

Emergency Service Use of Ontario Teens and Adults with Autism:

Adult Self-Advocate Study

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What we did and why we did it

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Background

Why did we do this study?

Adults with autism often have complex health care needs.

Ideally, these needs can be met in the community through proactive healthcare (e.g., family doctors, psychiatrists). For some individuals, 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 individuals with autism. **We know little, however, about the emergency service patterns and what might lead to this use in adults with autism.**

Objectives

This project aimed to better understand the emergency service use of adults with autism from across Ontario, *from their perspective.*

We aimed to describe the rates of emergency service use and the experiences of adults with autism in using emergency services, from their own perspective.

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

This study is the second part of a study we completed focusing on emergency service use in individuals with autism from the *family perspective.* To see the results from that study, [click \[here\]](#)

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, 66 adults with autism 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 **40 adults** in this report who were living independently. Participants were over the age of 17, did not report a diagnosis of intellectual disability, completed their surveys within 12-18 months, and met the cut-off score on an autism screener (Autism Quotient; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001).

Most participants (97.5%) completed the surveys online; a minority completed the surveys via mail or telephone interview.

Who we studied

Overview of the section

Self advocates

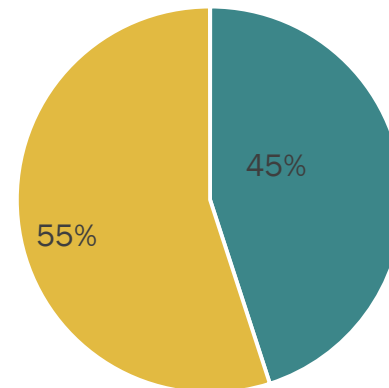
Self advocates

Who were the self-advocates
who completed the survey?

Although autism is more prevalent in males,
the majority of adults with autism who
completed our surveys were female.

Age
18-61 years old
(Mean age = 36 years)

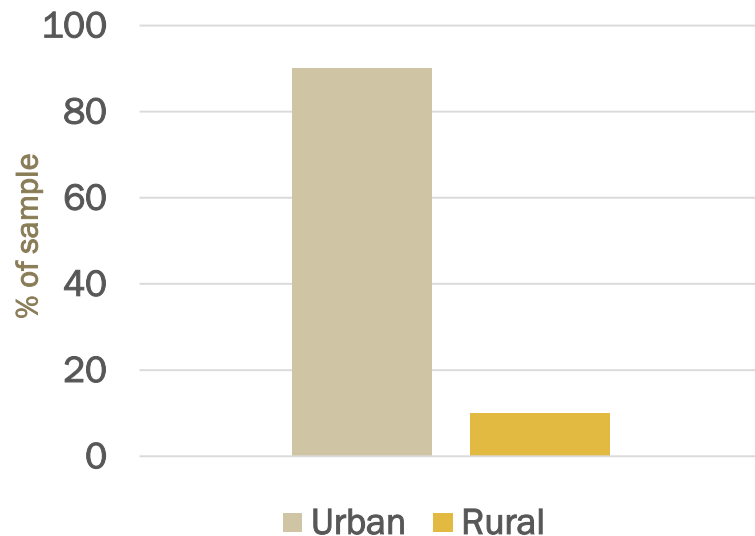
Sex/Gender



■ Male ■ Female

Self advocates

Where did participants live?



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

Self advocates

Marital Status

- 60.0% single/never married

Neighborhood income

- \$39,160 to \$97,706 (Mean = \$70,068.35)

Co-occurring psychiatric diagnosis

- 75% reported a co-occurring mental health condition

Education

- 62.5% obtained a college diploma or higher

Daytime activity

- 82.5% participated in a structured day time activity (e.g., school, work)

Co-occurring medical diagnosis

- 75% reported a co-occurring medical health condition

What we found

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Emergency department (ED)

Who visited the ED and why?

What happened in the ED?

Satisfaction with ED

Main messages

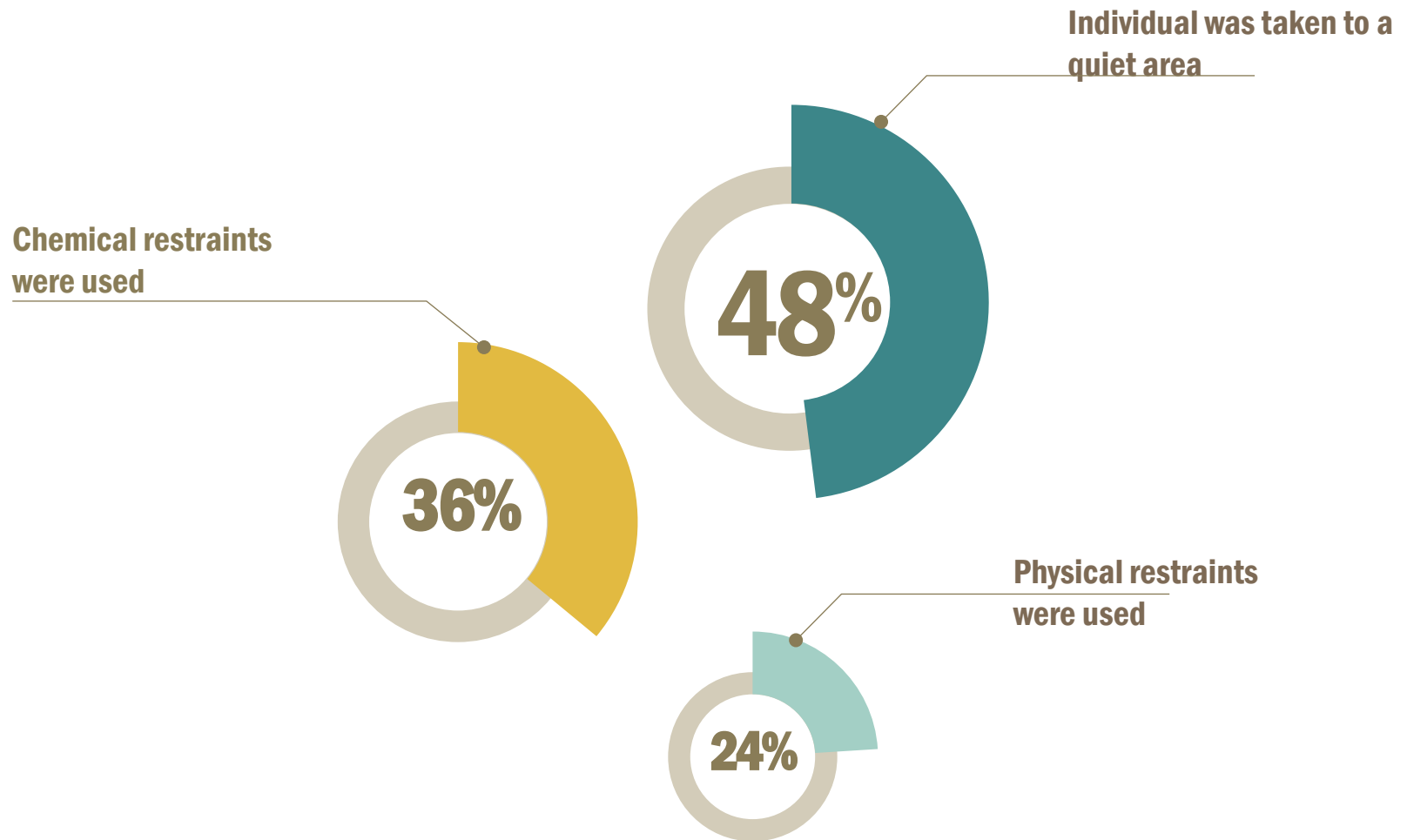
Who visited the ED and why?

Approximately 43% of individuals with autism went to the ED at least once during the follow-up period.

11 individuals who went to the ED provided details about a total 25 ED visits:

- Over half ($n = 14$, 56%) of ED visits were due to individuals presenting as danger to themselves.
- In a minority of cases, individuals went to the ED because they were a danger to others ($n = 2$, 8%)
- One ED visit was due to an individual requiring psychiatric medication
- The remaining reasons for ED visits were medical in nature (32% e.g., allergic reactions, food poisoning).

What happened in the ED?



Satisfaction with ED

How did adults with autism feel about their ED experiences?

Participants were asked to rate their satisfaction with their ED visit on a scale from 1 (very *dissatisfied*) to 5 (very *satisfied*):

- Responses ranged from 1 to 5, with an average score of *somewhat dissatisfied* (Median = 2.50; Mean = 2.73)

They should have put me in the secluded area sooner. I was a disruption to others in the waiting room because of my state of my mind.

-Individual who visited the ED for psychiatric concerns

The medical outcomes were fine and appropriate. The attitudinal interview approach of the physician was problematic to me. He only gave me two options for responding to his questions and seemed unable to entertain the possibility of my description of symptoms as being different from what he wanted or needed to hear.

-Individual who visited the ED for medical concerns

Main messages

Adults with autism may go to the ED at high rates and for a number of different reasons.

- Several ED visits were due to individuals indicating that they were a danger to themselves.
- [Click here](#) to read a commentary article about the need for more research on understanding and preventing suicidality in individuals with autism.
- Overall, participants were somewhat dissatisfied with their ED experiences.
- It is important for future work to include adults with autism to better understand how to improve ED experiences.

Police

Who interacted with police and why?

What happened when police were involved?

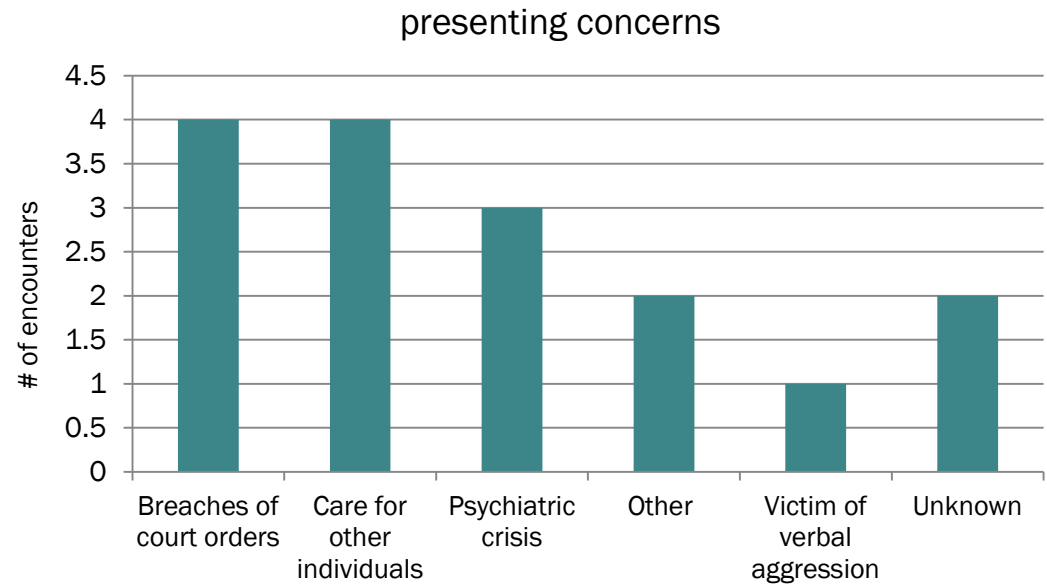
Satisfaction with police

Main messages

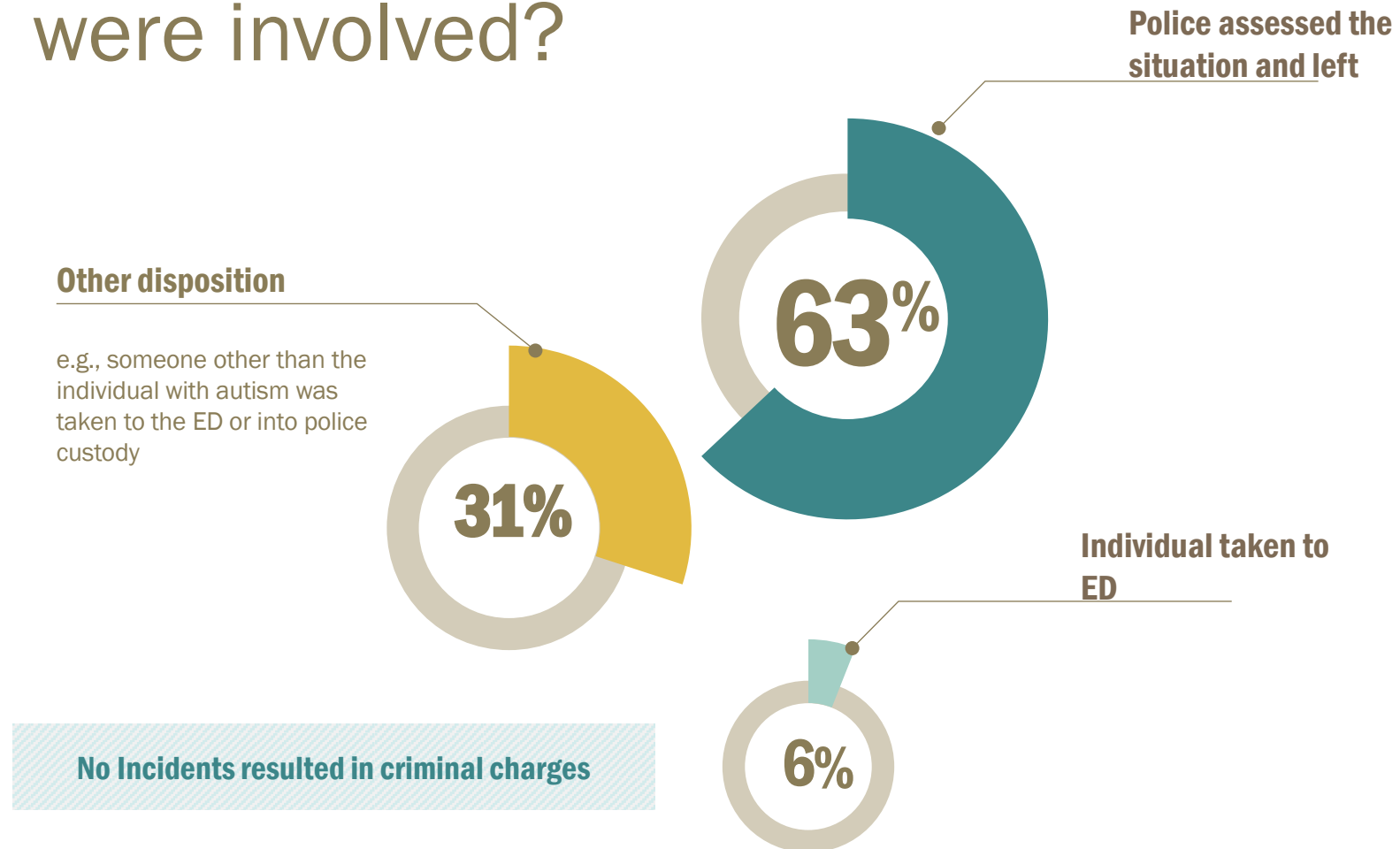
Who interacted with police and why?

10 individuals with police involvement
provided details about 16 incidents

Approximately 33% of
adults with autism
interacted with police at
least once during the 12-
18 month follow-up
period.



What happened when police were involved?



Satisfaction with police

How did adults with autism feel about their interactions with police?

Individuals were asked to rate their satisfaction with their interaction with police on a scale from 1 (very dissatisfied) to 5 (very satisfied):

- Responses ranged from 1 to 5, with an average score of *somewhat satisfied* (Median = 4.0; Mean = 3.68).

There were no issues with responding services, although the incident was very stressful for me.

– Individual with police involvement regarding care needs of another individual

Main messages

Adults with autism may interact with police at high rates and for several different reasons.

- Police officers play many different roles in the community, and it is important to understand that they may interact with adults with autism in a variety of situations.
- Overall, participants were somewhat satisfied with their police interactions.
- It will important for future research to better understand predictors of police satisfaction among adults with autism across a range of situations.

Predictors of emergency service use

Individuals who used either ED or police services at least once during the follow up period were **not significantly different** from those who did not use emergency services with respect to:

- Age
- Sex/gender
- Autism symptom severity
- Presence of co-occurring medical or psychiatric diagnoses
- Education
- Service affordability
- Structured day activity

These results highlight the importance of general preparedness and wide spread prevention efforts in the autism community and among emergency service providers.

Resources

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[Resources for adults 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](#)
- [HCARDD'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](#)

Resources for adults with autism

How can individuals with autism prepare for ED visits?

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

- [CAMH's Dr. Yona Lunsky discusses what to expect when you go to the ED](#)
- [H-CARDD's Going to the Hospital Health Handout](#)
- [AASPIRE healthcare tool kit](#) (click on patients and supporters)
- [MedicAlert Autism Program](#)

How can individuals with autism prepare for police interactions?

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

- [National Autism Society's Meet the Police Toolkit](#)
- [Autism Speaks' Interacting with Law Enforcement](#)

Published Papers

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Background

We learned a lot from the self-advocates who participated in our study.

In this section, we will highlight other findings from the adult self-advocate study about:

- health service use
- suicidality
- negative life events

Health service use

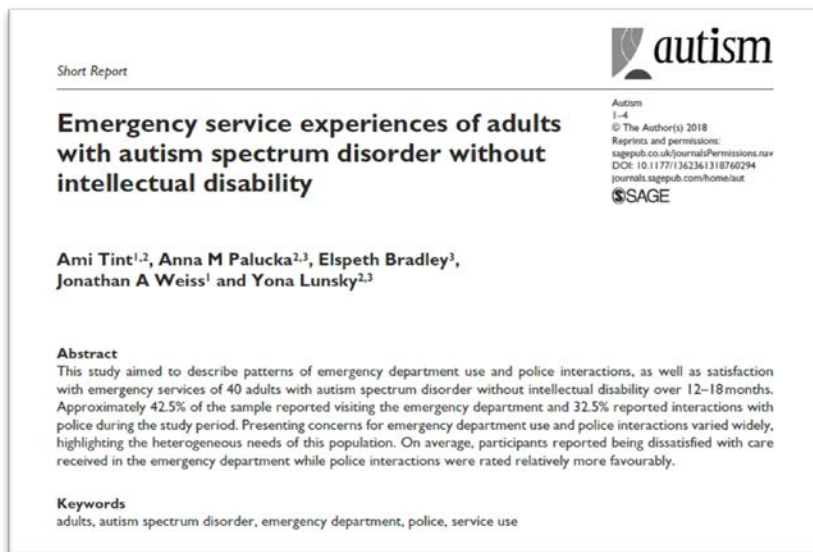


- Click [here](#) to read the abstract of our article on **health service use** published in the *Disability and Health Journal*.
- Click [here](#) to read a research snapshot of this article from the [ASD Mental Health Blog](#).

What is this research about?

Adults with autism encounter many difficulties finding and accessing health care services. To better understand their needs, this study looked at what medical and mental health services 40 adults (ages 18–61 years) with autism without intellectual disability used over a 12-18 month period, as well as adults' personal experiences accessing and using these services, barriers to service use, and reported unmet service needs. **Our results showed that beyond a family doctor, the most commonly used services were dentistry, individual counseling, and psychiatry. Adults with autism who had medical problems experienced significantly more barriers to service use than those who did not, and those who had medical and mental health problems were less satisfied with services.**

Emergency service use

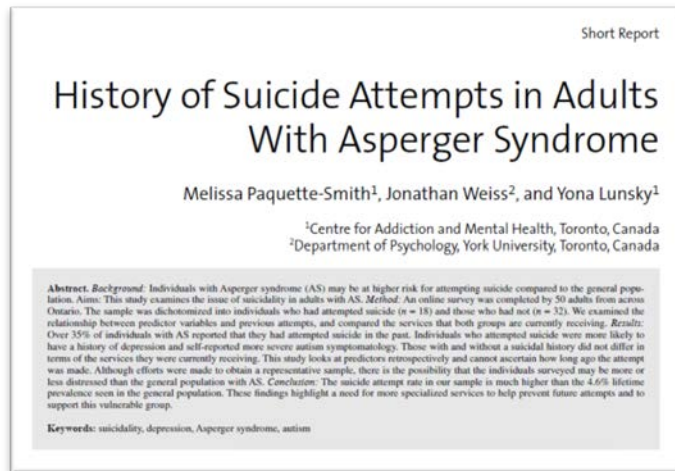


What is this research about?

This study looked at ED and police interactions in adults with autism that do not have intellectual disabilities. In the 12-18 month observation period, **43% of the sample reported visiting the emergency department at least once and 32.5% of the sample reported at least one interaction with police.** The presenting issues for ED and police visits varied widely. Generally, participants reported greater satisfaction with police services than with ED visits.

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

Suicidality



What is this research about?

This study examined the issue of suicidality in adults with Asperger Syndrome (AS). Fifty adults with AS from across Ontario completed an online survey. **Over 35% of individuals with AS reported that they had attempted suicide in the past. Individuals who attempted suicide were more likely to have a history of depression and self-reported more severe autism symptomatology.** The suicide attempt rate in this sample is much higher than the 4.6% lifetime prevalence seen in the general population. These findings highlight a need for more specialized services to help prevent future attempts and to support this vulnerable group.

- Click [here](#) to read our article on **suicidality** published in *Crisis: The Journal of Crisis Intervention and Suicide Prevention*.
- Click [here](#) to read a research snapshot of this article from the [ASD Mental Health Blog](#).

Negative life events



What is this research about?

This study looked at how often individuals with Asperger Syndrome (AS) experience different types of negative life events over a two-month period. The most frequently reported life events included: unemployment; financial problems; mistreatment; disruptions in interpersonal relations; change in living arrangements; and disruptions of routine at work or school. **The majority of respondents had at least one significant life event, 58.8% had experienced at least two, and 41.2% had at least three. A significant relationship was found between the number of life events and reported levels of distress.**

- Click [here](#) to read our article on **negative life events** published in the *Journal of Developmental Disabilities*.
- Click [here](#) to read a research snapshot of this article from the [ASD Mental Health Blog](#).

Thank you

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

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