

Mental Health Priorities through Stakeholder-Engaged Work

Practical Application through Understanding Warning Signs of Suicide Risk Adapted for Autistic Adults

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Acknowledgements & Disclosure of Conflicts



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- The views presented in this presentation are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute® (PCORI®), its Board of Governors, or Methodology Committee.
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Learning Objectives and Outline of Webinar:


At the conclusion of this webinar, participants will be able to:

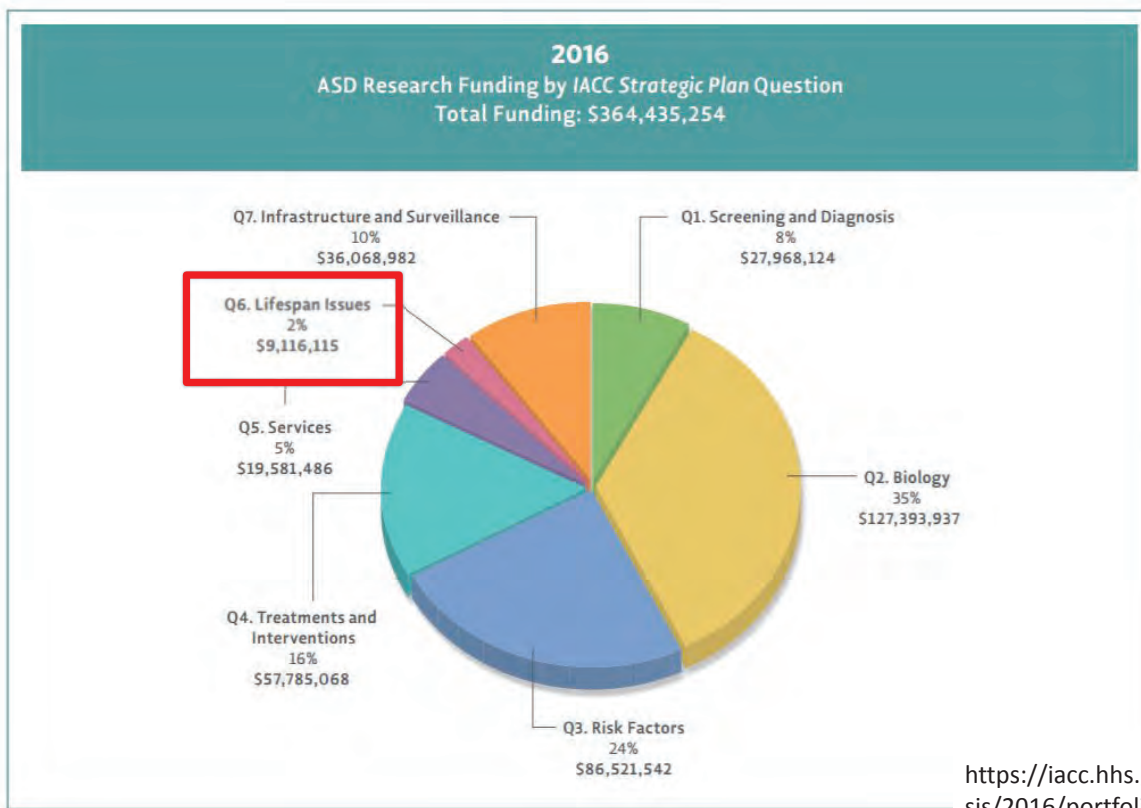
1. Identify top priorities of autistic adults for mental health research and practice.
2. Discuss warning signs of suicide and considerations to take when supporting autistic people who are experiencing crisis.



Information for Attendees

- We purposefully are using identity-first language in this presentation.
 - Identity-first language is preferred by many autistic individuals and acknowledges autism as an identity, not a disability or a condition.
 - We respect individuals who might prefer person-first, and it is always important to ask what language people prefer when engaging one-on-one

 - Trigger warning: We will be discussing suicide and thoughts that people might have that relate to suicide. Examples and case illustration will be provided. If this content is distressing, please feel free to leave.
 - If you are experiencing crisis or suicidal thoughts, please call 1-800-273-8255
 - Or text 'HOME' to 741741
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Fundamental Need to Ensure Autistic Individuals Are Involved in Setting Priorities for Research & Practice



- ❖ Pellicano et al. (2014) reported on priorities from within U.K., as shared by:
 - 122 autistic adults
 - 849 immediate family members
 - 426 professionals
 - 120 researchers

- ❖ Practitioners, researchers, funders, organizations, and others benefit from knowledge about how to best address priorities of the autistic adult community in collaborative ways.

Project Goals



To meaningfully include and engage autistic stakeholders in answering the following questions, in preparation for a patient-centered outcomes research CER study:

1). What are the health research priorities as identified by autistic adults?

2). What preferences for engagement and methods are successful when incorporating autistic adults as researchers in the research process?



Participatory Action Research Design



- Established a Project Team comprised of autistic and non-autistic individuals



- Established a paid Community Council of autistic adults and other stakeholders to inform and guide patient-centered outcomes research
 - 18 Community Council members joined and contributed
- Involved other stakeholder individuals and organizations in priority-setting



Involvement of the Community in All Steps



- All actions during the project were planned, discussed, reviewed and ultimately approved by the Community Council.
- All questions for surveys and focus groups were trialed, revised, and reviewed by the Community Council.
- All consent forms, flyers, and meeting documents were reviewed, revised, and approved by the Community Council.

We developed an Engagement and Compensation Guide which resulted from our shared work to understand the best ways to engage the autistic community:
<https://www.pcori.org/sites/default/files/AASET-Engagement-Guide-122018.pdf>

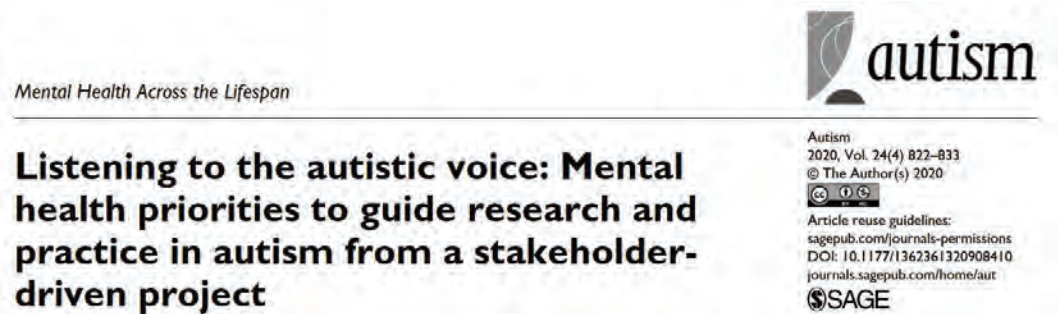
Approximately 400 people engaged with us over 2 years



- Participatory action research approaches 1/1/2017-12/31/2018
 - Large group stakeholder meetings
 - July 2017 (n=51)
 - November 2018 (n=64)
 - Online survey of autistic adults, launched Aug 2018 (n=249)
 - Face-to-face focus groups of autistic adults Aug-Nov 2018 (n=26)
 - We engaged a diverse group of autistic people, including women, men, non-binary individuals; those who were formally diagnosed and those who were self-identified as autistic; and a wide age range from 18-70years

Results of priorities revolved around the following themes:

1. Mental Health Interventions and Outcomes
2. Gender inequalities in diagnosis, treatment, and sexual well-being
3. Access to healthcare and needed accommodations to get care



Mental Health Research Priorities



- What is the impact of trauma on mental health outcomes in autistic individuals, and what approaches can be used to effectively address trauma among autistic adults (e.g. trauma-informed care)?
- What are the best indicators or measures of PTSD, trauma, and adverse childhood experiences in autistic individuals?

Mental Health Research Priorities

- What is the impact of social isolation, stigma, discrimination and other forms of marginalization on mental health and well-being in autistic individuals? Conversely, what is the impact of radical inclusion, such as being part of a social movement, on mental health and well-being?

Mental Health Research Priorities

- When, for who, and under what conditions do self-managed interventions and preferred activities used to address wellbeing and mental health result in improved quality of life and reduced mental health symptoms?
- What is the effect of employing community-available approaches and techniques such as exercise/physical activity, yoga, mindfulness and meditation, tai-chi, animal-assisted therapy, art and music-based approaches to well-being?



Mental Health Research Priorities

- What are the potential long- and short-term negative side effects or adverse outcomes of currently recommended therapies and interventions (including behavioural and pharmacological), as measured in autistic individuals across the life span?



Mental Health Research Priorities

- How can we develop better measurement tools for autistic quality of life, depression, anxiety, social well-being, and sleep as experienced by autistic adults?



“Outcomes that Matter To Me”

Table 4. Online survey participants who endorsed “This Outcome Matters to Me” and weighted rank ($n = 136$).

Outcome	“Yes—matters to me,” f (%)	Relative weighted rank ^a
Quality of life	130 (95.6)	1
Anxiety	122 (89.7)	2
Depression	111 (81.6)	3
Social well-being	107 (78.7)	4
Sleep	107 (78.7)	5
Interpersonal relationships	103 (75.7)	6
Suicidal ideation	92 (67.6)	7
Level of participation in activities of daily living	94 (69.1)	8
Level of participation in work	92 (67.6)	9
Suicidal attempts	87 (64.0)	10
Level of participation in your community	79 (58.1)	11
Intimacy and/or sex	76 (55.9)	12
Level of participation in leisure activities	77 (56.6)	13
Brain activity/EEG	47 (34.5)	14
Heart rate	44 (32.4)	15

^aWeighting for ranks were calculated as the sum of the number of participant responses ranking that item as “1,” “2,” . . . “15” multiplied by the weight. A rank of “1” was given a weight of 15, and a rank of “15” was given a weight of “1.”




AUTISM RESOURCE
 FOR WARNING SIGNS OF SUICIDE:
 CONSIDERATIONS FOR THE AUTISM
 COMMUNITY

Suicide statistics

- A diagnosis of autism is a risk factor for suicide
- 60% of newly dx autistic adults reported suicide ideation (SI) compared to 17% in the general population
- 35% had planned or attempted suicide compared to 2.5% in the general population
- Life expectancy of an autistic person is 36-54 years



WHY DO
AUTISTIC PEOPLE
NEED CRISIS
SUPPORT?



WHY DO
AUTISTIC PEOPLE
NEED CRISIS
SUPPORT?

Suicide is a leading
cause of premature
death in the autism
community.



PURPOSE:

Understand	Understand the need for considerations
Recognize	Recognize the differences
Support	Support autistic people as autistic people




STRUCTURE OF THE TOOLKIT:

- States warning signs for general public
- Shows need for considerations
- Supports for autistic people in crisis

WARNING SIGNS OF SUICIDE (for the general public)


These warning signs of suicide were taken from the American Association of Suicidology website. The list is not comprehensive of all the signs of suicide. AFSP, NIMH, SPRC

- Increased substance (alcohol or drug) use
- No reason for living; no sense of purpose in life
- Anxiety, agitation, unable to sleep or sleeping all of the time
- Feeling trapped – like there's no way out
- Hopelessness
- Withdrawal from friends, family and society
- Rage, uncontrolled anger, seeking revenge
- Acting reckless or engaging in risky activities, seemingly without thinking
- Dramatic mood changes
- Giving away prized possessions or seeking long-term care for pets



The following explanations are considerations to pay attention to when supporting an autistic person for suicide ideation and / or attempt.

Please Note:

- **Do not make any important, life-altering decisions based on the information in the following slides. All the warning signs for the general public pertain to autistic people too – with considerations about autism.**
 - **This information is here to broaden existing knowledge about autistic people.**
 - **Autistic people know the most about themselves. The job of professionals helping - is to make space for them communicate.**
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REMEMBER...

- The thinking process of autistic people is typically very literal.
- Consider the exact meaning of what you say.
- Remember – autistic people will answer what they are asked in a literal way and may give a response, but not the information you are looking for to help them.
- You must ask for exactly what you need or want to find out.
- All the information about communicating from the autism crisis toolkit is relevant in supporting an autistic person in crisis.



Example:

Asking a question too general and vague may render the autistic person speechless.

There are too many different answers to think about and process.

Autistic person might not get the help they need.

Examples: How are you? What do you need?

Better - How can I help?



CONSIDERATIONS FOR AUTISTIC PEOPLE

INCREASED SUBSTANCE (ALCOHOL OR DRUG) USE

- Typically not a challenge for most people on the spectrum.
- They may actually just be stimming or regulating themselves.

Consideration: autistic person may be presenting in a way that is misunderstood.

Solution: Investigate the situation further to understand what the autistic person is experiencing.

NO REASON FOR LIVING; NO SENSE OF PURPOSE IN LIFE

An autistic person may feel this way due to social isolation and a professional can take into consideration comments such as:

“I don’t belong to this world.”

“I’ve never fit into this world.”

Consideration: These statements may just be the reality of an autistic person not belonging to this world culturally, socially, or environmentally.

Solution: Investigate further to understand exactly what the autistic person is communicating.

ANXIETY, AGITATION, SLEEP ISSUES

Consideration:

These symptoms are aspects of autism.

How might one know if they are signs of suicide?

Solution: Investigate further -

- Use concise, specific language during the assessment or crisis call/text.
- Investigate any changes in levels of anxiety, agitation or sleep issues.

FEELING TRAPPED

- Autistic people can't escape their autism or how society in our culture treats them.
- There is no way out and an autistic person will most likely be very honest about it.

Consideration: is saying the truth about one's life as an autistic person a warning sign of suicide?

Solution: Investigate further with clear, concise, literal language.



HOPELESSNESS

It is a myth that autistic people do not have or feel emotions.
Many autistic people can't identify or express their emotions.

Autistic people are typically honest.

An autistic person may feel hopeless and say they feel hopeless because it's true.

Consideration: It may be a word choice, not an emotion.

Solution: Investigate further using clear, concise, literal language.



WITHDRAWAL

- Withdrawal serves as a coping mechanism for many autistic people.
- It can also be a warning for suicide.
- Determine any changes in the level and/or type of withdrawal.

Consideration: is withdrawal being used as self-care by an autistic person.

Solution: Investigate any changes in withdrawal patterns or behavior.



RAGE, UNCONTROLLED ANGER, SEEKING REVENGE

- An autistic meltdown can look like rage and uncontrolled anger.
 - A meltdown is an intense response to overwhelming events
 - A meltdown can be caused by sensory overload
 - Autistic people have difficulty expressing their emotions
 - It is an involuntary coping mechanism
 - A true autistic meltdown can not be stopped by will or want

Consideration: the autistic person is reacting to an overwhelming situation.

Solution: Keep the autistic person safe, do not overreact, show empathy.



ACTING RECKLESS OR ENGAGING IN RISKY ACTIVITIES

Being misunderstood is common for autistic people.

Over thinking / Perseverating / Deeply thinking


Impulsivity

Confusion

Stimming

Consideration: the autistic person is presenting differently than what they are experiencing internally.

Solution: Understand autistic people are misunderstood and try to see the person you are helping think differently than non-autistic people.



DRAMATIC MOOD CHANGES


Dramatic mood changes can be caused by:

*Overwhelming emotions *Sensory overload *Change

These mood changes would be different than autistic meltdowns.

Consideration: there may be other causes for dramatic mood changes in autistic people.

Solution: Reframing the situation to help them perceive what happened in a different way could help.



GIVING AWAY PRIZED POSSESSIONS OR SEEKING LONG-TERM CARE FOR PETS

- There are autistic people who have strong emotional connections to their possessions and many who are very much connected to their pets, some of whom serve as therapy pets.
- Autistic people may use more obscure objects, such as batteries, fruit, sticks, cereal boxes, and even sticks to be comforted and used as a coping mechanism.
- Autistic people can have attachment to objects throughout their lifespan.

Considerations: autistic people have different levels of attachment to objects as a way to cope. This may be a warning sign of suicide for autistic people.

Solution: Understand attachment to objects may be different for autistic people and further investigation is necessary.

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Autism Crisis Toolkit on the American Association of Suicidology website:

<https://suicidology.org/wp-content/uploads/2019/07/Autism-Crisis-Supports.pdf>

Autism Resource for Warning Signs of Suicide: Considerations for the Autism Community

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