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Opinion | Valuing disability and difference in society

Those sitting at the decision-making and policy tables are far removed from the day-to-day experience of children, youth and their families.

May 23, 2025 | 2 min read [🔖](#) [🔗](#)

Our system has not been built with the basic premise that people with disabilities and differences have value that they bring to our society, Dr. Mohammad Zubairi writes.

Alexandra Heck/Torstar file photo

By Dr. Mohammad Zubairi

Dr. Mohammad Zubairi is a developmental pediatrician and associate professor at McMaster University.

I have spent the last five years studying how we can better care for autistic children and youth who are brought to the emergency room.

While the reasons for their visits may be medical, more commonly parents are exhausted, in crisis and unable to cope with their child's behaviour.

The behaviour is not necessarily because of a child's underlying neurodevelopmental difference, although it is known that autistic people frequently experience the world differently. So may those with other neurodiverse conditions and identities. However, many people are trying to both understand and question what we mean by specific descriptions such as ADHD or autism spectrum disorder.

We are also at a moment in time when the value and worth of those with differences is being challenged, for example, through comments by politicians in the United States.

Advocacy organizations in Canada have had to ensure the progress we have made is not lost.

Conflict globally is also putting children at higher risk for disability, and while Canada ratified the UN Convention on the Rights of Persons with Disabilities in 2010, we have yet to develop a national disability strategy.

Disability is created when our current structures come in the way of someone's ability to function and meaningfully contribute. Amid all the above then, as clinicians, educators, policymakers and community members, we need to look in the mirror and ask ourselves: how much do we actually value disability and difference in our society?

When the Ontario government announced in 2023 funding for the extensive needs program, I breathed a sigh of relief. There was recognition that families of children and youth with complex needs require more support.

It is not perfect, but it is a start. Caregivers play an important role but cannot do it all by themselves and across all environments including home and school.

ARTICLE CONTINUES BELOW

Over the years, colleagues locally in Hamilton at CanChild have done a lot of work engaging families as research partners to better understand how we can actually meet their needs. There is recognition that needs vary and there is a diversity of experiences that families have had navigating the systems. Engagement with the communities that we serve is necessary and yet, we still have a far way to go in understanding and addressing the intersections of lived experience, including racism, and disability.

Getting it right is even more difficult because our systems act in siloes and those sitting at the decision-making and policy tables are far removed from the day-to-day experience of children, youth and their families.

Consider the parent unable to work because their child can only attend school for two hours per day as there aren't enough educational assistants.

Or the child who is brought to the emergency department every time they become aggressive and loud at home and the neighbours complain.

Or the parent who knows their child will eventually need to move to a group home but there just aren't enough spots available.

Or the parent who escaped trauma and war and does not trust the provider and only shares part of how their child's disability has impacted them and their family.

ARTICLE CONTINUES BELOW

Of course there are success stories, but those are the outliers. I can say this with confidence as I work with these children, youth and families and hear these stories daily. This is because our system has not been built with the basic premise that people with disabilities and differences have value that they bring to our society.

If we built systems differently, all of the above would be avoidable and we would not have to advocate for every child across multiple sectors including education, health and social services.

We have a long way to go and as we look to where our provincial and federal governments' priorities currently are, it is likely this situation will only get worse. That is, unless we will it otherwise.

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