


THE CANADIAN JOURNAL OF AUTISM EQUITY
LA REVUE CANADIENNE DE L'ÉQUITÉ EN MATIÈRE D'AUTISME

VOLUME 5 | ISSUE 1 | APRIL 2025

It Begins with a Diagnosis: Our Journey and the Promise of Canada's Autism Strategy

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RECOMMENDED CITATION: Linds, E., Linds, A., Shtaif, E., & Cooper, S. (2025). It Begins with a Diagnosis: Our Journey and the Promise of Canada's Autism Strategy. *The Canadian Journal of Autism Equity*, 5(1), 51–56.

It Begins with a Diagnosis: Our Journey and the Promise of Canada's Autism Strategy

Tout commence par un diagnostic : Notre parcours et la promesse de la Stratégie pour l'autisme au Canada

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Abstract

This narrative shares the story of a family's journey into understanding and supporting their child, beginning with the transformative moment of an autism diagnosis. The diagnosis helped them step into his beautiful universe filled with things that spin. The essay explores the role that Canada's Autism Strategy plays in shaping a brighter future for families like theirs. Focusing on the Strategy's priorities—screening and diagnosis, public awareness and acceptance, and tools and resources—it reflects on how these initiatives promise a more equitable and inclusive future. This is a story of love, discovery, and advocacy, grounded in the belief that change begins with understanding, and that every journey begins with a diagnosis.

Keywords

Diagnosis, Canada's autism strategy, early intervention, families, advocacy, policy reform, autism acceptance

Resumé

Ce récit raconte l'histoire d'une famille qui s'est efforcée de comprendre et de soutenir son enfant, en commençant par le moment transformateur qu'a été son diagnostic d'autisme. En effet, le diagnostic les a aidés à pénétrer dans l'univers magnifique et tournoyant de leur enfant.

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L'essai explore le rôle que joue la Stratégie pour l'autisme au Canada dans la construction d'un avenir meilleur pour des familles comme la leur. En se concentrant sur les priorités de la stratégie (dépistage et diagnostic, sensibilisation et acceptation du public, outils et ressources), l'autrice réfléchit à la façon dont ces initiatives promettent un avenir plus équitable et plus inclusif. Il s'agit d'une histoire d'amour, de découverte et de plaidoyer, fondée sur la conviction que le changement commence par la compréhension et que tout voyage commence par un diagnostic.

Mots-clés

Diagnostic, stratégie pour l'autisme au Canada, intervention précoce, familles, défense des droits, réforme des politiques, acceptation de l'autisme

“There is love, so much love, and also a longing - a feeling of standing on the edge of his universe, arms outstretched, hoping one day he'll reach back.”

I remember watching my child, G, mesmerized as he spun toy plates on the kitchen floor for hours. His eyes locked onto their motion, following each revolution with a focus so intense it felt like he was disappearing into another universe. His small hands, so confident and precise, moved like he was tracing the lines of a world only he could see. I saw both the beauty and the isolation that autism can bring. The way he connected with spinning was magical. But then, when we would call his name, it was as if we were echoes, distant calls he couldn't reach. There is love, so much love, and also a longing - a feeling of standing on the edge of his universe, arms outstretched, hoping one day he'll reach back.

Love brought us to the edge of his universe, and we needed to learn how to take the first step, to chart a course into his orbit, and to find supports that would help his star shine.

Diagnosis: Relief, Dreams, and Action

When our pediatrician initially suggested a “wait-and-see” approach, we felt a fierce urgency to act, to fight for early intervention so that he could find his voice. This intervention wasn't about 'fixing' him but about supporting his unique way of communicating. We wanted to understand him better and help the world see and appreciate who he truly is.

After some persistent advocacy, we were escalated to a local neuro-developmental centre and then came the waiting. We were told that assessing autism before age three was challenging due to the spectrum of typical toddler behaviour. So, we waited. We managed

his meltdowns in noisy spaces, trying to shield him from the chaos that overwhelmed him. We watched as his daycare turned him away, unable to handle his needs.

With the help of a known psychologist specializing in autism diagnosis, we scheduled a private, in-home assessment (which I acknowledge is a privilege that many cannot access). She administered the Autism Diagnostic Observation Schedule - Second Edition (ADOS-2) and the Autism Diagnostic Interview - Revised (ADI-R). We were sat down with a world of uncertainties, stuck in the doldrums unable to move, floating aimlessly. Finally, after what seemed like an eternity, we were given the validation we sought after. With the diagnosis in hand, we could finally access comprehensive support services—a step many individuals and families reach much later in the public system.

The diagnosis was the beginning of a remarkable journey. It was an invitation to truly understand him, to celebrate his strengths, and to immerse ourselves in his world. And what a world it is—a beautiful, spinning one.

Spinning was his passion, his joy, and his way of making sense of the world. At first, we simply observed as he spun toys, objects, and anything he could find. But soon, we joined him. We spun wood coins, plates, heavy objects, and light ones. It was the beginning of our shared language. As toys conducted their revolutions, so too there were revolutions in his development. His first word, ‘spin’, emerged from this connection. It opened the door to ‘round’, ‘start’, ‘stop’, and eventually a cascade of words tied to the joy of watching the world whirl.

We are in Alberta, and the diagnosis opened the door for us to access support services through our provincial health care system. A play therapist came to our home and met our child on his level. On our living room floor, they worked on social and emotional skills through play to develop tools to better navigate our world. Through play, they helped him build skills like turn-taking and following sequences, all while guiding him through the orbits of his own joy.

The diagnosis granted us weekly visits from an incredible youth worker at a local not-for-profit. She helped us learn about visual schedules, communication aids, and parenting strategies to create an environment at home where our child is fully supported.

The diagnosis also provided access to Program Unit Funding (PUF), an education focused funding grant, which allowed our child to attend a local school designed for children with disabilities with a great staff to student ratio. He accessed early intervention services like speech and occupational therapy which helped provide him the tools to communicate his needs to others.

Through this process, we became keenly aware of how precarious this journey could have been without timely diagnosis. For us, paying out-of-pocket for a private assessment meant bypassing years-long waitlists and gaining access to support. However, for many families, the cost of private assessments is prohibitive. This creates a devastating waterfall effect—delaying diagnosis, caregiver education, support services, and the opportunity to champion each child’s unique way of communicating and thriving. It’s a stark reminder that

equitable access to timely diagnosis and services is a necessity that should provide the foundation of any system designed to support autistic individuals and their families.

For our child who views the world through a different lens, and focuses so intensely, it transforms the mundane into something magical. When he receives support, autism for him is not a deficit, but a way of seeing the world that reveals the extraordinary.

For many autistic individuals with complex support needs, autism is a continual challenge for dignity, safety, comfort, and access to fundamental communication. Families caring for autistic individuals with complex support needs also face the challenges of caregiving without sufficient support, navigating systems to secure housing, respite care, and other essential services. Their needs are urgent and deserve attention and respect. It's crucial that support systems address both their immediate as well as their long-term well-being and autonomy.

Canada's Autism Strategy: A Vision for Change

When Canada's Autism Strategy⁴ was released on September 26, 2024, I couldn't sit still. I printed out the 46-page document, sat at my kitchen table, steam pouring out a cup of coffee at 11pm, and began reading line-by-line. My hands trembled impatiently as I held my highlighter, and not just because of the caffeine. I felt giddy, jittery with excitement, as if I'd just stumbled upon the ignition switch for a fire that had always burned inside me.

As I read through its pages, I thought about all the people on the spectrum who are a part of my life and how this document, this plan, has the potential to create real, lasting change for all of them.

Among its five priority areas, three spoke directly to us as a family:

Priority area 1: screening, diagnosis and services;

Priority area 4: public awareness and acceptance; and

Priority area 5: tools and resources.

They align with the hopes we hold and the dreams we envision for a more inclusive world.

Priority area 1: Screening, Diagnosis, and Services

For our family, the diagnosis was the turning point—it was the reason we could have play therapy sessions on our living room floor. Paying for a private assessment bypassed the waitlists of the public system and gave us the key to accessing support services. However, the stark reality remains: many families and individuals face significant delays and barriers.

There is also inconsistency across diagnostic systems. Families and individuals in one province may face dramatically different timelines and standards compared to others. Some may be told to wait years, while others are directed to long, fragmented processes with no

⁴ <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/canada-autism-strategy.html>

clear path forward. The diagnosis, which should be a bridge to support, often becomes a barrier in itself.

We're glad to see that Canada's Autism Strategy recognizes these systemic failures and offers a vision for change. Its focus on creating consistent, equitable national standards for screening and diagnosis, reducing wait times, and increasing capacity in the healthcare system addresses the very challenges we witnessed. For families like ours, this priority represents hope: hope that every autistic individual will be supported as early as possible to thrive as their authentic selves.

Priority area 4: Public Awareness and Acceptance

There is a unique kind of heartbreak that comes with seeing your child repeatedly misunderstood by the world. But for every moment like that, there are a hundred moments of wonder and joy seen through their eyes. My child's love of spinning is a gift, and it has recently grown into a focused interest for circuits and systems, for understanding how the world moves and works.

The Strategy's commitment to public awareness campaigns gives us hope for a future where our society goes beyond tolerating differences to cherishing and celebrating them. I believe in creating a culture of belonging, where every autistic individual feels seen, respected, and loved for who they are.

Priority area 5: Tools and Resources

When we started this journey, it felt like piloting a rocket-ship through uncharted space. We had no map, no clear destination, and no guide to help us navigate the complexities of his unique universe. Each discovery, whether it be a resource or a strategy for managing sensory overload, felt like finding a star in the vast expanse of the unknown, illuminating just enough to move forward. Every step required trial, error, and relentless determination.

The Tools and Resources priority of Canada's Autism Strategy promises to change this for families like ours. It aims to build a shared map for every parent, caregiver, and autistic individual, equipping them with evidence-based, accessible, and culturally relevant tools. With this, families and autistic individuals can chart their course with purpose and know they are not alone in their mission.

Our journey is only a small part of a vast and diverse spectrum of experiences, and every story in this community is unique and equally valuable. Listening to autistic individuals and self-advocates has shown me the importance of removing barriers to uplift and support the autistic community.

The release of Canada's Autism Strategy offers hope. It's a promise—a fragile yet powerful one. For my family, it is a promise that the love we have—the fierce, unyielding love that pushes us to advocate, to learn, and to fight—can create real, lasting change.

The stakes are too high, the love too deep, and the future of every autistic Canadian too important for anything less.

And I believe it begins with a diagnosis.

If you'd like to read the Canada Autism Strategy, please visit:

<https://www.canada.ca/en/public-health/services/publications/diseases-conditions/canada-autism-strategy.html>

Poem and Art by Emi Linds

extraordinary

dream on, little one
the world is loud
but your dreams are louder
let them hold on
to what they know
as you
forge the extraordinary

