

My story:

Alina Cameron, received her Masters of Science in Medicine from the University of Manitoba where she specialized in community health sciences and epidemiology. She and her family of 5 reside in Slate River, a rural area just outside of thunder Bay. Alina's 4 YO daughter, Fiona, was diagnosed as severely Autistic (non-verbal) at around 2 years of age, although the family knew from around the age of 4-6 months that there was something unique about her. At that 6-month mark, the family put on their advocacy boots and started looking for answers, pushing for that important early diagnosis, through a long gauntlet of health professionals, therapists, psychometrists, and waitlists. The family is currently still waiting for developmental/behavioural therapy, consistent communication therapy, occupational therapy, and respite services.

The family took part in an early intervention study to get something in the form of temporary therapy/guidance. Alina is currently forsaking her career in epidemiology/public health, learning different strategies, and trying her best to do therapies at home. This is financially stunting her, the family, and adding great stress to their lives. The family have spent considerable monies trying to bridge the gap, by turning common areas of the home into therapy centres for their daughter. Other costs incurred for Fiona include: food (she is restrictive in her diet), clothes (she chews to self sooth), and home repairs/renos to fix damage she has done/make things safer for her. Moving to a larger city centre, for care, is currently not an option for this family.

What does Fiona's care look like:

Fiona is a beautiful, clever, and happy little person. She is so full of sunshine and love. She enjoys spinning things in new and creative ways. She is an expert problem solver, is highly creative, and has shown a great propensity to try things in new and innovative ways because she is fearless. This also means that she requires continuous supervision due to her being a flight risk, and having no awareness of things that could endanger her. Our home is a fortress. Every door, window and cabinet, drawer, closet and cubby must be locked for her safety, and ours. Fiona has sensory processing issues, needs an extensive sensory diet daily, and is not yet toilet trained. She has night disturbances, meaning she is up in the middle of the night for hours needing care. It affects the functioning of the entire household. She has recently started school and is thriving there; we were lucky this year and ended up with an amazing classroom team made up of a teacher, teaching assistant, and full time SSP whom Fiona adores. I spend my afternoons providing the therapy she needs, as best I can tell, based upon what I can learn from online and what I could grab at the local service providers in terms of courses.

This life style impacts our immediate family, extended family, and everyone else we come in contact with. They all have to sacrifice their time and money in order to help us out...or we wouldn't get by. They are all giving up resources/energy/time to ensure my child is safe and happy. I want to recognize here and now that as tired as I am, not all families have that type of support.

Our daughter's care, like that of many others like her, is 24 hours a day, 7 days a week, 365 days a year. There is never a time that an ASD parent/caregiver is not "ON". You can't ever let your guard down or someone is getting hurt, or something is getting destroyed.

And then there is therapy, advocacy, dietary problems, physician appointments, behavioral issues, sensory diets, waitlists, endless paperwork where we have to continuously prove her disability, ableist rhetoric from random strangers, and dealing with family that just doesn't get it.

How we see things:

We are exhausted. Quite honestly, we don't have the energy or time to have to deal with the current political mess surrounding our child's care, life with Autism is stressful and exhausting enough. With the Ford government's changes not only are we losing therapeutic capacity, and access to supporting programs, but we are going to have to figure out how to navigate an entirely new system again. Who has time for this coming administrative nightmare? All of the changes made by the current government add up to increasing barriers to acquiring care/support.

I believe in the tenants of the social determinants of health and I myself have scientifically observed and measured the value of preventative approaches to health care. Why are we still waiting for therapies that are considered beneficial to a CHILD?

By ignoring the systemic issues, and not creating a solid foundation upon which to build a strong program, the new OAP will fail us. By allowing the proposed changes to the new OAP to proceed we are going to be negatively impacting the determinants of health not just for Autistic individuals but also their entire families, and therefore, communities. This pause in services will snowball into increased costs to social and health services down the road, and contribute to morbidity amongst this cohort. We will easily be able to track these issues back to the current government. We need an equitable program, that is needs based, and we need more therapist boots on the ground doing the work. Throwing a tiny bit of money at families in NWO, where no effort has been made to expand services or address local issues, will just mean we are still waiting but now on private waitlists.

I am angry that as a Canadian I am waiting for a form of Health Care, for my child, that she presently needs and is absolutely entitled to. I am shocked that the hole in services growing larger as we speak because again, someone isn't paying attention to the epidemiology or lack of services capacity in Northwestern Ontario. This is my child's life trajectory. Any parent in my shoes would feel this way.

I feel the Northwest region of Ontario is consistently left behind. There is an enormous and damaging gap here and it needs to be addressed, now.