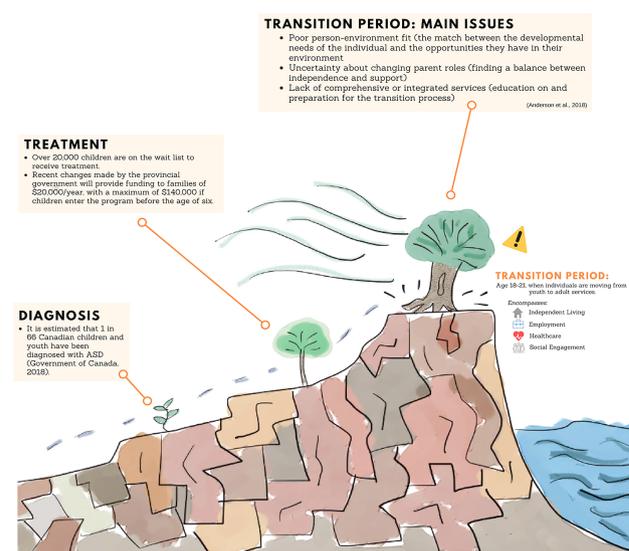


# AUTISM CARE IN 2030: THE TRANSITION PERIOD

## Changes in Autism Care from 2019 to 2030

### THE PROBLEM AS OF 2019



Our group chose to focus on the transition stage of autism care, which is the period in life where young adults leave the education system and enter the working world. This period provides unique challenges surrounding things like housing, employment, and healthcare. One major driver of this issue is the lack of funding that adults with autism receive. Despite the fact that autism can last a lifetime, the majority of funding and service efforts are focused on young children. In 2019, what little services do exist are being further diminished by the government through extreme funding cuts. This leaves transitioning adults with no way to support themselves, resulting in an increased burden on their caregivers, who undergo burnout or loss of funds themselves, and cannot always provide support. As a result, many young adults with autism are faced with increased levels of homelessness, become involved in the justice system, and make frequent visits to the emergency department.

Currently, in Ontario, the Ministry of Children, Community and Social Services is responsible for the care of all individuals with autism. This is a small ministry with very little reach, meaning that it is unable to cater towards the needs of young adults with autism who are going through the transition period. These adults are not provided with employment opportunities, housing support, or mental health care, which are all essential for them to become contributing members of the community.

Our artifact is a newspaper article from the year 2019 which outlines the story of Rimando, who is a young adult with a disability. Rimando is anticipating serious problems following impending budget cuts, which will axe an independent facilitating service that he relies on to function as a member of the community. Independent facilitators provide transitioning youth with support throughout their journey. "If this funding is cut and the program shuts down, there is no way for me to move forward," he says. "I won't know what to do next." This presents uncertainty as to where these transitioning young adults will be able to access care. Parents unable to manage or co-ordinate their adult son or daughter's daily life believe the only options are day programs, which cost as much as \$35,000 a year, or residential care, that typically runs at \$140,000 annually.

### HOW IT LOOKS IN 2030



January 18, 2028: The Government of Ontario shifted the sole responsibility of autism care from the Ministry of Children, Community and Social Services to be distributed among the following ministries, thereby forming the Integrative Autism Spectrum Team:

- Ministry of Children, Community and Social Services
- Ministry of Health and Long-term Care
- Ministry of Municipal Affairs and Housing
- Ministry of Training, Colleges and Universities
- Ministry of Economic Development, Job Creation and Trade
- Ministry of Education

Thus, turning autism care into an inter-ministry responsibility. These six ministries were chosen in an effort to target the major pain points identified through consultation with the Ontario autistic community which consisted of families, community and private organizations, service-providers, healthcare professionals, and self-advocates.

During community consultation, the following areas of concern were raised: 1) appropriate housing 2) access to therapeutic intervention 3) meaningful employment 4) educational reforms (particularly for those nearing the transition period) 5) health-care providers knowledgeable about autism care.

As these concerns directly involve multiple ministries and necessitate expertise in a range of areas, an inter-ministry approach was identified as the optimal solution for providing holistic autism care.

Following the implementation of this inter-ministry approach to autism through the Integrative Autism Spectrum Team, the Government of Ontario appointed Michael Ajit as the Autism Care Inter-Ministry Facilitator.

The Autism Care Inter-Ministry Facilitator is responsible for:

- Determining how the budget for autism care gets divided among the ministries
  - Engaging in continuous consultation with community stakeholders
  - Developing a provincial housing action plan for folks with autism who require assisted-living environments
  - Working with the Ministry of Education to re-evaluate how children are prepared for the transition period for long-term success
  - Expanding autism-supportive training provided to health care providers
- Michael Ajit previously worked as a policy advisor for autism care when it was the sole responsibility of the Ministry of Children, Community and Social Services. He is a caregiver for a son with autism and was motivated to do this work after the challenges his family had during the transition period.



### WHY IT WORKS

The pain points addressed by stakeholders back in 2019 were multi-faceted challenges touching on a range of policy arenas such as employment, housing, and service provision. By designating autism care as the sole responsibility of one ministry (as was the case in 2019), siloed ministries posed a barrier for collaboration between ministries.

By dispersing the responsibility of providing autism care to six different ministries, it turned autism care into an inter-ministry responsibility where ministries work together to co-design ideas. The Inter-Ministry approach transformed the issue of autism care from a Ministry of Children, Community and Social Services priority to an Ontario Ministries priority, thus placing it on the agendas of multiple government ministries. This has been particularly helpful for advancing service provided during the transition period which was an area that the Ministry of Children, Community and Social Services was unable to provide adequate support in prior to the implementation of the inter-ministry approach.

Since integrating the inter-ministry approach, the biggest wins have been:

- Making progress on the creation of an innovative, multi-ministry social housing model specific to autism. This housing model will address the issue of sustainable and affordable housing for adults with autism that require assisted living by offering in-house therapeutic interventions and meaningful employment opportunities.
- Streamlining the transition period for young adults with autism by creating a toolkit that shares information on key areas of concern such as future education, employment, health, and housing.

In 2019, all autism care funding was to be used and allocated by the Ministry of Children, Community and Social Services. Faced with increasing budget cuts, an inter-ministry model was introduced as a way to better utilize a limited amount of funding. With the official implementation of this model in 2028, the autism funding budget was dispersed across the six different ministries. As the different ministries already had social or physical capital in place that could be used to address specialized issues in autism care, this made funding stretch further than it ever did before. It also realized the potential for projects (such as the social housing model) where multiple ministries could work collaboratively to tackle multifaceted challenges. Additionally, by having multiple ministries join in on the discussion of autism care in Ontario, it paved way for a long-needed holistic approach to addressing the challenges faced by those with autism and their families.

#### Ministry of Children, Community and Social Services

- Especially concerned with the diagnosis and early intervention stage
- Dedicated team to research the experiences of autism on a community level
- Finding ways for existing youth services to better meet needs for individuals with autism

#### Ministry of Health and Long-Term Care

- Re-evaluating existing mental health services to better serve patients with autism, particularly in instances of comorbidity with other diseases
- Implement training for helping professionals to better assist autistic patients

#### Ministry of Municipal Affairs and Housing

- Surveying current housing infrastructure available for individuals with autism requiring supportive living environments
- Creation of social housing in collaboration with other ministries

#### Ministry of Training, Colleges and Universities

- Evaluating barriers to success in post-secondary education for individuals with autism
- Assessing ways to encourage employers to employ more accessible work structures
- Finding opportunities to improve transition period for individuals entering work force

#### Ministry of Economic Development, Job Creation and Trade

- Prioritizing efforts to create meaningful and sustainable economic opportunities for individuals with autism that are currently marginalized in the economic market
- Mediating negative economic impacts on full-time caregivers

#### Ministry of Education

- Evaluating opportunities to integrate early intervention into educational curriculum
- Creating transitional support workers to assist individuals with autism nearing the transition period