

Partnerships in Autism Mental Health Research

Yona Lunsky

McMaster University

May 26, 2023

PARTNERSHIPS

If we don't count, they don't count

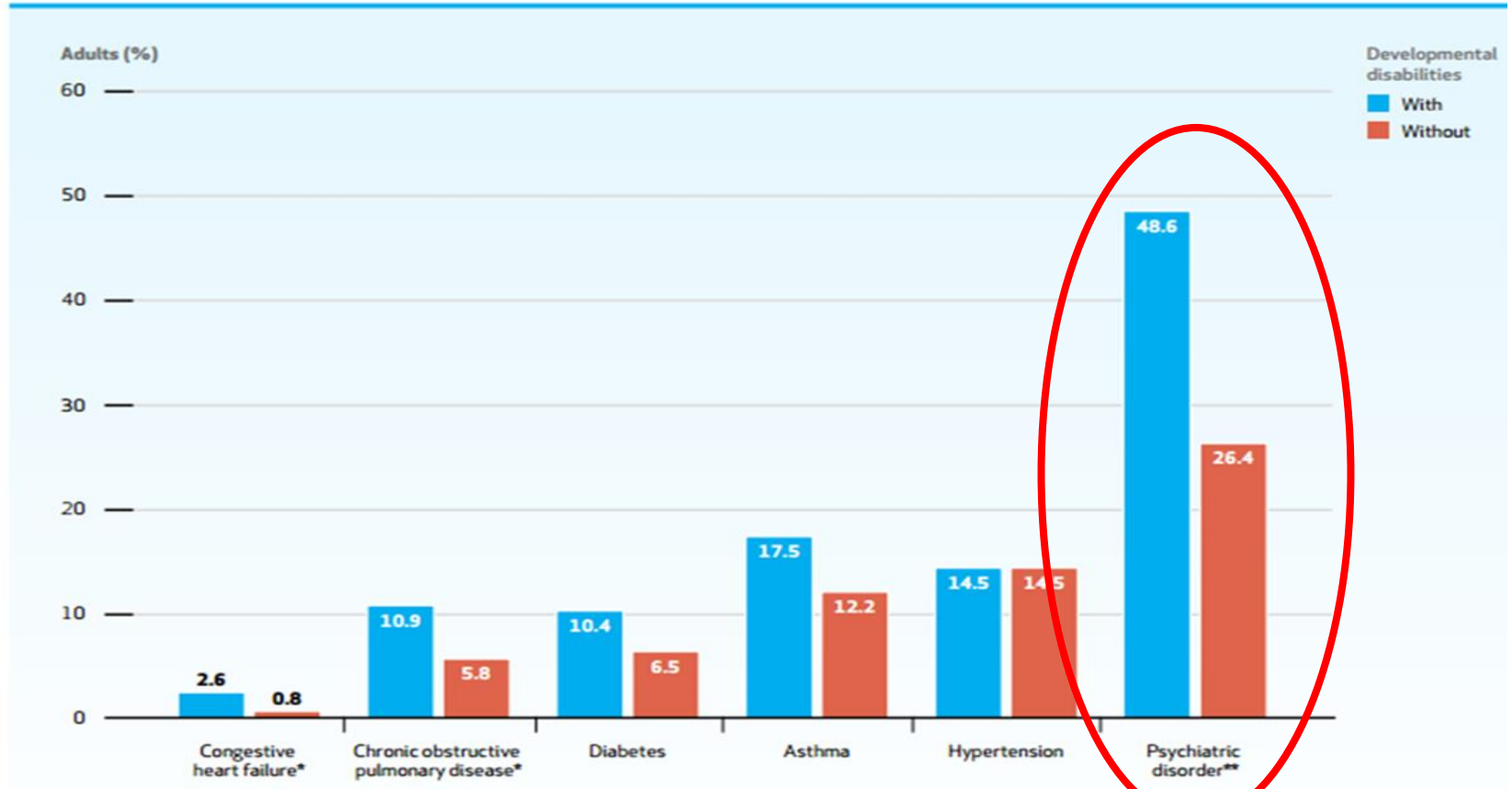
The H-CARDD program

Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario

December 2013

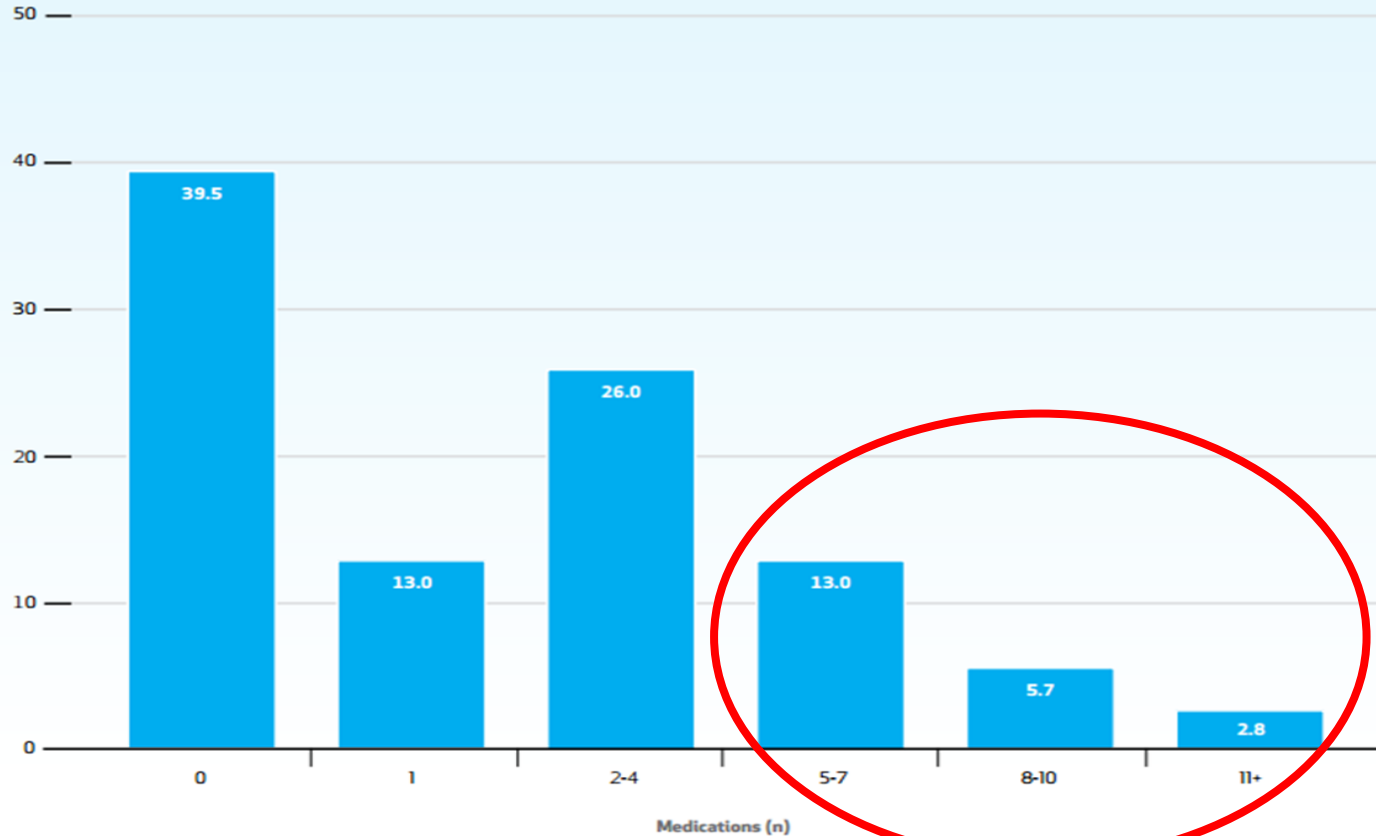


Co-occurring conditions

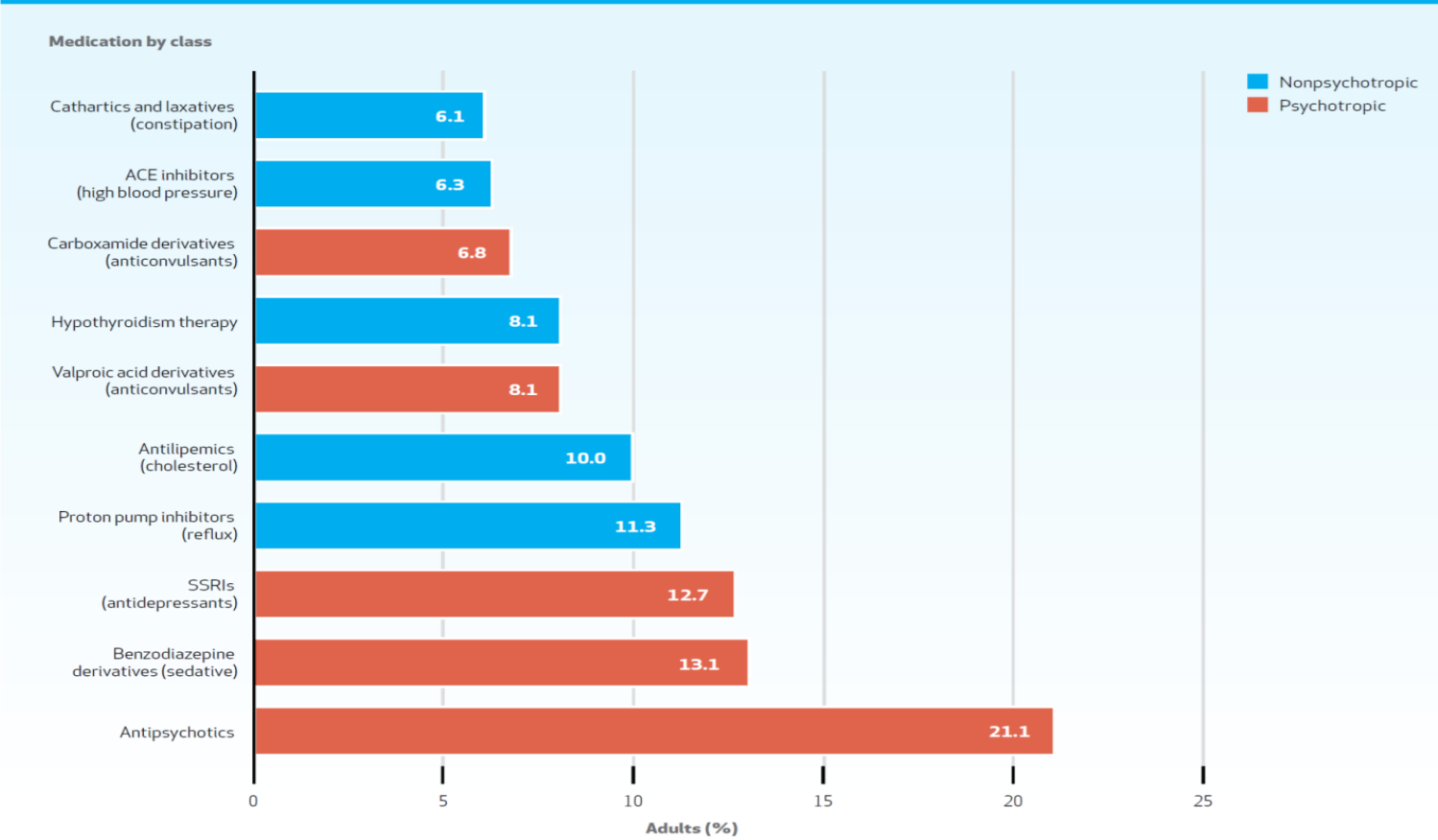


Medication Use

Adults (%)



Most commonly prescribed medications



Note: The categories displayed are not mutually exclusive. Some individuals were dispensed medications from multiple classes.

Antipsychotics common for adults with intellectual and developmental disabilities



Six-year Canadian study shows prescriptions often occur in adults with no psychiatric diagnosis

Study looked at health care data of 51,881 adults 18 to 64 years of age with intellectual and developmental disabilities (IDD) from 2010 to 2016.

IDD includes conditions such as Down syndrome, fetal alcohol syndrome and autism.

39% of Ontario adults with IDD were dispensed antipsychotic medication.

Among them:

Almost 1/3 did not have a documented psychiatric diagnosis.



Researchers say more scrutiny is needed in how antipsychotics are prescribed for this vulnerable population.

Lunsky Y et al. *Can J Psychiatry*. 2017.

Institute for Clinical Evaluative Sciences
ices.on.ca

ODPRN



Health Care Access Research
and Developmental Disabilities

2017

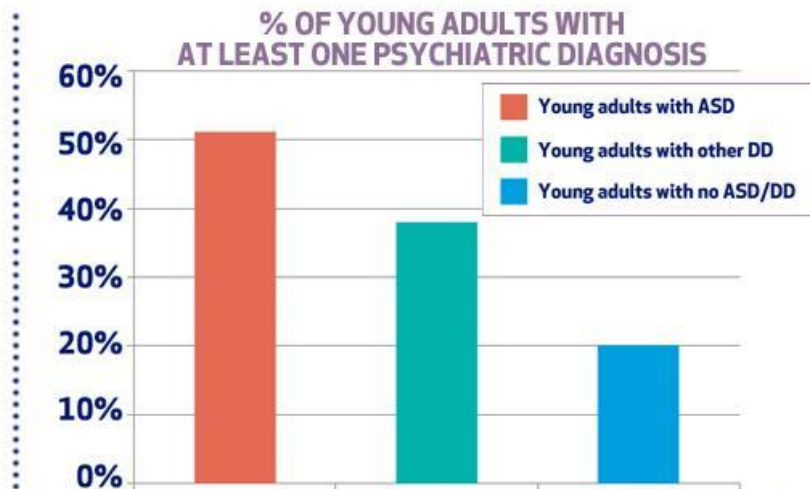
Half of young adults with autism have a psychiatric diagnosis



Research shows mental health care and prevention should be prioritized for those with autism spectrum disorder (ASD) and other developmental disabilities (DD) in Ontario

Study compared 5,095 young adults 18 to 24 years of age with ASD to peers with and without other forms of DD.

People with ASD have deficits in socio-communicative ability and behaviour. They experience difficulties with health, mental health and challenging behaviours, which can lead to increased service use.



Weiss J et al. *J Autism Dev Disord.* 2017.

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ices.on.ca

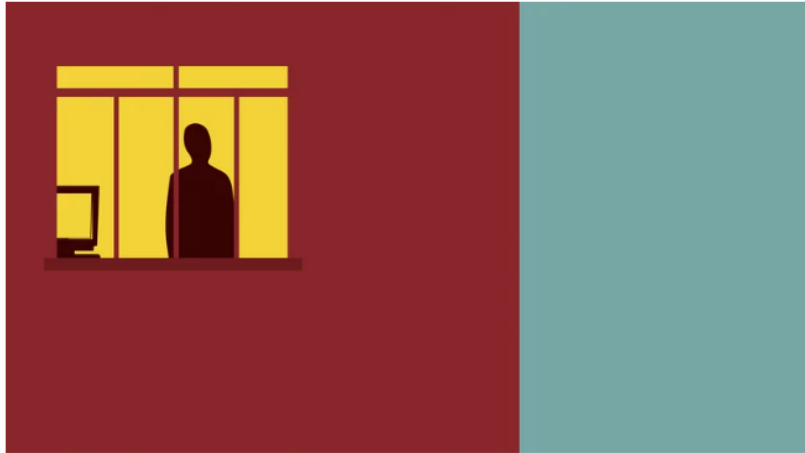


YOUR HEALTH

Many Young Adults With Autism Also Have Mental Health Issues

October 1, 2017 · 5:00 AM ET

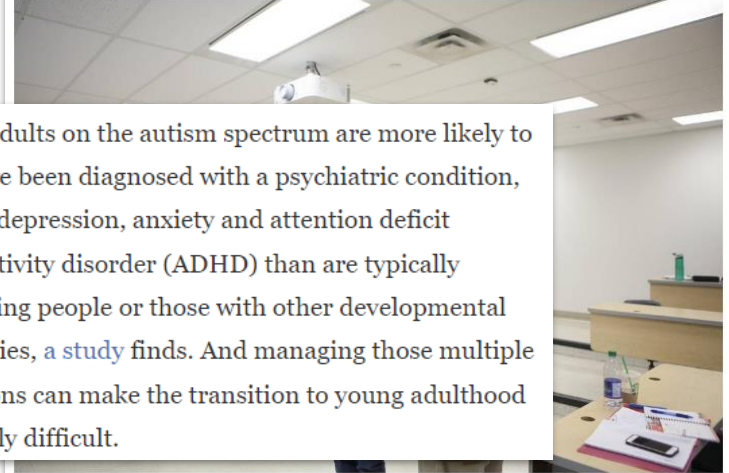
By Tara Haelle



MENTAL HEALTH

Young adults with autism more likely to have psychiatric problems: study

Researcher suggests findings highlight a need to focus on mental health care for individuals with autism spectrum disorder



Young adults on the autism spectrum are more likely to also have been diagnosed with a psychiatric condition, such as depression, anxiety and attention deficit hyperactivity disorder (ADHD) than are typically developing people or those with other developmental disabilities, [a study](#) finds. And managing those multiple conditions can make the transition to young adulthood especially difficult.

Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities in Ontario

February 2019



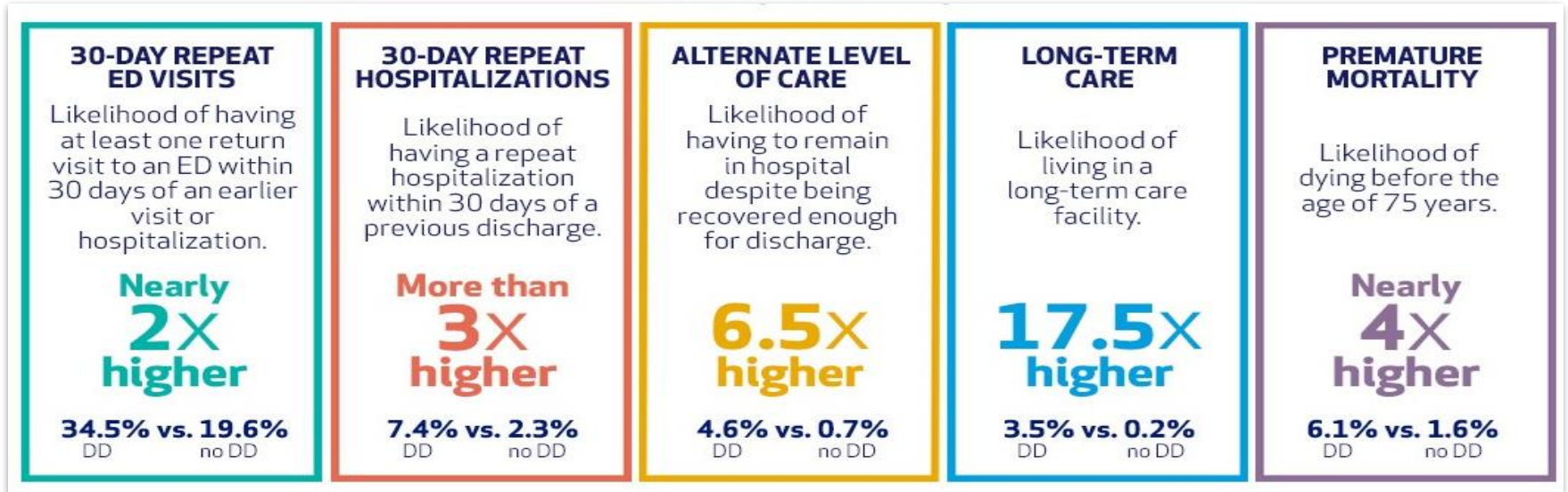
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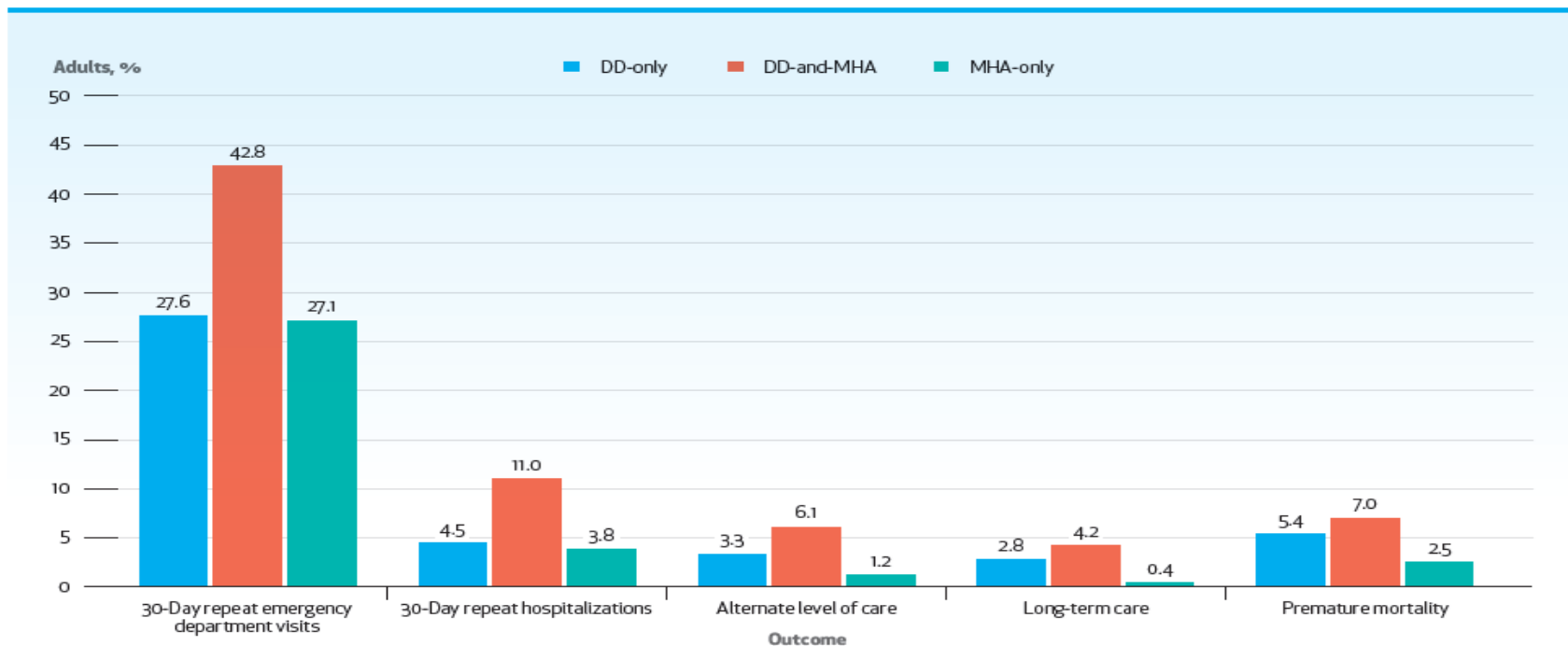
Health Care Gaps for Adults with DD

6 Year Period (FY 2010-2015)



Lin E, Balogh RS, Durbin A, Holder L, Gupta N, Volpe T, Isaacs BJ, Weiss JA, Lunskey Y. *Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities in Ontario*. Toronto, ON: ICES; 2019.

Outcomes by DD and Psychiatric Disorder



Lin, E., et al.. (2021). Looking across health and healthcare outcomes for people with intellectual and developmental disabilities and psychiatric disorders: Population-based longitudinal study. *The British Journal of Psychiatry*, 218(1), 51-57. doi:10.1192/bjp.2020.202

Autistic Adults - Health conditions, service use, and mortality



RESEARCH ARTICLE

Premature mortality in a population-based cohort of autistic adults in Canada

Yona Lunsky ✉, Meng-Chuan Lai, Robert Balogh, Hannah Chung, Anna Durbin, Patrick Jachyra, Ami Tint, Jonathan Weiss, Elizabeth Lin

First published: 28 May 2022 | <https://doi.org/10.1002/aur.2741>



Funding information: Canadian Institutes of Health Research, Grant/Award Number: PHE103973

<https://doi.org/10.1002/aur.2741>




Original Article

Health conditions and service use of autistic women and men: A retrospective population-based case-control study

Ami Tint¹ , Hannah Chung², Meng-Chuan Lai^{1,3,4,5,6}, Robert Balogh⁷, Elizabeth Lin^{1,3}, Anna Durbin^{2,3,8} and Yona Lunsky^{1,2,3} 

Autism
1–17
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Partnerships in Knowledge Exchange

Research Summary

Health problems and health service use of Autistic women and men in Ontario



What did we learn?

We found differences in the types health care services used

Compared to adults **without** developmental disabilities Autistic adults got **more help** for mental and physical health problems.



Autistic men and women used most **psychiatric services more often.**



Autistic men and women also used most **health care services more often.**

Autistic adults over three times as likely to die early, Ontario study finds

By Louise Kinross

Autistic adults in Ontario were more than three times as likely to die early as people of the same age and sex in the general population, according to a population-based **ICES study** believed to be the first of its kind in Canada.

"We need to start asking questions about whether there are things we're doing in our health system that contribute to why a group of people is more likely to die young," says lead investigator Dr. Yona Lunsky, director of the Health Care Access Research and Developmental Disability Program at CAMH. The study was published in *Autism Research*.

A Research Summary

Differences in death: comparing Autistic adults and non-Autistic adults in Ontario, Canada



What did we learn?

We looked at people who were the same age and sex and we learned:

1) Autistic adults were three times more likely to die early than people without developmental disabilities.

3X

2) People with other developmental disabilities were more likely to die than Autistic people.



3) Males and females died of different causes.



**“When all is said and done,
a lot more is said than done”**

Sample: About My Health

Surrey Place Developmental
Disabilities Primary Care Program

1 My Information

Name Julie Green	Birthday 1965 11 06	I like to be called <input type="checkbox"/> He <input checked="" type="checkbox"/> She <input type="checkbox"/> They
---------------------	------------------------	--

My Address 62 Sandringform St, Hamilton ON L3k 4T4	My phone number 905232-5555
---	--------------------------------

My health card number 55 443333 T4	Expiry date: Jan 28, 2024
---------------------------------------	------------------------------

I live (check all that apply)

<input type="checkbox"/> Alone	<input type="checkbox"/> With family	<input type="checkbox"/> With parents	<input checked="" type="checkbox"/> With roommates	<input type="checkbox"/> Other
<input type="checkbox"/> With spouse/partner	<input type="checkbox"/> With friends	<input type="checkbox"/> In a group home	<input type="checkbox"/> In supported independent living	third floor, triplex

2 Things I want you to know about me (Note: think about who will be seeing the form when you decide what to include)

My interests and what I like to do I love singing, meeting people, dancing, going to folk dancing on Thursdays	Important people in my life my mom, my brother, Josie my staff	Difficult life experiences I have had that I want you to know about My dad died and I miss him a lot. My mom can't walk very well anymore
---	---	--

3 My emergency contact

Name Frank Green	Relationship to me my little brother
---------------------	---

Address 25 Round Street, Burlington ON L4R 3S2	Phone number 905 443-5540
---	------------------------------

4 Do I have someone who I want to help me make my health care decisions? Yes No

Name Frank Green	Relationship to me my little brother
---------------------	---

Address SEE ABOVE	Phone number
----------------------	--------------

5 Is there someone I want to be told about my health care appointments? Yes No

Name Kerry Ann Brown	Relationship to me my worker
-------------------------	---------------------------------

Address same as my address	Phone number same as me
-------------------------------	----------------------------

DEVELOPED BY: Surrey Place, Developmental Disabilities Primary Care Program

PAGE: 1 of 3

6 Important things about my health

Medical history and conditions I have arthritis in my knee I used to have seizures when I was little but not now I used to take medications to help me feel calm (risperidone) but now I don't. It made me tired and I gained some weight on them. Now when I am upset I take some space I am starting to wear glasses because I can't read or see the TV well I had some teeth pulled and I see a special dentist because brushing is hard and I get nervous when I go	Things I am allergic to and what happens to me (if known) I am not allergic to anything
---	--

7 My family doctor (or nurse practitioner)

Name Virginia Walker	Phone number 905 334-5732
-------------------------	------------------------------

Address 35 Family Doctor Lane Ontario	Fax number 905 334-5735
--	----------------------------

8 My pharmacy

Name Appleton Pharmacy	Phone number 905 336-4439
---------------------------	------------------------------

Address 334 Main Street East, Hamilton ON	Fax number
--	------------

9 My medications (please attach or bring medication list)

Do I have drug coverage? <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	My drugs are paid for <input checked="" type="checkbox"/> Ontario Disability Support Program (ODSP) <input type="checkbox"/> Ontario Drug Benefit (ODB) <input type="checkbox"/> Other <input type="checkbox"/> I don't know
---	---

How do I take my medications?

Whole Crushed Mixed with Food Other I don't swallow pills very well so my staff crush the pills for me

10 How can you make my health care visit better?

What makes me uncomfortable, scared, or nervous about seeing the doctors and nurses?
I don't like surprises and I don't like to get touched anywhere near my private area. I also get scared about blood or my teeth

If I am... Scared/nervous Uncomfortable/overstimulated In pain/hurting Sad Angry	I show it by: I say I am scared. Sometimes I laugh when I am nervous I don't know I just worry but I usually tell others I think that is a hard question for me. Sometimes I say I'm trying to talk but I might know the sign or the other way. I may get very sad quickly if you ask me about something sad or if I remember I miss my dad. worry or panic. But I never push my doctor. Sometimes when I get mad I might push my roommates	You can help me by: explaining what you are doing, asking my staff, making jokes talking me down and what you care doing to solve. I like when staff ask my sign if it is hurting. I have some ideas. Listen and let me say and then I'm able to talk about something else that makes me happier give me space and time to count and calm down
---	--	--

Sample: My Health Care Visit

Surrey Place Developmental
Disabilities Primary Care Program

FILL OUT BEFORE GOING TO THE VISIT BY ME AND PERSON SUPPORTING ME

1 Appointment information

My Name
Julie Green

Name of person supporting me
Kerry Ann Brown

Appointment type
 Family Doctor Walk-in Clinic Other (e.g., dentist, eye doctor, specialist, X-ray, etc.):
 Hospital Visit Emergency Room Visit

Things to bring with me
 OHIP card Comfort items (e.g., snacks, books, games, etc.)
 ODSP card (if going to the dentist or eye doctor) Any medications I need to bring with me

2 Why am I going to the appointment? (Note: Let the doctor know if you've already had an appointment for this reason)

EXAMPLES: Feeling sick, I got hurt, I need a check up, something hurts in my body, illness, injury, need more medication, medication changes or concerns, stress with family or friends, need forms filled out, etc.

My stomach has been hurting me a lot.
I used to eat more at dinner but sometimes now I feel sick.

3 Have any of these been bothering me in the last week (or longer)?

Health Concern:	Is there a problem?	What is the issue?	Is monitoring chart(s) attached?
Pain	<input checked="" type="checkbox"/>	my stomach	<input type="checkbox"/>
Eating	<input checked="" type="checkbox"/>	I don't like to eat dinner sometimes	<input checked="" type="checkbox"/>
Bathroom or toileting	<input checked="" type="checkbox"/>	It hurts when I try to go to the bathroom	<input checked="" type="checkbox"/>
Energy or tired or sleep	<input checked="" type="checkbox"/>	I am feeling more tired, I don't like to get up in the morning	<input checked="" type="checkbox"/>
Emotions or feelings	<input checked="" type="checkbox"/>	I am a bit grouchy	<input type="checkbox"/>
Relationships	<input type="checkbox"/>		<input type="checkbox"/>
Sexual health	<input type="checkbox"/>		<input type="checkbox"/>
Other (e.g., falls, hearing, vision)	<input type="checkbox"/>		<input type="checkbox"/>
Medication	<input type="checkbox"/>		<input type="checkbox"/>

During My Health Care Visit

Surrey Place Developmental
Disabilities Primary Care Program

FILL OUT WITH A HEALTH CARE PROVIDER

1 Appointment summary (If the health care provider does not fill out this section, a copy of their note from the appointment or a letter summarizing the required information can be attached. If attaching a document, please check this box:)

What did we talk about and do?
We did a physical exam to check Julie's stomach. We also talked about changing eating habits so that Julie is eating more fibre.

Next steps (Things like: tests or exams I need to do like: X-ray or blood work, appointments to see a different doctor or health professional, need to come back to see the doctor I saw today, things I or the people supporting me can do to be healthier at home)

Start taking metamucil and come back to see the doctor if I don't start to feel better.

2 Medications (Were there changes to my medications?) Yes No

New Medications (if any)	
Medication Name	Why do I need to take this medication?
1. Metamucil	To increase fibre intake
2.	
3.	

Things to remember to do before I leave

Don't forget to:
 Make sure this page is completed
 Schedule any upcoming appointments with the front desk Appointment date: _____
 If there is a referral, make sure I know whether I need to call to follow up Referral: _____

Doctors Name: Dr. Pringsell Signature: _____ Date: 4/13/19

After My Health Care Visit

FILL OUT AFTER THE VISIT WITH THE PERSON SUPPORTING ME

Comments about the visit:
Things like: I loved the visit go? What did I need to do next? What could we do differently next time?
 The doctor was nice and explained things well. I like talking to him. Next time we will remember I also need my hospital card and I will probably have to wait because the hospital is very busy. I will bring a drink because it is a long time and I get thirsty.

Training Videos & Toolkits



H-CARDD Best
Practice Series for
Clinicians →



Commonly Missed Diagnoses: Head-to-Toe Assessment

- H** Headache and other pain, or Hydrocephalus related issue (ex. Shunt blockage)
- E** Epilepsy
- A** Aspiration pneumonia or dysphagia
- D** Drugs! Patients are at high risk for adverse effects or polypharmacy.
Have a follow up plan if prescribing psychotropics!
- T** Teeth! Dental abscesses or impacted teeth can cause pain, aggressive behavior, food refusal
- O** Ocular or Otolaryngology issue – Vision problem, Hearing issue, Obstructive Sleep Apnea (up to 80%)
- T** Tummy – GERD, Constipation, Bowel obstruction and volvulus
- O** Osteoporosis and atypical fractures, pressure sores
- E** Etiology or cause of IDD - is it known? – some genetic syndromes have important acute presentations
(ex. Calcium disturbance in William's Syndrome)
- S** Serious illness can present atypically – ask caregivers how this patient expresses pain.
Is there a subtle sign that they are very ill?
- S** Screen for abuse



All Behaviour is Communication!

AUTISTIC



Physical

Processing

Emotional

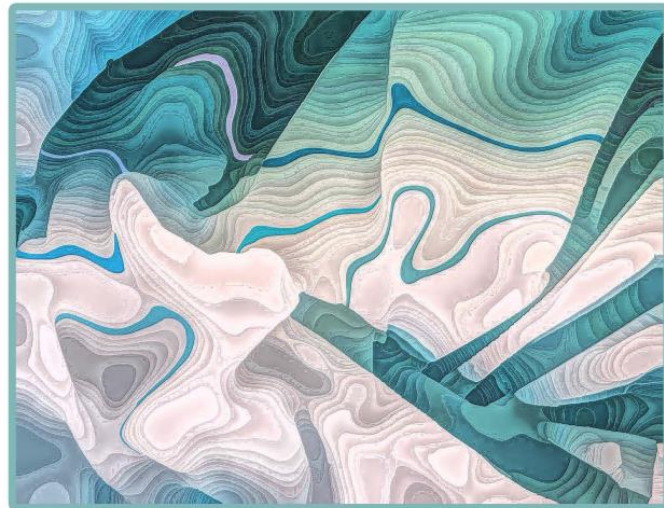
Sensory

Predictability

Acceptance

Communication

Empathy



MORE THAN WORDS:
SUPPORTING EFFECTIVE
COMMUNICATION WITH AUTISTIC
PEOPLE IN HEALTH CARE SETTINGS

E·S·R·C
ECONOMIC
& SOCIAL
RESEARCH
COUNCIL

University
of Brighton

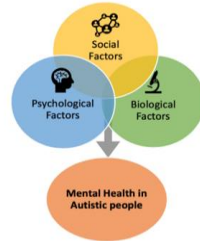


The AM-HeLP Guide



Mental Health Literacy Guide for Autism

Written by the Autism Mental Health Literacy Project (AM-HeLP) Group



Social factors

The big picture: growing up Autistic in a non-Autistic society







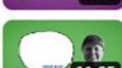
The four components of mental health literacy²



AM-HeLP Animated Video Series

AM-HeLP - 1 / 12



-  Introduction to Mental Health
AM-HeLP
5:53
-  Autism and Diversity
AM-HeLP
6:12
-  Understanding Supports for Autistic Mental Health
AM-HeLP
8:35
-  COMPRENDRE LA LITTÉRATIE EN SANTÉ MENTALE
AM-HeLP
6:14
-  INTRODUCTION À LA SANTÉ MENTALE
AM-HeLP
6:26
-  AUTISME ET DIVERSITÉ
AM-HeLP
7:18
-  COMPRENDRE LA SANTÉ MENTALE POUR LES...
AM-HeLP
11:05

Depression and Autism: A youth-to-youth guide to coping and getting help



Why we
Created
this
Package

Autism
and
Depression:
What can it
Look Like?

A Note to
Caregivers

Getting Help

Coping
Strategies

A Note to
Mental
Health
Professionals

Depression in autism:
A youth to youth guide on
coping and getting help

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and Youth Depression

Coping Strategies

Mental Health Tips from youth to youth:

Different strategies will help different people when they are experiencing depression. Here are some ideas of strategies that worked for some autistic youth:



Make sure you're eating and drinking enough. Keep a supply close by of 'safe' food
(e.g., a food that you know you can always eat).



Find creative ways to communicate what you're thinking without words
(e.g., through art, music, dance).



Take time to recharge your social batteries. Know what activities are draining and what activities give you energy
(e.g., give yourself time to rest and recover after spending time with other people).



Have a simple goal to accomplish or routine to follow every day
(e.g., put on a clean shirt; make yourself a cup of coffee in the morning).



Spend time in a safe and comfortable environment.
(e.g., somewhere that you can rest, maybe in your room or a space that is quiet and predictable).



Find someone to be your 'safe person'
(e.g., someone you trust and feel comfortable with that you can reach out to for support).



“ Having a plant, just a small thing to take care of and that I'm in charge of, helps me to get my butt out of bed in the morning **”**

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Depression in autism:
A youth to youth guide on
coping and getting help

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and Youth Depression

A Note to Caregivers*

“



Do your best to be part of the care team and listen to your loved one. You know your loved one well, allow them to lead as autonomy matters to youth and it is relationship building. Ask for what you need. ”

Coping with depression is difficult for youth, and it's also extremely challenging for other family members too. Here are some tips and resources from other caregivers of autistic youth experiencing depression who have offered some of their reflections and lessons learned about the process:



Education is key.

Depression can sometimes look like laziness or a lack of motivation. Learning about presentations of depressive symptoms in autism is key to understanding your youth and how to support them.



If you see depressive symptoms, trust your instincts.

You may see signs of depression in your youth that may not be visible or present at the time of the medical appointment. Share this information with the medical professional.



Establish trust and communication.

Have conversations with your youth so you know what they feel comfortable sharing with others. It is important to respect their privacy. Consider letting youth know that you may need to share private information when it relates to their safety.



It's not their fault. It's not your fault. It's not personal.

Recognize that depression may be expressed as hostility, rejection, and irritability.

* In this tip sheet, we use the term 'caregiver' to mean anyone who provides support and is caring for an autistic transition aged youth struggling with mental health, this could include: parents, siblings, grandparents, chosen family, etc.

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SCAN ME

<https://www.camh.ca/-/media/files/cundill-centre/depression-and-autism-full-pdf.pdf>

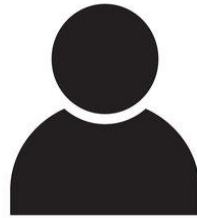
Intervention partnerships



Family



Provider



Individual



Critical Ingredients across programs

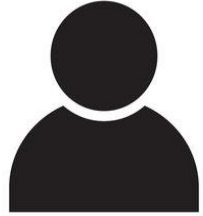
- Co-created and co-delivered
- Currency
- Community building
- Core team behind the scenes



Family



Provider



Individual



Reducing Distress in Mothers of Children With Autism and Other Disabilities: A Randomized Trial

WHAT'S KNOWN ON THIS SUBJECT: Mothers of children with neurodevelopmental disabilities often experience poor health, high stress, anxiety, and depression. Highly stressed parents are less effective in their parenting roles, risking their children's developmental progress.

WHAT THIS STUDY ADDS: Evidence-based interventions in mindfulness and positive psychology significantly reduce distress in mothers of children with disabilities. Well-trained peer-mentors are effective interventionists. Adult-oriented services are needed for these mothers to improve their mental health and sustain their caregiving over the long-term.

abstract



BACKGROUND: Compared with other parents, mothers of children with autism spectrum disorder or other neurodevelopmental disabilities experience more stress, illness, and psychiatric problems. Although the cumulative stress and disease burden of these mothers is exceptionally high, and associated with poorer outcomes in children, policies and practices primarily serve the identified child with disabilities.

METHODS: A total of 245 mothers of children with disabilities were consented and randomized into either Mindfulness-Based Stress Reduction (mindfulness practice) or Positive Adult Development (positive psychology practice). Well-trained, supervised peer mentors led 6 weeks of group treatments in 1.5-hour weekly sessions, assessing mothers 6 times before, during, and up to 6 months after treatment. Mothers had children with autism (65%) or other disabilities (35%). At baseline, 85% of this community sample had significantly elevated stress, 48% were clinically depressed, and 41% had anxiety disorders.

RESULTS: Using slopes-as-outcomes, mixed random effects models, both treatments led to significant reductions in stress, depression, and anxiety, and improved sleep and life satisfaction, with large effects in depression and anxiety. Mothers in Mindfulness-Based Stress Reduction versus Positive Adult Development had greater improvements in anxiety, depression, sleep, and well-being. Mothers of children with autism spectrum disorder improved less in anxiety, but did not otherwise differ from their counterparts.

CONCLUSIONS: Future studies are warranted on how trained mentors and professionals can address the unmet mental health needs of mothers of children with developmental disabilities. Doing so improves maternal well-being and furthers their long-term caregiving of children with complex developmental, physical, and behavioral needs. *Pediatrics* 2014;134:e454-e463

AUTHORS: Elisabeth M. Dykens, PhD,^{1,2,3,4,5,6} Marisa H. Fisher, PhD,⁷ Julie Lounds Taylor, PhD,^{8,9} Warren Lambert, PhD,¹⁰ and Nancy Miodrag, PhD¹¹

¹Hastler Center for Research on Human Development and University Center of Excellence on Developmental Disabilities, Departments of ²Psychology and Human Development, ³Pediatrics, and ⁴Psychiatry, Vanderbilt University, Nashville, Tennessee; and ⁵Department of Child and Adolescent Development, California State University Northridge, Northridge, California

KEY WORDS

autism spectrum disorders, developmental disabilities, maternal stress and mental health, mindfulness based stress reduction, positive psychology

ABBREVIATIONS

ASD—autism spectrum disorders
BAI—Beck Anxiety Inventory
BDI—Beck Depression Inventory
ES—effect size
MBSS—Mindfulness-Based Stress Reduction
PAD—Positive Adult Development
PSI—Parenting Stress Index-Short Form

Dr Dykens developed the study rationale, aims, and design, led and supervised the implementation of the study, and drafted and revised the final manuscript. Dr Fisher managed data entry and quality, conducted preliminary descriptive statistics, completed figure 1's Consolidated Standards of Reporting Trials flow diagram, and critically reviewed the final manuscript. Dr Taylor assisted with data analyses and interpretation, drafted the results section, constructed and revised tables 2 and 3, and critically reviewed the final manuscript. Dr Lambert conducted data analyses by using slopes as outcomes, drafted the power analysis and statistical approach sections, created and revised figures 2 and 3, and reviewed the final manuscript. Dr Miodrag assisted with data interpretation, provided background literature on maternal stress and mindfulness practice, conducted preliminary analyses in mothers of children with autism, and reviewed the final manuscript, and all authors approved the final manuscript as submitted.

This trial has been registered at www.clinicaltrials.gov (identifier: NCT01110345).

(Continued on last page)



Dykens, E. M., Fisher, M. H., Taylor, J. L., Lambert, W., & Miodrag, N. (2014). Reducing distress in mothers of children with autism and other disabilities: a randomized trial. *Pediatrics*, 134(2), e454–e463. <https://doi.org/10.1542/peds.2013-3164>

ORIGINAL PAPER



Group Virtual Mindfulness-Based Intervention for Parents of Autistic Adolescents and Adults

Y. Lunsky^{1,2} · C. Albaum³ · A. Baskin¹ · R. P. Hastings^{4,5} · S. Hutton¹ · L. Steel¹ · W. Wang⁶ · J. Weiss³

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Abstract

Mindfulness-based approaches have been shown to be effective in improving the mental health of parents of youth and adults with autism and other developmental disabilities, but prior work suggests that geography and caregiving demands can make in-person attendance challenging. The purpose of this study was to evaluate the feasibility, acceptability and preliminary outcomes of a mindfulness-based group intervention delivered to parents virtually. It was feasible to deliver this manualized intervention. Twenty-one of 39 parents completed the intervention and completers reported high satisfaction ratings. Parents reported reduced levels of distress, maintained at 3-month follow-up, and increased mindfulness. Changes reported following intervention were similar to changes reported in a prior study of parents competing an in person mindfulness group.

Keywords Mindfulness · Parents · Autism · Virtual intervention



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Neurodevelopmental Centre

Mindfulness for Caregivers

Azrieli Adult Neurodevelopmental Centre

▶ Latest Episode

Join Sue Hutton and Lee Steel for a mindfulness podcast series for caregivers.

Mental Health · Updated Monthly

Episodes

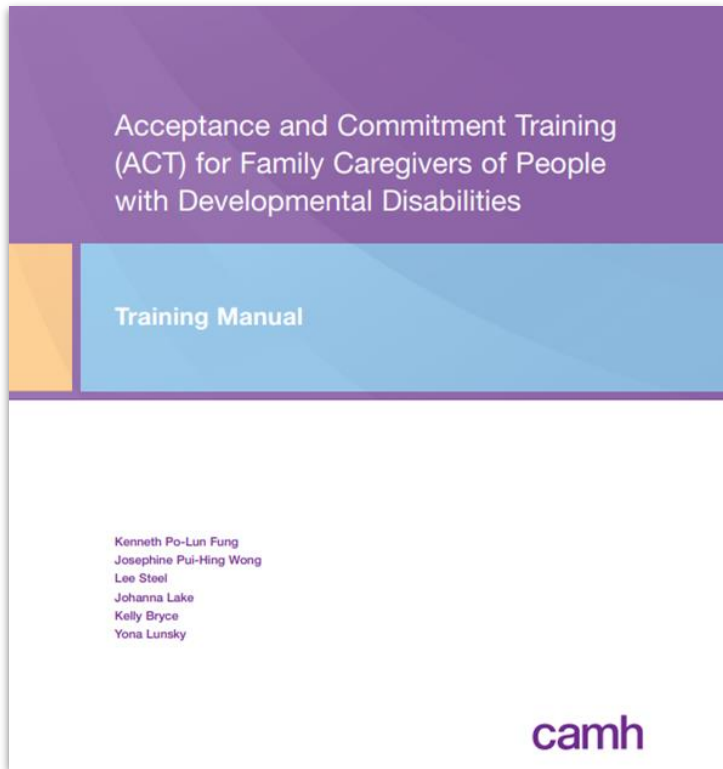
OCT 4, 2021

Making mindfulness work for you as a caregiver

In this episode Sue and Lee discuss practical ways for how caregivers can incorporate mindfulness into the busy lives often focused on everyone around us – but not our...

▶ 44 mins





<https://www.camh.ca/en/health-info/guides-and-publications/acceptance-and-commitment-training-for-family-caregivers>

Autism
OnlineFirst
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<https://doi.org/10.1177/13623613231172241>



Original Article



Parent, child, and family outcomes following Acceptance And Commitment Therapy for parents of autistic children: A randomized controlled trial

Andrea L Maughan ¹, Yona Lunsky ², Johanna Lake ², Jennifer S Mills¹, Kenneth Fung³, Lee Steel², and Jonathan A Weiss ¹

<https://journals.sagepub.com/doi/full/10.1177/13623613231172241>



<https://actforcaregivers.com/>

ACT joint facilitation model

I feel that the co-facilitation team of a caregiver and a clinician effectively meets the needs of participants to support them in their ability to empathize and connect with facilitators. It's a broad spectrum approach to understanding!

- caregiver facilitator

Facilitator Perspective

Benefits

- Unique Skills
- Lived experience & Clinical training
- Empowered
- Personal growth
- Appreciation of caregiver experience

It was incredibly valuable to facilitate with a caregiver, I think it made a huge difference in the overall experience for caregiver participants. Our caregiver co-facilitator brought a very warm, genuine and engaging energy that seemed to put participants in the group at ease. I believe this model really changes the dynamic and allows for more authentic sharing and openness.

- clinician facilitator

"I like that the caregiver facilitator had lived-experience. This provided both a sense of trust and safety and also validated the material as being personally relevant rather than simply 'peer-reviewed scholarly content' directed at us."

- workshop participant

Workshop Participant Perspective

Benefits

- Balance of perspectives
- Inclusive
- Relatable, Lived experience
- Supported, Validated
- Vulnerable
- Trust

"I loved that caregivers and clinicians co-facilitated the workshop. It demonstrated collaboration and a feeling of focus on the participants. Felt multiple perspectives were considered and included."

- workshop participant

100%
of **facilitators** reported that it was valuable and essential to co-facilitate with a caregiver/clinician

96%
of **participants** reported that there was a benefit of having other caregivers as co-facilitators



Family



Provider



Individual



Virtual Group–Based Mindfulness Intervention for Autistic Adults: a Feasibility Study

Yona Lunsky^{1,2} · Brianne Redquest¹ · Carly Alba³ · Sue Hutton¹ · Maxine Share¹ · Daniel Share-Strom¹ · Jonathan Weiss³

Accepted: 17 May 2022 / Published online: 13 June 2022

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Abstract

Objectives Although mindfulness-based interventions have been shown to be helpful in autistic adults, limited research has explored virtual delivery in the autism community. This study explored a group-based mindfulness intervention, based on input from autistic adults, and evaluated its demand, acceptability, implementation, practicality, adaptation, and limited efficacy testing.

Methods Informed by an online needs assessment survey of 77 autistic adults, 37 autistic adults completed a manualized course delivered virtually. Participants completed pre, post, and follow-up surveys and provided qualitative feedback.

Results There was a demand for the course, adaptations were successful, and participants found the intervention helpful. Open-ended feedback highlighted advantages and challenges with the intervention, including meeting with other autistic adults, and unique aspects of the mindfulness instruction. Participants maintained gains at three-month follow-up, and increased mindfulness, and self-compassion.

Conclusions Autism-informed adaptations to standard mindfulness-based interventions in mindfulness, self-compassion, and distress by autistic adults. Continued exploration of virtual mindfulness toward autistic adults will be important, during and post-pandemic.

Keywords Autism · Adulthood · Mindfulness · Telehealth · Feasibility · COVID-19

What did we do?

We made a virtual group mindfulness course for Autistic adults.

Autistic adults did a survey to help researchers make a group mindfulness course for Autistic adults.



Our team of Autistic adults and clinicians made a six-week course.

50 Autistic adults signed up for the course.

The group met on a 60-minute video call every week.

They learned and practiced new mindfulness skills each session.

Women's Health
Volume 18, January-December 2022
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<https://doi.org/10.1177/17455057221142369>

SAGE
journals

The Health of Autistic Women: State of the Field and Future Directions - Original Research Article



Virtual group-based mindfulness program for autistic women: A feasibility study

Brianne Redquest^{1,2,3} · Ami Tint³ · Laura St. John³ · Sue Hutton³ · Pamela Palmer³ · Yona Lunsky^{3,4}

Background: Autistic women experience life differently than autistic men. For example, autistic women tend to be diagnosed significantly later than autistic men, they experience a higher number of traumas, and are at increased risk for mental health conditions. Given gender-specific life experiences, autistic women may benefit from gender-specific group-based supports. Virtual mindfulness has been shown to be helpful in improving well-being among autistic adults; however, limited research has explored the impact of virtual mindfulness when it is delivered to a group of autistic women only.

Objectives: The aim of this article is to describe a preliminary evaluation of a virtual mindfulness program piloted for autistic women. Five key areas of feasibility were assessed in the current study: demand, implementation, acceptability, practicality, and limited efficacy testing.

Methods: Twenty-eight women participated in a 6-week virtual autism-informed mindfulness program and were asked to complete measures assessing psychological distress, self-compassion, and mindfulness at pre and post. Participants were also asked to complete a satisfaction survey after the program.

Results: Results showed that the program was feasible in terms of demand, implementation, practicality, and acceptability. While quantitative results showed there were no changes in psychological distress, self-compassion, and mindfulness from pre- to post-program, qualitative results showed some benefits.

Conclusion: Given the unique challenges that some autistic women experience, offering groups to autistic women may have some value and it would be important to continue exploring this topic area.

Keywords

autistic women, feasibility, virtual mindfulness

<https://pubmed.ncbi.nlm.nih.gov/35729967/>

<https://journals.sagepub.com/doi/full/10.1177/17455057221142369>



Mindfulness for YOU Series

H-CARDD

Public ▾

6 videos • 139 views • Last updated on Dec 1, 2022



▶ Play all

↻ Shuffle

This video is one in a series of videos on mindfulness for neurodivergent and autistic adults that have been created at the CAMH Azrieli Adult Neurodevelopmental Centre.

This video project was supported by the Public Health Agency of Canada.

The video series shows some creative ways that neurodivergent and autistic adults can practice mindfulness in a way that aims to meet the needs of neurodivergent adults.

Mindfulness is a practice we can do regularly to assist with our well-being in

☰ Sort



Mindfulness For YOU 01 - Stimming & Fidgeting: Making it Mindful

H-CARDD • 120 views • 5 months ago



Mindfulness for YOU 01 - Stimming & Fidgeting: Making it Mindful (No Music)

H-CARDD • 60 views • 5 months ago



Mindfulness For YOU 02 - Accepting Myself As I Am: A Movement Meditation

H-CARDD • 79 views • 5 months ago



Mindfulness For YOU 02 - Accepting Myself As I Am: A Movement Meditation (No Music)

H-CARDD • 46 views • 5 months ago



Mindfulness For YOU 03 - Nature Meditation

H-CARDD • 110 views • 5 months ago



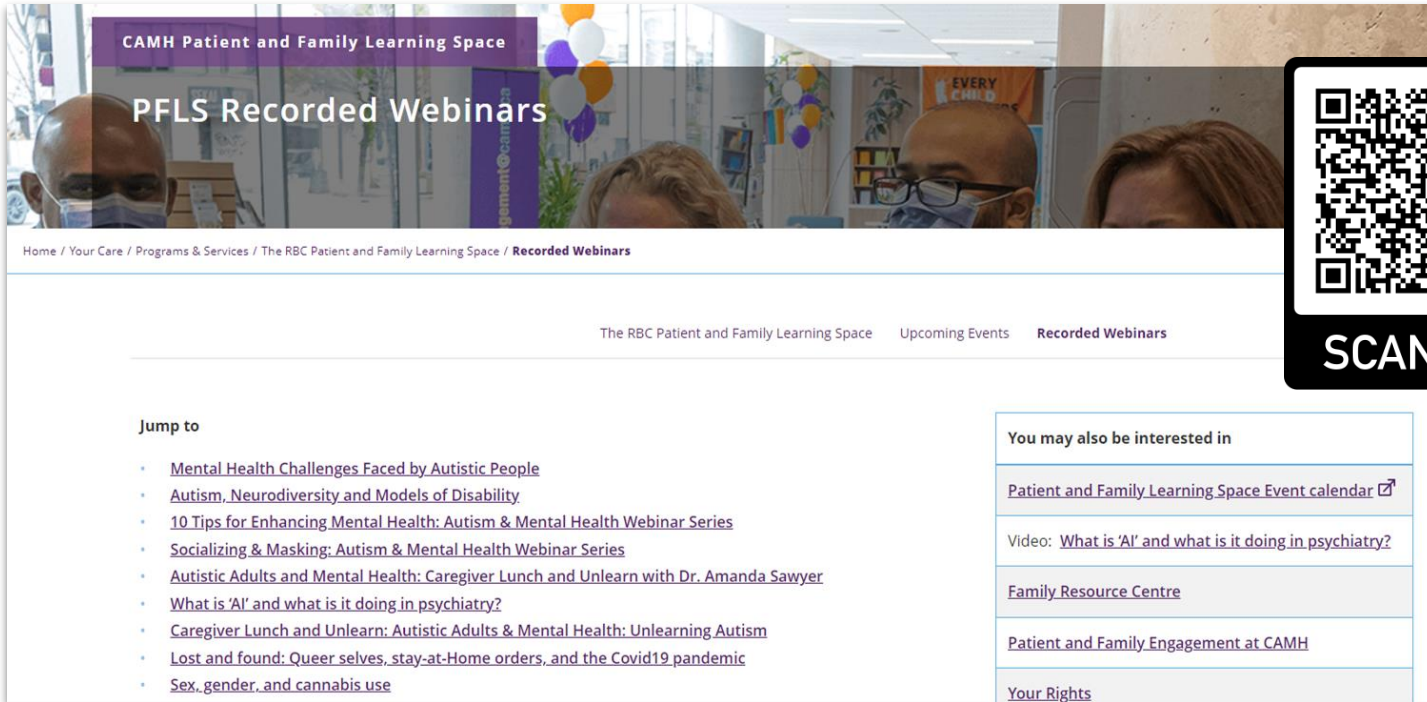
Mindfulness For YOU 03 - Nature Medication (No Music)

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SCAN ME

CAMH Patient and Family Learning Space



The screenshot displays the website's header with the title "CAMH Patient and Family Learning Space" and "PFLS Recorded Webinars". Below the header is a navigation menu with "Recorded Webinars" selected. The main content area features a "Jump to" section with a list of webinar titles and a "You may also be interested in" sidebar with several related links.

CAMH Patient and Family Learning Space
PFLS Recorded Webinars


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The RBC Patient and Family Learning Space Upcoming Events **Recorded Webinars**

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- [Mental Health Challenges Faced by Autistic People](#)
- [Autism, Neurodiversity and Models of Disability](#)
- [10 Tips for Enhancing Mental Health: Autism & Mental Health Webinar Series](#)
- [Socializing & Masking: Autism & Mental Health Webinar Series](#)
- [Autistic Adults and Mental Health: Caregiver Lunch and Unlearn with Dr. Amanda Sawyer](#)
- [What is 'AI' and what is it doing in psychiatry?](#)
- [Caregiver Lunch and Unlearn: Autistic Adults & Mental Health: Unlearning Autism](#)
- [Lost and found: Queer selves, stay-at-Home orders, and the Covid19 pandemic](#)
- [Sex, gender, and cannabis use](#)

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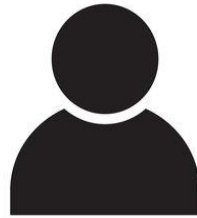
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Family



Provider



Individual



Project ECHO

Project ECHO is a “hub and spoke” technology enabled education and capacity building model

ECHO Core Principles:

- » Use technology to leverage scarce resources
- » Share best practices
- » Utilize case-based learning
- » Improve and monitor outcomes
- » *“All teach, all learn”*

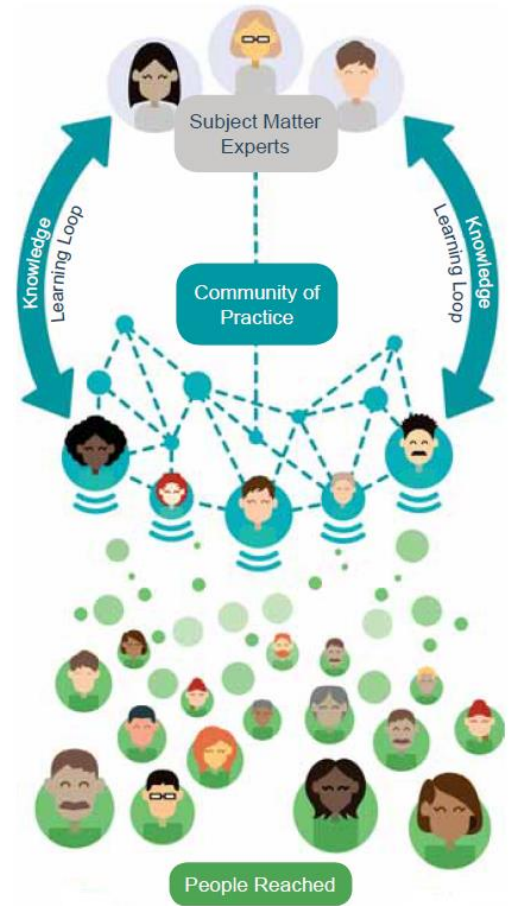


Figure 1. Project ECHO Model. From University of New Mexico School of Medicine.

Studies on ECHO AIDD

JOURNAL OF MENTAL HEALTH RESEARCH IN INTELLECTUAL DISABILITIES
2023, VOL. 16, NO. 1, 23–36
<https://doi.org/10.1080/19315864.2022.2148789>



The Development and Pilot Evaluation of ECHO Mental Health for Adults with Intellectual and Developmental Disabilities

Yona Lunsy^{a,b}, Nicole Bobbette^{a,c}, Janet Durbin^{a,b,d}, Angela Gonzales^e, Elizabeth Grier^f, Renisha Iruthayanathan^g, Nadia Mia^e, Cheryl Pereira^h, Lee Steel^g, Anupam Thakur^{a,b,e}, Kendra Thomson^{a,h}, and Sanjeev Sockalingam^{i,b,j}

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ABSTRACT

Introduction: Health and social service providers have limited expertise with regard to assessing and treating psychiatric disorders in adults with intellectual and developmental disabilities. The aim of this study was to describe the development and pilot evaluation of a virtual capacity-building program (Project ECHO) focused on supporting the mental health of adults with these disabilities in Ontario, Canada.

Keywords

intellectual disability;
developmental disability;
interprofessional education;
mental health; virtual

JMIR MENTAL HEALTH

Thakur et al

Original Paper

Virtual Education Program to Support Providers Caring for People With Intellectual and Developmental Disabilities During the COVID-19 Pandemic: Rapid Development and Evaluation Study

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Abstract

Background: People with intellectual and developmental disabilities are at increased health-related risk due to the COVID-19 pandemic. Virtual training programs that support providers in caring for the physical and mental health needs of this population, as well provide psychological support to the providers themselves, are needed during the pandemic.

Objective: This paper describes the design, delivery, and evaluation of a virtual educational COVID-19-focused Extension for Community Healthcare Outcomes program to support providers during the COVID-19 pandemic in caring for the mental health of people with intellectual and developmental disabilities.

Methods: A rapid design thinking approach was used to develop a 6-session program that incorporates mindfulness practice, a wellness check, COVID-19-related research and policy updates, a didactic presentation on a combination mental health and COVID-19 related topic, and a case-based discussion to encourage practical learning. We used the first 5 outcome levels of Moore's evaluation framework—focusing on participation, satisfaction, learning, self-efficacy, and change in practice—which were rated (out of 5) by care providers from health and disability service sectors, as well as additional reflection measures about innovations to the program. Qualitative feedback from open-text responses from participants were analyzed using modified manifest content analysis.

Results: A total of 104 care providers from health and disability service sectors participated in the program. High levels of engagement (81 participants per session on average) and satisfaction (overall satisfaction score: mean 4.31, SD 0.17) were observed. Self-efficacy (score improvement: 19.8%), support, and coping improved. Participants also rated the newly developed COVID-19 program and its innovative components highly. Open text feedback showed participants felt that the Extension for Community Healthcare Outcomes program expanded their knowledge and competency and created a sense of being part of a community of practice; provided value for the COVID-19 innovations; supported resource-sharing within and beyond program participants; and facilitated changes to participants' approaches to client care in practice and increased participants' confidence in supporting clients and families.

Lunsy et al., 2022 <https://www.tandfonline.com/doi/abs/10.1080/19315864.2022.2148789>

Thakur et al., 2021 <https://mental.jmir.org/2021/10/e28933/>

ECHO Autistic mental health in adulthood (ECHO-AIDD)

Hub: Psychiatrist, Psychologist, Family Physician, Social Worker, Occupational Therapist, Behaviour Therapist, Nurse, Autistic and Family Advisors

Spokes: Healthcare providers and developmental disability service providers who support autistic with mental health concerns

Piloted in Spring 2023, funded by the Ontario Ministry of Health



Part of **Project ECHO Ontario Mental Health** at CAMH and the University of Toronto (camh.echoontario.ca)

Open to service providers who work in primary care, mental health, and social services

The power in partnerships

9 lessons on partnerships

1. Don't just look good – be good and do good
2. We are not all equal – We are not all the same
3. Pay people what they are worth (in the right currency)
4. It takes time & resource
5. Strength in numbers
6. Cultivate a brave space
7. Make the implicit explicit
8. Don't get too comfortable
9. Don't wait to get all your ducks in a row (Sue Robins)



It takes a team

Family Caregivers

Adeen Fogle
Amy Baskin
Lianne
Elliette Stanley
Lee Steel
Nathan Dawthorne
Jodie Siu

Autistic Adults

Alex Echowitz
Mirella B
Joel Ashton-Fogle
Jan Wozniak
Riley Goldsmith
Megan Pilatzke

Clinicians/Scientists

Ami Tint
Johanna Lake
Yona Lunsky
Sue Hutton
Kenneth Fung
Anupam Thakur
Nadia Mia
Angela Gonzales
Liz Grier
Nicole Bobbette
Jonathan Weiss

Staff/Trainees

Yousef Safar
Tiziana Volpe
Afrooz Ghadimi
Teresa Kelly
Sabrina Campanella
Frances Routledge
Avery Chua
Munazzah Ambreen
Soumya Mishra

Connect with us!



ALT: white text all about, next line purple text autism and mental health.
On dark grey image, with branch and leaves with water droplets

camh | Azrieli Adult
Neurodevelopmental Centre

ALT: CAMH Azrieli Adult Neurodevelopmental Centre

LEARN ABOUT UPCOMING EVENTS & PROGRAMS FOR AUTISTIC ADULTS AND CAREGIVERS

What's on this page?

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[Autistic Adults Autism and Mental Health Webinar Series](#)

[Caregiver Lunch and Unlearn Series](#)

[Mindfulness Video Series for Autistic Adults](#)

[Resources](#)



SCAN ME

Autism and Mental Health Series Peer Support Program

WEB: Welcome Everybody
Peer Support for Autistic Adults

WHEN? 5:30-6:30 p.m. EDT weekly for 7 weeks starting Tuesday, May 30, 2023

WHERE? Online videoconferencing (WebEx)

WHO? Autistic adults (18+) living in Canada

WHAT? These **Autistic-led**, free-to-join groups will be a place to connect and share experiences with other Autistic adults



To learn more about upcoming events and programs for Autistic adults visit www.azrieli-anc.com/autism-mental-health or contact us at hcardd@camh.ca or 437-328-6761

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Azrieli Adult Neurodevelopmental Centre

It is funded in support of the
Public Health Agency of Canada

[Register Here](#)

Learn more about Welcome Everybody (WEB) [in this recorded webinar from AIDE Canada and Autism Ontario](#). Two scientists and three Autistic self-advocates from the Neurodevelopmental Centre share their experience facilitating, and evaluating WEB.

[Watch Here](#)



SCAN ME

WEB: Welcome Everybody Peer Support for Autistic Adults

Starts Tuesday, May 30, 2023, 5:30-6:30 PM EDT for 7 weekly sessions.

These Autistic-led groups will be a place to connect and share experiences with other Autistic adults.

This program is free and open to Autistic adults 18 years of age or older.



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