. At the Summit, it was apparent that siblings have all sorts of creative and meaningful ideas. We see things, we know things. Sometimes we are the bridge between our parents, and our brother or sister who needs help. We serve as translators at medical appointments if English is not our parents’ first language, or if the information needs a cultural or generational translation. Being closer in age to our family member than our mothers or fathers, we also have a unique perspective, the inside scoop of life as siblings outside of the family home – we play together, we see how others play with us and who behaves cruelly. We also know the unspoken rules about how to act, where to go, and how to dress. With the right supports, we can bring that wisdom to the caregiving table.

The sibling relationship is unique. Of all familial relationships, ours is the longest lasting. At the Summit, I discovered that siblings have many shared experiences in common, but sadly, a thread that resonated in almost all of my conversations was that we lacked a space to talk about them, leaving us feeling unseen. If we are invisible, that means we can’t see each other, we can’t connect with one another, and we can’t be part of the conversations happening around us. This leaves a huge hole in our collective efforts to make things better for our brothers and sisters with disabilities.

My sibling-kin were everywhere at the Summit. I know this because it provided a safe space to say, “I am a sibling”. The organizers were intentional about recognizing the importance of including siblings, which allowed us to be seen and to find each other. As a result, when Summit discussions delved into examples of caregiving challenges and innovations, we were all reminded to think about their relevance not only to parents, adult children, and spouses but also to brothers and sisters of all ages. Being included – being seen - also meant that siblings had the opportunity to discover new opportunities and connect with allies they might not have encountered before.

I learned many things at the Caregiving Summit about innovations in caregiving from coast to coast to coast, as well as from abroad. I also felt so much love. I am grateful to the Azrieli Foundation and the [Canadian Centre for Caregiving Excellence](#) for recognizing the importance of amplifying the sibling voice and providing us with a platform and a seat at the table.



1st photo: Stephane Alexis at the Summit Gala speaking about his experience as a sibling caregiver and how it has guided his art work. 2nd photo: Allison Barkoff from the US Administration for Community Living giving a Plenary talk on the US Caregiving Strategy and weaving into her address her role as a sibling.

Understanding the Experiences of Siblings of People with Disabilities

Do you work for a community agency, service provider or disability organization? We want to know what your agency is doing to support siblings right now. How are you helping us to be seen and to feel seen (because they are not the same thing although they relate to one another)? Do you want to learn more and do more? You can start by completing our very brief survey looking at how agencies include siblings in the work that they do. [Fill out our brief survey.](#)

Are you a sibling of a person with a disability? Watch our webcast, [Understanding the Experiences of Siblings of People with Disabilities](#). The session sheds light on some of the research we have done on siblings of individuals with neurodevelopmental disabilities, and the challenges, joys, and important roles that siblings play in the lives of their family members with disabilities. After watching the video, you will have the chance to [answer 3 questions to help us with our work](#):

1. After watching the video, do you have any additional questions?
2. Do you have advice for parents on how they can include siblings in future planning?
3. What do you want service providers and policy makers to know about your experience as the sibling of a person with a disability?

Lastly, if you have a brother or sister with a disability, know that you are not alone. There is a seat waiting for you at the Siblings Canada table. Even though the Summit is over, that seat is there, with an open invitation for you to come by and join us whenever you feel ready.

You can find us at <https://canadiancaregiving.org/siblingscanada/>.