

Youth and Caregiver Perspectives of Mental Health and Navigating Support

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AutismONTARIO

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Disclaimers & Statements

General Disclaimer

- Opinions are of the presenters
- Make informed decisions

Language

- Identity-first (e.g., autistic person)
- Person-first (e.g., person with autism)

Professional Disclaimer

- Specific questions
- Additional Resources

Trigger/Content Warning

For immediate support call 1-833-456-4566

“Get Support” Document, attached

Access backend support via Q&A

Plan for Today



Introduce Mental Health



Background to the project



Hear from youth/caregivers

Goals for Today



Listening and learning from the perspectives of youth/parents, and experiences with the project. Power and importance of these stories when they come together



Not focusing on the complexity of how to provide mental health care to neurodivergent youth



Not focused on best practices in mental health care, that is the next step of the project



What is Mental Health?



Photo credit: I am Autism UK

What is Mental Health?

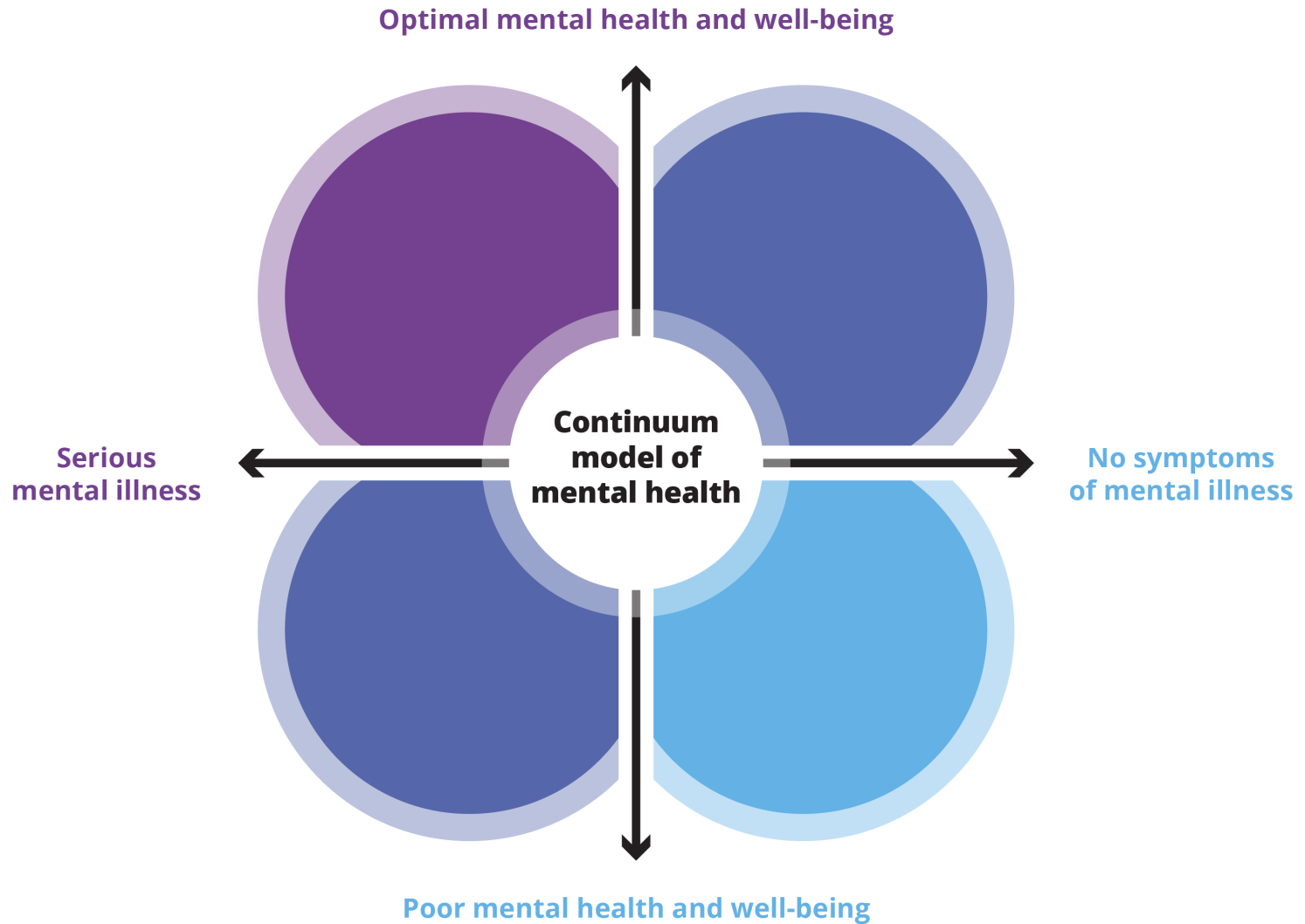
- Mental health includes our emotional, psychological, and social well-being.
- It affects how we think, feel, and act. It also helps determine how we handle stress, relate to others, and make choices.
- Mental health is important at every stage of life, from childhood and adolescence through adulthood.

Influences of Mental Health

- Biological factors, such as genes or brain chemistry
- Life experiences, such as trauma, grief, war
- Family history of mental health challenges



Continuum Model of Mental Health



“Everyone is deserving of **hope and help, connection, and access to high quality** mental health care”.

Dr. Juveria Zaheer

Mental Health and Autistic Youth

Research suggests youth and young adults with neurodevelopmental differences such as autism, experience high rates of mental health challenges (Augustine, 2021).

More likely to visit the Emergency Department for psychiatric reasons (Weiss et al., 2018).

Youth Mental Health

Difficulty accessing and receiving appropriate care.

Long wait times to accessing community and private care, especially during COVID ERA.

Youth Mental Health

US study: Health care professionals expressed limited knowledge, lack of experience and low confidence delivering mental health care with autistic adults (Maddox et al., 2020).

Further tools needed on how to deliver supportive discussions about mental health for youth, among healthcare professionals.

Prompts a need for further work in this area.

Background to the Project

Youth/Parent POND PAC identified mental health as an area in need of further research and support with Dr. Anagnostou



How can healthcare professionals support the mental health of youth?



Partnered with Dr. Lunsky and Dr. Jachyra

Background to the Project

Most of the research conducted with healthcare professionals, parents/caregivers



Youths' perspectives on mental health support absent



Important to include youth, understand their experiences and find ways to support mental health

Research Questions

How would youth with neurodevelopmental disorders like to be spoken to about their mental health?

What is important to youth with neurodevelopmental disorders when discussing their mental health?

What are the components of supportive mental health discussions?

Methods

Youth with neurodevelopmental disorders created a digital story



Created virtually over 7 workshops
(3 hours each)



Digital stories on their experiences
with mental health support

Methods

Created in partnership with
Community Storytelling Strategies
Toronto



Youth shared what experiences looked
like when they went well



Youth also shared what experiences
looked like when healthcare
interactions when poorly



Participant Demographics

9 participants, aged
16-21 years

6 identified as males, 3
identified as females

Range of diagnoses:
autism, OCD, ADHD,
Tourette's syndrome. Co-
occurring conditions such
as: GAD, MDD.

Screening the Digital Stories



Website link:

[HTTPS://BRAININSTITUTE.CA/RESOURCE
S/POND-YOUTH-DIGITAL-STORIES](https://braininstitute.ca/resource/s/pond-youth-digital-stories)

Youth Share their Perspectives

Parents Share their Perspectives

Take Away Messages



Connection before correction (build rapport)



Language matters



“Medical professionals need to understand that what you say to patients can stick with them forever” (Harm and Healing Story)

“You only cry for help if you believe there is help to cry for”

– My Truth, the difficult climb

Acknowledgements

**Youth and
Parents**

**Youth/POND
PARENT PAC**

**Community
Story
Strategies**

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Anagnostou**

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Feedback Survey

- Please answer each question in the survey
- The questions include items with:
 - A Likert scale (i.e., a 5-point scale with a range of responses)



- Selecting only one answer (single answer)
- Selecting all answers that might apply (multiple selections)
- Text boxes where you type your answer

Thank You for Attending

“ No family or person on the spectrum in Ontario should ever feel alone, experience autism as a barrier to inclusion, or be without meaningful resources and opportunities. ”

MARG SPOELSTRA
Executive Director, Autism Ontario

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