

Emergency Service Use of Ontario Teens and Adults with Autism:

Family Caregiver Study

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What we did
and why we
did it

Overview of the section

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Background

Why did we do this study?

People with autism and their families often have complex health care needs.

Ideally, these needs can be met in the community through proactive healthcare services (e.g., family doctors, psychiatrists). For some families, however, there are times when these needs extend beyond community resources and require unplanned care, or emergency service use (e.g., emergency department, police).

There are significant financial costs associated with high rates of emergency service use among people with autism. More importantly, parents of children with autism have reported stressful experiences and significant emotional costs of emergency service use. **We know little, however, about the emergency service patterns and what might lead to this use in teens and adults with autism.**

Objectives

This project aimed to better understand the emergency service use of teens and adults with autism from across Ontario.

We aimed to describe rates of emergency service use, associated clinical and family predictors of service use, and the related experiences of people with autism and their family members.

Findings from this study can inform people with autism, their families, emergency service providers, and policy makers of the relevant variables that need to be taken into account to improve service provision for this population.

Survey methods

What did we do?

Participants were recruited through flyers and email lists associated with Ontario autism advocacy and service organizations. We also conducted a series of public engagement sessions through Autism Ontario to explain the project to potential participants.

Between 2012-2013, 396 family caregivers volunteered to complete an initial baseline survey, five brief bi-monthly surveys, and a longer final survey a year to 18 months later.

We included data from **284 families** in this report. Included families completed their surveys within 12-18 months, and had a child over the age of 11 who met the cut-off score on an autism screener (Social Communication Questionnaire; Rutter, Bailey, & Lord, 2003).

Most participants (78.5%) completed the surveys online; a small portion completed the surveys via mail or telephone interview.

Who we studied

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[Family caregivers](#)

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Family caregivers

Who were the caregivers who completed the survey?

Sex/Gender

- Female (94%)

Age

- 31-79 years (M= 49.5)

Marital Status

- 76.4% married/common law

Immigrant status

- 23.6% were not born in Canada

Education

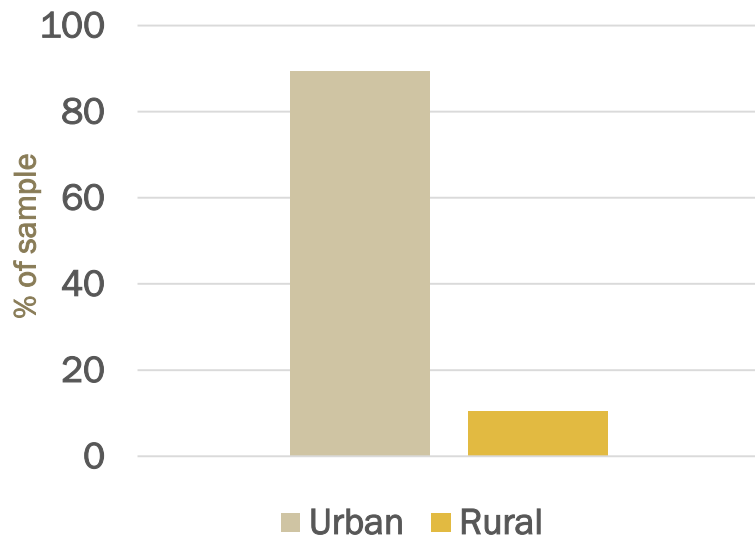
- 73.6% obtained a college diploma or higher

Neighborhood income

- \$33,030 - \$107,742 (Mean = \$65,597)

Family caregivers

Where did participants live?



Approximately 10% of participants resided in rural areas, which is comparable to overall provincial rates.

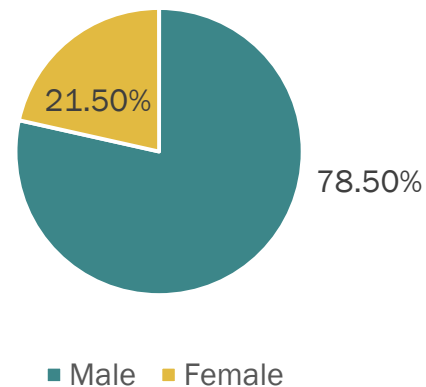
Individuals with autism

Who were the individuals with autism?

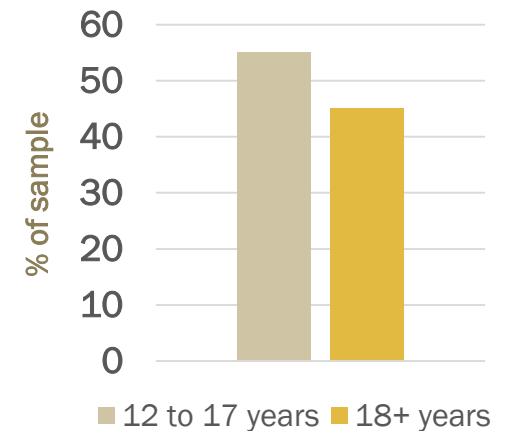
As is commonly seen in autism research, the sample was largely comprised of males.

Individuals with autism ranged in age from 12 to 56 years (Median age = 17 years).

Sex/Gender



Age



Individuals with autism

Intellectual disability (ID) status

- 47.5% were reported to have ID

Co-occurring conditions

- 34.5% were reported to have a medical condition
- 46.5% were reported to have a psychiatric condition

Place of residence

- 91.7% lived with their families at baseline

Daytime activities

- 86.3% participated in a structured day time activity (e.g., school, job, day program)

What we found

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Emergency department (ED)

Who visited the ED?

Psychiatric vs. medical ED visits

What happened in the ED?

Satisfaction with ED

Main messages

Lunsky ,Y., Weiss, J.A., Paquette-Smith, M., Durbin, A., Tint, A., Paulcka, A.M., & Bradley, E. (2017). Predictors of emergency department use by adolescents and adults with Autism Spectrum Disorder: A prospective cohort study. *BMJ Open*, 7(7), e017377. [click [here](#) to read]

Lunsky ,Y., Tint, A., Weiss, J.A., Paulcka, A.M., & Bradley, E. (2018). A review of emergency department visits made by youth and adults with autism spectrum disorder from the parent perspective. *Advances in Autism*, 4(1), 10 -18. [click [here](#) to read]

Who visited the ED?

Approximately 22% of people with autism went to the ED at least once during a 12-month period.

Significant predictors of ED use included:

- having an ED visit in the year prior to the study
- reporting 2 or more negative life events at baseline
- family distress

A combination of clinical need and contextual variables predicted ED use.

Lunsky ,Y., Weiss, J.A., Paquette-Smith, M., Durbin, A., Tint, A., Paulcka, A.M., & Bradley, E. (2017). Predictors of emergency department use by adolescents and adults with Autism Spectrum Disorder: A prospective cohort study. *BMJ Open*, 7(7), e017377. [click [here](#) to read]

Lunsky ,Y., Tint, A., Weiss, J.A., Paulcka, A.M., & Bradley, E. (2018). A review of emergency department visits made by youth and adults with autism spectrum disorder from the parent perspective. *Advances in Autism*, 4(1), 10 -18. [click [here](#) to read]

Psychiatric vs. medical ED visits

Why did individuals go to the ED?

We asked family caregivers to provide details about their family member's ED visit to better understand why individuals went to the ED. We included descriptions from **49 ED visits**.

31 Medical ED visits:

- Most common reasons: injury, gastrointestinal issues, infection

18 Psychiatric ED visits:

- Most common reasons: self harm and/or suicidality, physical assault towards family, danger to self and others

Psychiatric vs. medical ED visits

We found distinct predictors of psychiatric vs. medical ED visits.

Being on medication, family distress, and negative life events were associated with **both medical and psychiatric ED visits**.

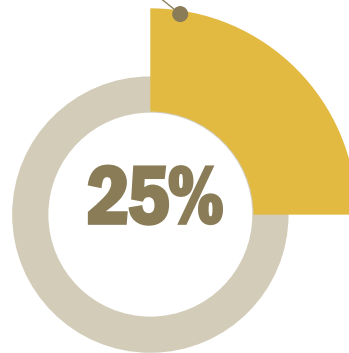
Low neighborhood income, living in a rural area, and having visited the ED during the previous year were associated with **medical** but not psychiatric emergencies.

Having a history of aggression, as well as being from a family that immigrated to Canada were associated with **psychiatric** but not medical ED visits.

medical ED visit	psychiatric ED visit
parent immigrant	parent immigrant
neighborhood income	neighborhood income
urban-rural residence	urban-rural residence
ED visit in prior year	ED visit in prior year
history of aggression	history of aggression
on medication	on medication
family distress	family distress
2+ negative life events	2+ negative life events

What happened in the ED?

**Chemical restraints
were used**



**Individual was taken to a
quiet area**



**Physical restraints
were used**



Satisfaction with ED

[My daughter] swallowed a piece of her necklace...stating she wanted to die, threatening to kill herself no matter what it takes. Nobody takes her seriously because of her autism. All autistic kids are put into one basket, and whatever they do is blamed on autism and doctors wash their hands and walk away.

- Mother of individual brought to ED for psychiatric emergency

How did parents feel about their family member's ED visit?

He handled it well. The staff at urgent care were amazing - kind, soft-spoken, very understanding and so helpful.

- Mother of individual brought to ED for medical emergency

Parents were asked to rate their satisfaction with their son/daughter's ED visit on a scale from 1 (very dissatisfied) to 5 (very satisfied):

The wait time was too long, only to find out that there were no crisis team resources available at that time. [We] would have had to wait longer, but having waited three hours, with no dinner, and a stressful afternoon with the police, we finally gave up and went home.

- Mother of individual brought to ED for psychiatric emergency

- Parents' responses ranged from 1 to 5 (Mean = 3.42)
- Approximately 51% of individuals indicated that they were *very dissatisfied* to *somewhat dissatisfied*.

*We need much more than writing a prescription and saying
goodbye. How about suggestions for treatment?
Observation at the hospital? Services for families in crisis
when a child can no longer safely stay in the home for the
sake of both the child and the family?*

Mother of individual with autism brought to ED for psychiatric emergency

Main messages

Teens and adults with autism and their families may experience emergencies at high rates.

Certain families may be at a greater risk of visiting the ED than others.

- Red flags for ED visits may include: **previous ED visits, stressful life events, and significant family distress.**
- One size does not fit all. Different families may be at greater risk for different types of ED visits.

Police

Who interacted with police?

Why were police involved?

What happened when police were involved?

Satisfaction with police

Main messages

Who interacted with police?

Approximately 16% of individuals with autism interacted with police at least once during a 12 to 18 month period.

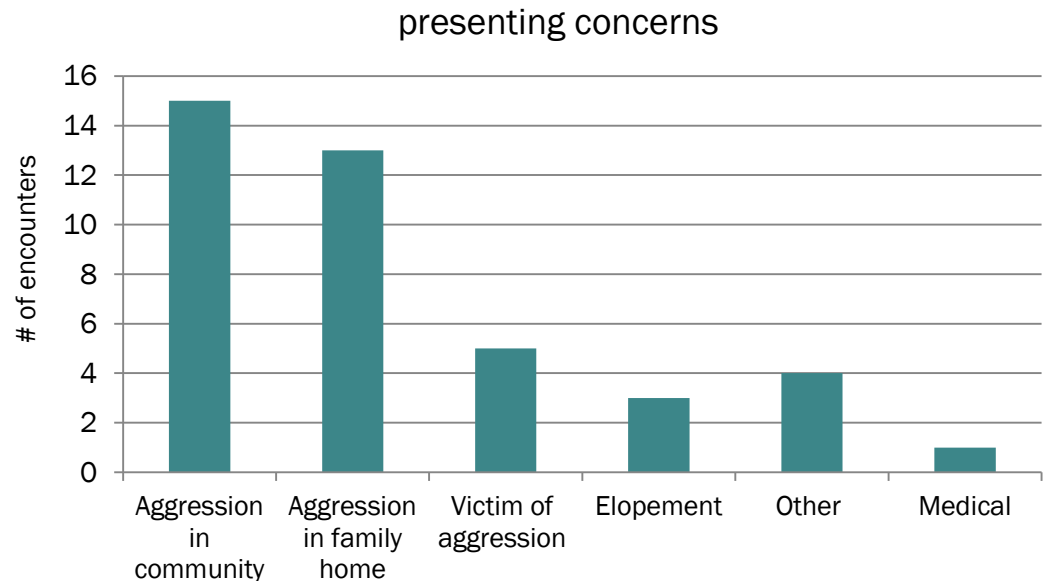
Compared to those without police interactions, individuals who interacted with police were more likely to:

- be older
- live outside the family home
- have a history of aggression
- have no structured day time activity
- have parents with high caregiver strain
- have families who were unable to afford services

Why were police involved?

Family caregivers of half of those with police involvement provided details about combined total of **47 police encounters**.

Aggressive behaviors were the primary concern requiring police involvement.

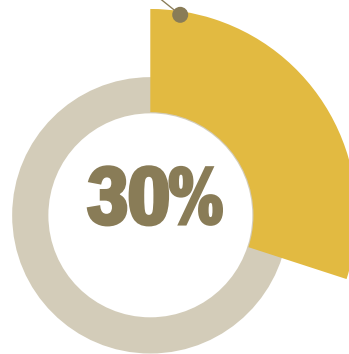


Each time police have been involved it's when [daughter] threatens to harm herself or harm myself or others - her emotion of anger is extreme and unyielding. There is concern for safety of all involved and of property. Calming tactics are always attempted first but often fail.

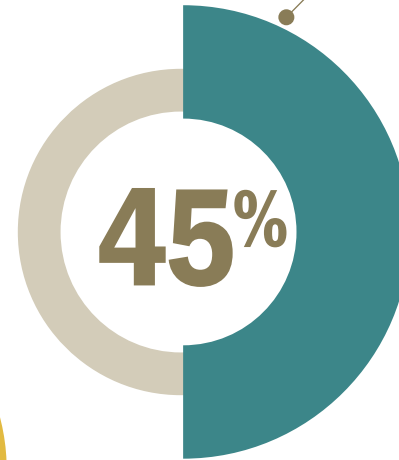
Mother of individual with autism and police involvement

What happened when police were involved?

Police escorted individual to ED



Police assessed the situation and left



Other disposition

e.g., police escorted individual to shelter



Individual taken into police custody



Satisfaction

How did parents feel about their family member's interactions with police?

Parents were asked to rate their satisfaction with their son/daughter's interaction with police on a scale from 1 (very dissatisfied) to 5 (very satisfied):

- Parents' satisfaction ratings ranged from 1 to 5 (Mean = 3.85)
- Majority of parents (63%) reported being *satisfied to very satisfied*.

[She] is registered with the police in a program for ASD people. They treated her carefully every time.

- Mother of individual with police involvement due to aggression

The police are getting better at dealing with autism. They're listening more.

- Mother of individual with police involvement due to aggression

I did not appreciate that the police didn't let me ride in the back of the police car with my son. Police let me ride in the police car when [son] was younger but now that he is 14 years old, he ...can ride alone. However, my son has autism and this makes him younger than he really is...

- Mother of individual with police involvement due to aggression

Main messages

Teens and adults with autism may interact with police at high rates.

Certain families may be at a greater risk of interacting with police than others.

- Red flags for police interactions may include:
 - Older age
 - Living outside the family home
 - No structured daytime activities
 - History of aggression
 - High caregiver strain
 - Families unable to afford services

Summary

[What do these results mean?](#)

[Sharing our results](#)

What do these results mean?

- Nearly 1 in 4 teens and adults went to the ED
- 1 in 6 interacted with police over the course of the study.

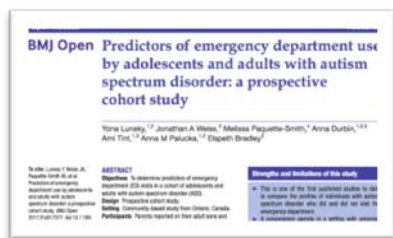
These results tell us that we need to work on:

- **Preventing** emergency situations for people with autism and their families
- **Preparing** for emergency situations

Sharing our results

This report is based on the results of two peer reviewed publications:

- Click [here](#) to read our article on **ED use** published in *BMJ Open*.
- Click [here](#) to read a *CAMH news article about the paper*



- Click [here](#) to read our article on **police interactions** published in the *Journal of Autism and Developmental Disorders*.
- Click [here](#) to read a *CBC article about the paper*
- Click [here](#) to read a *CAMH news article about the paper*



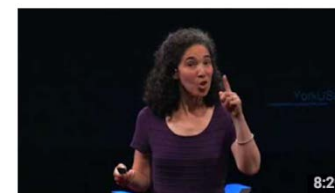
Dr. Yona Lunsky talked about the project and what findings mean for families and health care practitioners in these videos:

- [Finding your way through the healthcare maze: Lessons from research on health services and autism](#)



59:58

- [What's the Big Emergency? Improving healthcare access | Yona Lunsky | TEDxYorkUSalon](#)



8:28

Resources

Overview of the section

[Resources for service providers](#)

[Resources for families and
individuals with autism](#)

Resources for service providers

How can ED clinicians prepare to care for individuals with autism?

Click on the links below to view resources developed by different organizations to educate ED clinicians about providing care for individuals with autism (and other developmental disabilities):

- [H-CARDD's Emergency Toolkit](#)
- [H-CARDD's Autism & The Hospital Emergency Room Guide](#)
- [Autism Society's Information for Paramedics and Emergency Room Staff](#)
- [AASPIRE healthcare tool kit](#) (click on Health care providers)

How can police officers prepare to interact with individuals with autism?

Click on the links below to view resources developed by different organizations to educate police about interacting with individuals with autism:

- [Dennis Debbaudt's Law Enforcement Response Tips](#)
- [The National Autistic Society's Guide for Police and Staff](#)
- [Developmental Disabilities Justice Tool Kit](#)

Resources for families and individuals with autism

How can families and individuals prepare for ED visits?

Click on the links below to view resources developed by different organizations to assist families in preparing for ED visits:

- [H-CARDD's Going to the Hospital Health Handout](#)
- [Developmental Disabilities Primary Care Initiative's Guidance about Emergencies for Caregivers](#)
- [Story about visiting the emerge](#) for individuals with autism
- [Magnus Mode's Emergency Room Digital Card Deck \(click on health\)](#)

Tools for ED visits

- [H-CARDD's About Me patient tool](#) provides ED staff with important information about the patient
- [H-CARDD's My exit interview](#) helps to transfer important information about visits to caregivers and medical professionals
- [AASPIRE healthcare tool kit](#) for patients and caregivers
- [MedicAlert Autism Program](#)

Stories/Videos about ED visits

- [CAMH's Dr. Yona Lunsky discusses what to expect when you go to the ED](#)
- [A story about ED visits](#) from the perspective of a parent

Resources for families and individuals with autism

How can families and individuals prepare for police interactions?

Click on the links below to view resources developed by different organizations to assist families in preparing for police interactions:

- [CAMH's Jillian Carlyle discusses how to provide police with premise warnings and de-escalation techniques](#)
- [National Autism Society's Meet the Police Toolkit](#)
- [Autism Speaks' Interacting with Law Enforcement](#)

Stories about Police visits

- [A story about a family's experience](#) with police

Videos about Police visits

- [Autism Ontario Webinar](#) about engaging local first responders

Published Papers

Overview of the section

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[Medication use](#)

[Sex/gender differences](#)

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Background

We learned a lot from the families who participated in our study.

In this section, we provide summaries of all the papers we've published in connection with this project. Topics include:

- emergency service use
- parent self-efficacy
- caregiver burden
- medication use
- sex/gender differences

Emergency service use

What is this research about?

In this paper, we examined factors that contributed to emergency service use over a two-month period. We found that **a combination of need and enabling variables predicted emergency service use. The strongest predictors were previous ED use in the last year, a history of hurting others and having no structured daytime activities.**

Predictors of emergency service use in adolescents and adults with autism spectrum disorder living with family

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ABSTRACT

Introduction The use of emergency services among adolescents and adults with autism spectrum disorder (ASD) transitioning into adult health services has not been well described.

Objectives To describe emergency service use including emergency departments (EDs), paramedics, and police involvement among adolescents and adults with ASD and to examine predictors of using emergency services.

Methods Caregivers of 396 adolescents and adults with ASD were recruited through autism advocacy agencies and support programmes in Ontario to complete a survey about their child's health service use. Surveys were completed online, by mail and over the phone between December 2010 and October 2012. Parents were asked to describe their child's emergency service use

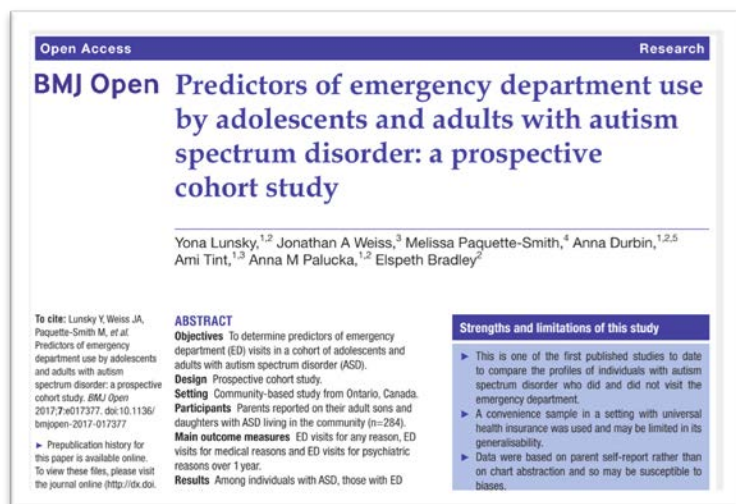
Key messages

What is already known on this subject

- ▶ Individuals with autism spectrum disorder (ASD) are also more likely to use emergency services than the general population.
- ▶ Most of what we know about hospitalisations and emergency use in individuals with ASD comes from the analysis of administrative health which speaks of the magnitude of the issue (ie, high rates of use), but does not provide in-depth clinical information on what leads to these visits or details about the visits themselves.
- ▶ No studies have examined predictors of emergency department (ED) visits among

- Click [here](#) to read our article on **emergency service use** published in *Emergency Medicine Journal*.
- Click [here](#) to read a research snapshot of this article from the [ASD Mental Health Blog](#).

Predictors of emergency department visits



What is this research about?

In this paper, we examined factors that contributed to the use of hospital emergency departments (ED) over the course of one year. **Individuals who visited the ED in the one year time period were more likely to have used the ED in the year prior. They also were more likely to report high levels of family distress and negative life events at baseline.** Considering the link between previous and future ED visits, effective care plans need to be in place following the first ED visit to help deal with future emergencies when they arise.

- Click [here](#) to read our article on **emergency service use** published in *BMJ Open*.
- Click [here](#) to read a research snapshot of this article from the [ASD Mental Health Blog](#).

Experiences in using the emergency department

A review of emergency department visits made by youth and adults with autism spectrum disorder from the parent perspective

Yona Lunsky, Ami Tint, Jonathan A. Weiss, Anna Palucka and Elspeth Bradley

Yona Lunsky is based at the Centre for Addiction and Mental Health, Toronto, Canada and is at Department of Psychiatry, University of Toronto, Toronto, Canada. Ami Tint and Jonathan A. Weiss are both based at the

Abstract

Purpose – Past research has shown individuals with autism spectrum disorder (ASD) visit hospital emergency departments (ED) at high rates. In order to assist individuals with ASD, their families and health care providers to improve ED care, it is important to understand these encounters in greater detail. The purpose of this paper is to provide a descriptive summary of the ED experiences of adolescents and adults with ASD, from the perspective of their families.

Design/methodology/approach – A subset of data from a larger prospective cohort study was used. Specifically, 46 parents of adolescents and adults with ASD provided details concerning 49 ED visits over a

What is this research about?

This paper describes the experiences that families of adolescents and adults with autism had in using the emergency department (ED). Individuals visited the ED for a variety of medical reasons (e.g., injury) and mental health reasons (i.e., being at risk to themselves). Although, overall parents reported that they were satisfied with the care received in the ED, they provided recommendations to improve the ED experiences of their family members with autism. Parent's recommendations included, specific accommodations for their child, greater empathy from ED staff and a need for more autism services at the hospital and in the community.

- Click [here](#) to our article on **families' experiences in using the ED** published in *Advances in Autism*.
- Click [here](#) to read a research snapshot of this article from the [ASD Mental Health Blog](#).

Parent self-efficacy

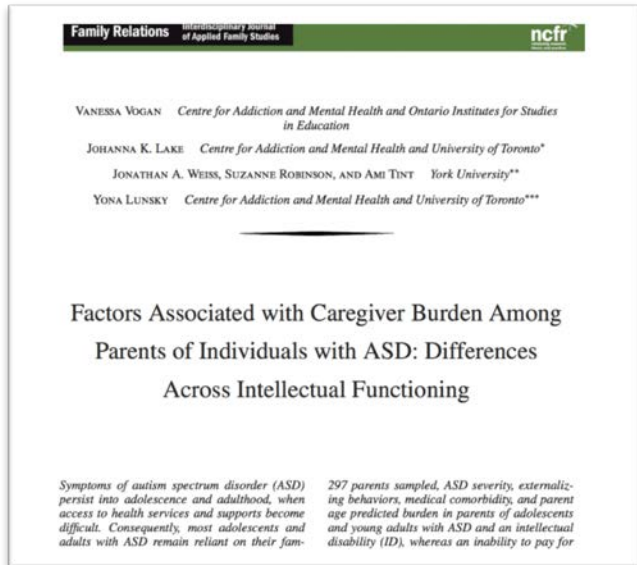


What is this research about?

Many parents of adolescents and adults with autism report feeling unsure about how to access services and find the right kind of care. This study looked at how well 324 parents thought they were able to access and provide care (i.e. their perceived 'self-efficacy') to their sons or daughters with autism (between 12–25 years of age). **Our results showed that lower self-efficacy was related to having an older child, being born outside Canada, experiencing more barriers to service access, and caregiver burden.** Given the crucial role that parents often play in the lives of individuals with autism across the lifespan, it is important that service providers support the efforts of parents to provide and access care.

- Click [here](#) to read our article on **parent self efficacy** published in the journal *Autism*.
- Click [here](#) to read a research snapshot of this article from the [ASD Mental Health Blog](#).

Caregiver burden



- Click [here](#) to read our article on caregiver burden published in *Family Relations*.
- Click [here](#) to read a research snapshot of this article from the [ASD Mental Health Blog](#).

What is this research about?

As health services and supports become increasingly difficult for adolescents and adults with autism to access, these individuals rely on their families for support, often resulting in caregiver burden among parents. This study investigated factors associated with burden in parents of adolescents and young adults with autism to understand how these factors differ across varying levels of their child's intellectual functioning. Of the 297 parents sampled, **autism severity, externalizing behaviours, medical comorbidity, and parent age predicted burden in parents of adolescents and young adults with autism and an intellectual disability (ID), while inability to pay for services predicted burden in parents of individuals with autism and no ID.**

Medication use



What is this research about?

Psychotropic medications are frequently used to treat mental health and behavioral issues in adolescents and adults with autism. In this study, the research team found that parents of **young adults (18-30 year olds) with autism were less likely to try non-pharmacological approaches before using psychotropic medication compared to parents of adolescents (12-17 year olds)**. Also, parents of young adults were less satisfied with the perceived expertise and monitoring of medication use than parents of adolescents.

- Click [here](#) to read our article on **medication use** published in the *Journal of Child and Adolescent Psychopharmacology*.
- Click [here](#) to read a research snapshot of this article from the [ASD Mental Health Blog](#).

Sex/gender differences



What is this research about?

We know very little about the service use patterns of girls and women with autism. In this study, caregivers of 61 adolescent girls and women with autism and 223 boys and men completed an online survey. Many adolescent girls and women with autism were reported to have mental and physical conditions and their parents reported high levels of caregiver strain. Overall, few differences were found between males and females, although **a greater proportion of girls and women used psychiatry and ED services compared to boys and men.** These results suggest that girls and women with autism may share many of the same high clinical needs and patterns of services use as boys and men with autism.

- Click [here](#) to read our article on **sex/gender differences in service use** published in *Autism Research*.
- Click [here](#) to read a research snapshot of this article from the [ASD Mental Health Blog](#).

Involvement with police



What is this research about?

This study described the interactions that individuals with autism and their families had with police and their satisfaction with police services. **Approximately 16% of individuals reported having some form of police involvement over the course of the year.** Individuals with autism that used police services were more likely to be older, have a history of aggression, live outside the family home, and have parents with higher rates of caregiver stress and greater financial difficulties. Most parents reported being satisfied (or very satisfied) with their child's encounters with police.

- Click [here](#) to read our article on families experiences in using the ED published in *Journal of Autism and Developmental Disorders*.
- Click [here](#) to read a research snapshot of this article from the [ASD Mental Health Blog](#).

Next steps

Overview of the section

[What's next?](#)

What's next?

In this report, we highlighted results from our [family caregiver study](#) in which families of individuals with autism shared their experiences with emergency service use. To better understand the experiences of individuals across the spectrum, we also conducted a similar survey with adults with autism who live independently. [Click here](#) to read about our [adult self advocate study](#).

For more information about autism research, visit the [ASD Mental Health Blog](#).

For more information about health care research and developmental disabilities, including health care resources, visit the [H-CARDD website](#).

Thank you

We thank all of the families for their time and participation.

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