Mental Health Literacy Guide for Autism

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

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Co-Principal Investigators: Drs. Jonathan Weiss & Yona Lunsky
Research Coordinator: Paula Tablon Modica
Research Associate: Dr. Jonathan Leef
Advisers: Aaron Bouma, Alex Echakowitz, Elsbeth Dodman, Patricia D. George, Lianne Goldsmith, Lindamarie Gossen, Tom Jackman, Pari Johnston, Kate Keto, ShanEda Lumb, Dr. Kimberly Maich, Tim Martens, Amond McKenna, Lachina Tycho Mckenzie, Nathan Moore, Iris Parker, Marie Porter, Rosanne Purnwasie, M. S. M. Kennith James Skwleqs Robertson, Gizzelle Rocha, Maxine Share, Todd Simkover, Louise Tardif, Sue Walters, Courtney Weaver, Margaux Wosk, and Shirley-Ann Yamashita
Note: 2 advisers asked to remain anonymous
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Contact information: For more information on the Mental Health Guide for Autism or AM-HeLP, contact Dr. Jonathan Weiss, Department of Psychology, York University at: jonweiss@yorku.ca.

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Foreword

It is my pleasure to provide a foreword to this *Mental Health Literacy Guide for Autism*. This guide developed out of a desire to increase awareness, knowledge and acceptance around issues relevant to the mental health of Autistic adults. It is meant to be read by everyone, especially by Autistic adults, by family members, by professionals and by policy-makers and leaders to increase their understanding about mental health within the context of autism.

Starting with some existing materials, our core team consulted with a large and diverse group of Autistic adults and family members of Autistic adults from many parts of Canada, getting input on the chapter content and format over a period of nearly two years. Advisers did not represent any specific organization or group. We wanted to learn from them about what they thought was needed to support mental health. The content of this guide does not necessarily represent any specific adviser's views or ideas.

Some advisers were also keen to provide their first-hand Autistic experiences in different sections, which we have kept as quotes, to bring a first-person account of the content we cover. These perspectives and opinions complement the broader content, acknowledging that there are different ways of doing things and that each person's experience is unique. I hope that as you read this, you generate more ideas around how to promote mental health and address mental health problems when they arise.

It became clear in consulting with advisers just how passionate they were in changing the way Autistic adults are treated in Canada and beyond. There is a sincere desire and recognition that for well-being to occur, our society must accept people for who they are, with all their diversity. There was a strong focus on the social contexts for mental health: that the current states of mental health for Autistic adults lie in their experiences in the world—and that solutions must be found in how to change these contexts for the better, moving beyond the traditional focus on the individual. I hope that all who read this document reflect on how autism is understood and how Autistic adults are supported.

It was also clear that many Autistic adults feel hurt, marginalized, stigmatized and disenfranchised by non-Autistic society at large. Many advisers described negative experiences that they have had, or that other Autistic people have had, with non-Autistic-led organizations, providers and advocacy groups. As well,

some advisers shared similar experiences that they have had with some Autistic-led organizations. There was a general concern that adviser contributions in this guide could end up serving goals and organizations that advisers did not support. I have elected to use a disclaimer section that follows this foreword to reflect some of these concerns. I ask readers to keep them in mind as they review the guide. I believe that these sentiments reflect the belief that for things to be better, systems of care need to improve, and for that to happen, these systems must learn from Autistic people.

This guide is meant to be used openly and freely to benefit the mental health of Autistic adults by increasing readers' awareness of mental health within the context of autism. Knowing more can empower us to do more.

Sincerely,

Dr. Jonathan Weiss

DISCLAIMERS

Autistic advisers informed the development of this guide, but this process and the writing was not led by Autistic people. As was pointed out to us, there may continue to be some aspects that have a "neurotypical lens."

The views expressed in this guide do not necessarily reflect the views of all contributing advisers or authors, and not all the ideas that emerged in consultations were included. Throughout, we did include unedited adviser quotes that reflect a variety of perspectives and opinions, to capture some of the diversity of what people experience and want. There is no single perspective that is endorsed.

The content of this guide focuses on mental health. As such, there is content that may be triggering to some readers.

The information provided in this guide is not meant to be a substitute for mental health care. Its purpose is to increase awareness and share knowledge, not to provide readers with skills in mental health care provision.

Some advisers do not support the notion of a national autism strategy in Canada and are concerned that this guide will be used by non–Autistic-run advocacy groups, who do not represent their views, for a national strategy. Some advisers expressly asked that this material "not benefit the Applied Behaviour Analysis industry in any way."

This guide should be reviewed and taken in its entirety. There was concern shared that only portions of this guide would end up being considered to suit any one particular organization's agenda.

The use of this guide does not mean an endorsement of any organization or movement.

Some sections were written expressly with the Canadian mental health context in mind, though much of it is not specific to the Canadian context.

Contents

Introduction

Welcome to the *Mental Health Literacy Guide for Autism!* This guide is meant to provide information about the mental health needs of Autistic adults. The guide was developed in consultation with Autistic adults and parents and siblings of Autistic adults. Autistic adults shared their mental health experiences and provided ideas of what was needed to promote their well-being.[a]

Who should read the guide?

The guide is for Autistic adults and the Autistic community, as well as for the autism community, such as families, caregivers, service providers, educators, institutions, organizations, agencies and policy-makers.

Purpose of the guide

The guide's main purpose is to improve mental health literacy in Autistic adults in Canada. This means sharing knowledge and combating myths about autism, Autistic experiences and the unique mental health needs of Autistic people.

Some of the goals for this guide are:

- to provide knowledge about mental health as it relates to Autistic adults
- to communicate this knowledge through the lens of lived Autistic experiences in order to provide the most relevant, useful and valid information
- to be a resource that Autistic people can use to help understand the mental health systems across Canada
- to be a resource for Autistic and autism communities, families, mental health practitioners and service providers
- to inform people about the mental health needs that may be experienced by Autistic adults.

What are the limitations of this guide?

Every effort has been made to produce a guide that is a helpful tool. However, this guide does not address the specific needs of everyone. It is meant to be a starting point. It is recommended that readers further investigate the topics by accessing other resources.

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[a] The authors acknowledge that the advisory group was made up of Autistic adults or parents who were all physically and verbally able to share and represent their lived experiences.

Terms within the guide

Identity-first language

There have been major changes in the last 30 years that have profoundly shaped the ways in which autism is discussed, defined and described. There are some recommendations for **identity-first language** (e.g., "Autistic person") or for **person-first language** (e.g., "people with autism").

> Throughout the guide, the terms **Autistic person** or **Autistic people** will be used when communicating about autism.

While traditionally, person-first language was the recommended method for describing autism, many advocates and authors have highlighted the issues with this approach for the Autistic community.[1] There is relative consensus among disabled advocates in general and those in the Autistic community in particular, that identity-first language is the preferred way of talking about autism. Autism is seen as an inseparable part of who Autistic people are. At the same time, some family members, service providers and Autistic people themselves may still prefer person-first language or the use of a different term other than "Autistic."

The use of **identity-first language is meant to recognize, affirm and validate the ownership of an identity as an Autistic person**. "Autistic" is not a derogatory term. It is seen as a source of pride. We discuss stigma and autism in **Section 1**.

Gendered and gender-neutral language

The term **"sex"** refers to the biological characteristics of being male, female or intersex, while the term **"gender"** refers to the psychological, social, behavioural and cultural attributes related to assigned gender and non-binary genders. **"Gender identity"** refers to the subjective experience of being a boy, a girl, a man, a woman, non-binary, transgender, agender, genderqueer or gender-neutral.[2]

Throughout the guide, we use gender-neutral and gender-inclusive language as much as possible.[b] We talk more about gender and autism in **Section 3.**

> **Sex** refers to the biological characteristics of being male, female or intersex.
>
> **Gender** refers to the psychological, social, behavioural and cultural attributes related to one's assigned gender and non-binary gender.
>
> **Gender identity** refers to the subjective experience of being a boy, a girl, a man, a woman, non-binary, transgender, agender, genderqueer or gender-neutral.

Medical and non-medical references

Another common debate involves the language used when describing mental health. **Labels and diagnostic terms that are often used can be stigmatizing and overly pathologizing. They can imply something to be disapproved of, or as something "abnormal" or "unhealthy."** The stigma and negative perceptions with medical terms can cause emotional pain for Autistic people. It is important to acknowledge the limitations and potential consequences in using medicalized language.

> Throughout the guide, we aim to use a minimal number of medicalized terms, unless required for the sake of clarity.

Throughout the guide, we try not to use medicalized terms (e.g., using the word "disorder"), unless it was felt to be required for clarity or to inform about common words used by professionals, or unless such terms were used by Autistic advisers when sharing their experiences. **Section 7** discusses the diagnostic process, including the advantages and disadvantages of using certain language.

Structure and layout of the guide

The structure and layout of the guide helps provide both depth and range. Each section starts with a snapshot (a quick summary) of what will be discussed, and parts of the guide use visual summaries. The first few chapters aim to present general information, including definitions for autism, mental health and more. The guide then becomes more specific, discussing common mental health triggers, strategies to promote mental health wellness and formal mental health systems in Canada. We end the guide with a List of Resources and a Glossary of Terms.

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[b]According to the United Nations, "gender-inclusive language means speaking and writing in a way that does not discriminate against a particular sex, social gender or gender identity, and does not perpetuate gender stereotypes."[3]

References

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