

# Autism After The Age of 18: Investigating Mothers' Perspectives

Nadine Minott, Kirsten Penrose, Kelly Carr, Patti Weir, Nadia R. Azar, Chad A. Sutherland and Sean Horton

APEX Research Group, Department of Kinesiology, University of Windsor

## Introduction

**80%** of individuals with autism spectrum disorder (ASD) are >18 years old.<sup>1-2</sup>

Little research is focused on ASD in adulthood, especially the **experiences of their parental caregivers.**<sup>3,4,8-11</sup>

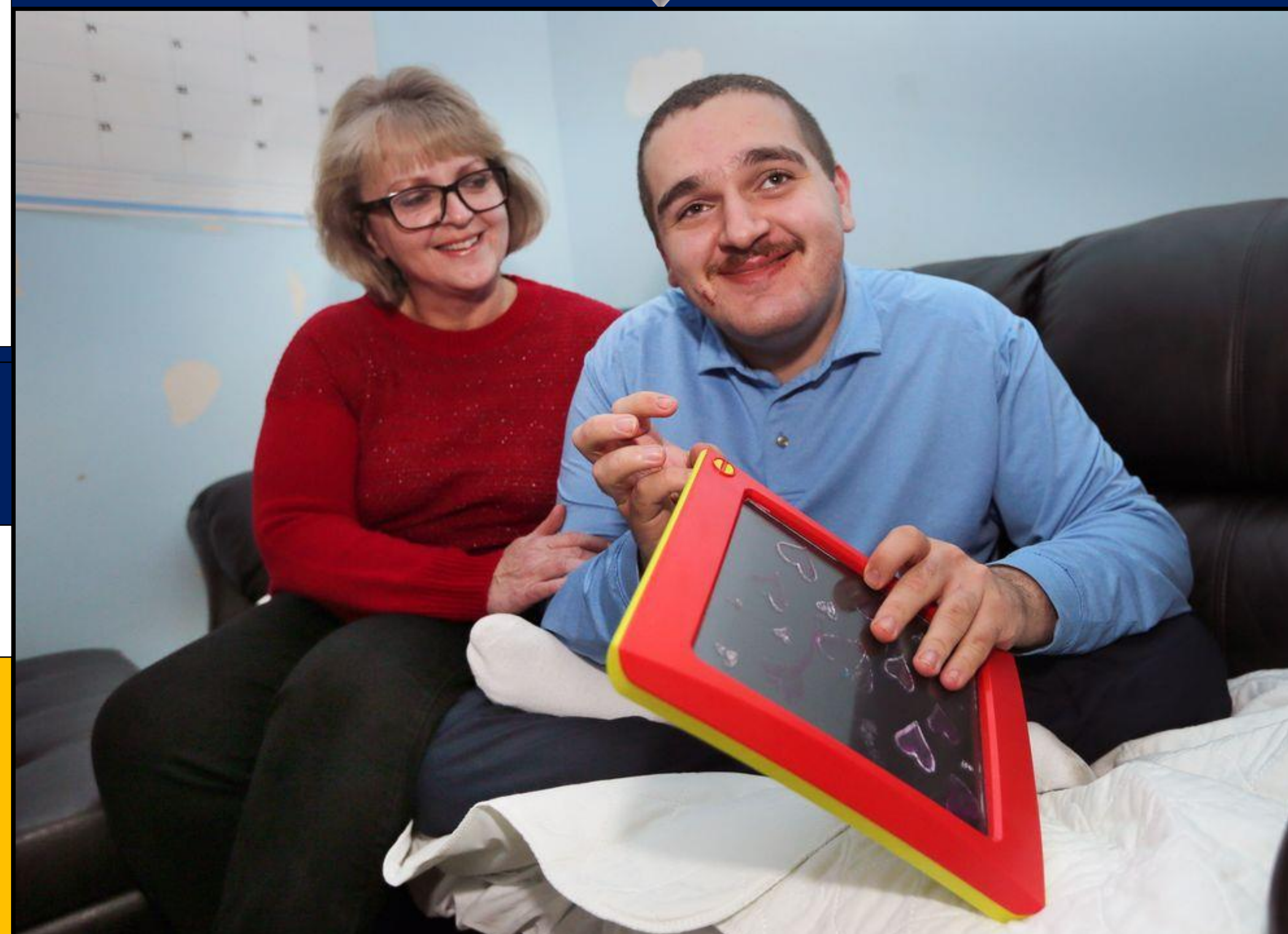
### Adult children with ASD

- **Age out** of formalized supports.<sup>5-9,12</sup>
- Reach a '**service cliff**' resulting from limitations in:
  - policies
  - services
  - resources



## Purpose

To employ a strength-based perspective when examining the lived experience of mothers caring for their adult child with ASD and an intellectual disability (ID).



## Participant Quotes

"When he was first diagnosed, we were told to put him in an institution... We've had a lot of struggles but... we've come a long way."

"They turn 12 and [services] start getting lower. Then these kids turn 18 and there is nothing."

"He's pretty good at carrying heavy things for me... He'll carry the groceries to the van and bring them into the house."

"You don't know what's going to happen when you're not here and you have to make sure that that's all set in place. So that's a big fear. When I'm gone, who's going to take care of him?"

## Methods

### Participants

**10 mothers** (M= 47.2 years; 8 employed, 2 retired) of adult, male children (M= 27.6 years) diagnosed with ASD-ID.

Adult children co-resided with their mothers (6), lived in group homes (2), or in alternate living arrangements (2).

### Data Collection

#### Strengths-based perspective

- Semi-structured interviews (1 to 2 hours).
- Probed for strengths, available resources, and overcoming challenges.

### Data Analysis

Inductive thematic analysis

## Results

### 1 Transition to Adulthood

- (1) autism is lifelong
- (2) suitability/availability of supportive services
- (3) cost/funding

### 2 Uncertainty Regarding the Future

- (1) aging caregivers
- (2) residence considerations
- (3) permanency planning

## Discussion

- Mothers' lifelong caregiving experiences involve a **delicate balance** between their personal aging process and the changing needs of their child throughout adulthood.
- Results confirmed a '**service cliff**'.
- Mothers' aging processes were benefited by close companionship, help with household tasks and community engagement through advocacy.
- Mothers adopted elements of a strength-based approach when caring for their adult children with ASD-ID.

<sup>1</sup> Nightingale (2012). *Nat Rev Drug Discov*, 11, 745-746.

<sup>2</sup> Marsack-Topolewski & Church (2019). *Am J Intellect Dev Disabil*, 124(2), 145-156.

<sup>3</sup> Wright et al. (2013). *Autism Insights*, 5, 21-73.

<sup>4</sup> Marsack & Preethy (2017). *J Autism & Dev Disorders*, 47, 2378-2389.

<sup>5</sup> Marsack-Topolewski & Weisz (2020). *Fam Soc*, 101(2), 190-204.

<sup>6</sup> Weiss et al. (2020) *INSAR*, 1-9.

<sup>7</sup> Friedman et al. (2013). *Neuropsychiatry*, 3(2).

<sup>8</sup> Stoddart et al. (2013). *J Autism & Dev Disorders*, 1-9.

<sup>9</sup> Happé & Charlton (2012). *Gerontology*, 58, 70-78.

<sup>10</sup> Wright (2017). *Autism Canada*. The-Odyssey-of-Autism-Aging.pdf (autismcanada.org).

<sup>11</sup> Jennings (1987). *NASW*, 430-433.

<sup>12</sup> Hare et al. (2004). *NAS*, 8(4), 425-444.