
Autistics, Autism Awareness Campaigns, and the Mental Health Care System

— Kit Mead —

Association for Autistic Community Conference 2016

Presentation Structure (1/2)

- Our mental health, autism awareness campaigns & mental health care
- My arguments and theories
- The formal data we lack
- Q&A, discussion period

Presentation Structure (2/2)

- Informal data collection (Google Forms survey) results
- Q&A, discussion period
- What I think the results mean and why they matter
- Moving Forward
- Q&A, discussion period

Autistics' Mental Health, Autism Awareness Campaigns, and Mental Health Care



Our Mental Health (1/2)

- **Psychiatric disabilities**
 - high rates of co-occurring psychiatric disabilities
- **Psychiatric hospitalization**
 - Study: Autistic children more likely to be psychiatrically hospitalized
- **Trauma rates**
 - Studies: autistic children are as likely to experience trauma

Our Mental Health (2/2)

- **Social isolation & bullying**
 - Many reports of social isolation and bullying
- **Suicide**
 - Autistic adults (without an intellectual disability) nine times more likely to die by suicide

Autism Awareness Campaigns

- Often spread harmful messages
- Kanner, Bettelheim, Ransom Notes Campaign, Autism Speaks' "I am Autism" video, Autism Speaks' "A Call for Action."

WE HAVE YOUR SON. WE ARE DESTROYING HIS
ABILITY FOR SOCIAL INTERACTION AND DRIVING HIM
INTO A LIFE OF COMPLETE ISOLATION.
IT'S UP TO YOU NOW.

ASPERGER
SYNDROME

We have your son.

We will make sure he will
not be able to care for
himself or interact socially
as long as he lives.

*This is only the beginning.

Autism

Mental Health Care System (1/2)

- Crisis setting possibilities
 - not really prepared to treat anyone like a person, but we risk other forms of ableism
 - our autistic traits seen as noncompliance
 - pressure to “treat” autism

Mental Health Care System (2/2)

- Non-crisis settings possibilities
 - pressure to “treat” autism
 - being denied access to transition-related medical care
 - professionals not believing we’re autistic
 - professionals not working with different communication styles

My Arguments and Theories

My Arguments and Theories

- Autism awareness campaigns can:
 - increase effects of our long-term psychiatric disabilities
 - be linked to our developing some psychiatric disabilities
 - be linked to many of us having short-term or situational mental health incidents
 - give rise to social isolation and bullying

The Data We Lack and Why It Matters

The Data We Lack: Rates for Different Backgrounds and of Trauma/PTSD

- Suicide rates for those of us with known long-term psychiatric disabilities versus those of us without
- Suicide rates for those of us with different backgrounds
- Psychiatric disability rates for those of us with different backgrounds
- Exact rates of trauma and/or PTSD for us, and best approaches

The Data We Lack: Effects of Awareness Campaigns

- If autism awareness campaigns can negatively impact self-image and mental health
- If autism awareness campaigns can link to mental health incidents
- Our full interaction with the mental health system

The Data We Lack: Why It Matters (1/3)

- We are diverse and have different experiences.
- No best practices to address our trauma and/or PTSD
 - More research could help professionals have more tools for a person seeking help.
 - We might be able to help each other with trauma.

The Data We Lack: Why It Matters (2/3)

- Some people think that social isolation and so on happen only because of autism itself. But awareness campaigns:
 - reach and hurt us
 - can make people think awful things about autism
 - can lead to us going through traumatic “therapies”

The Data We Lack: Why It Matters (3/3)

- Autistics should be able to access mental health care if they want to...
 - without fear
 - without ableism and pressure to “treat” autism.
- We still don’t have the right tools to better serve autistics:
 - in mental health crises.
 - in non-crisis settings.

Q&A, Discussion Period (15 minutes)

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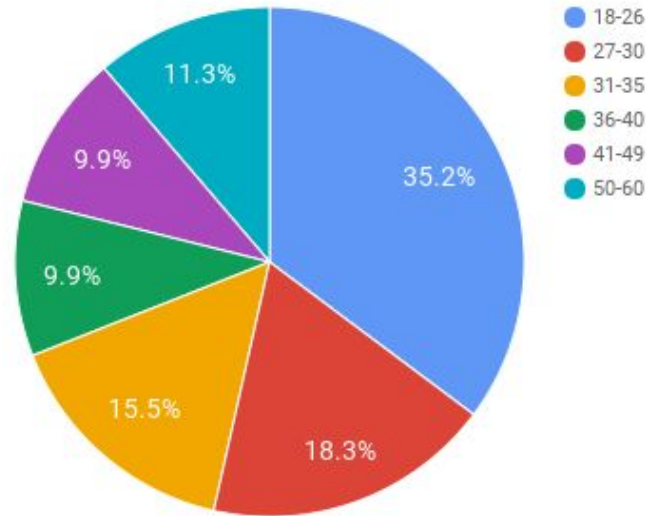
- Please ask me any questions you have!
- This will likely lead into a discussion based on people's questions and comments.
- Here is a possible discussion topic anyway: What other data are we missing?

Informal Data Collection through Google Forms Survey: Results

Identities (demographics): Age Range

- 18-60

Age range



Identities (demographics): Gender Identities

- gender non-conforming woman
- cis woman
- trans man
- genderqueer
- cis man
- agender
- genderless
- non-binary
- can't conceptualize gender
- demigirl
- gendervague
- bigender
- trans woman
- genderfluid

Identities (demographics): Sexual & Romantic Identities

- gay
- lesbian
- bisexual
- straight or heterosexual
- asexual
- demipanromantic
- queer
- bi/ace/aro spectrum
- pansexual
- polyamorous
- aromantic
- biromantic
- gray-asexual
- panromantic
- unknown

Identities (demographics): Racial Identities

- White
- Black
- Middle Eastern
- mixed race - unspecified
- mixed race - White/Native American/Romani
- mixed race - Asian/White
- mixed race - Native American/White
- Asian
- Latinx

Identities (demographics): Ethnic Identities

- White/Hispanic
- Ashkenazi Jewish
- Jewish - unspecified
- Welsh/Scottish/mixed - unspecified
- Indian

Identities (demographics): Religious Identities

- Christian - both Protestant & Catholic
- atheist/none
- agnostic/agnostic atheist
- eclectic pagan
- pantheist
- Jewish (Reform or Reconstructionist)
- Jewish (unspecified)
- Zen Buddhist
- Unitarian Universalist-atheist
- Norse pagan
- Redwood-based earth religion

Identities (demographics): Mental Health and Neurodivergence - other than autism (1/2)

- generalized anxiety disorder
- traumatic brain injury
- major depressive disorder
- nonverbal learning disorder
- OCD
- social anxiety disorder
- ADHD
- PTSD
- dysthymia/depression
- dermatillomania
- verbal dyspraxia
- dyscalculia

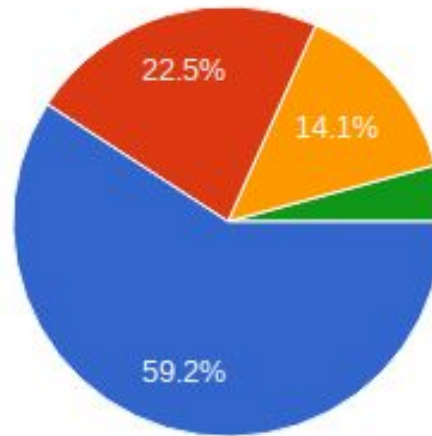
Identities (demographics): Mental Health and Neurodivergence - other than autism

- depersonalization derealization disorder
- complex PTSD
- anorexia
- various learning disabilities
- schizoaffective disorder
- dyspraxia
- prosopagnosia
- agoraphobia
- dissociative identity disorder
- sensory processing disorder
- psychosis
- borderline personality disorder

Life Experiences: Rates of Trauma and PTSD

- Over 75% have experienced trauma.
- Almost 25% have a PTSD diagnosis from the trauma.
- Minority have no trauma or PTSD diagnosis.

GRAPH RESULTS

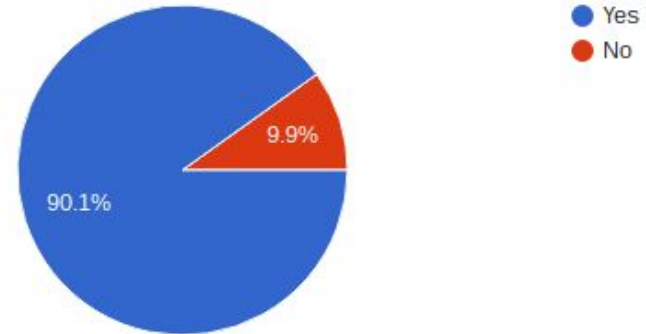


- I have experienced trauma and do not have a PTSD diagnosis
- I have experienced trauma and have a PTSD diagnosis
- I have not experienced trauma
- Other

Life Experiences: Bullying and Social Exclusion

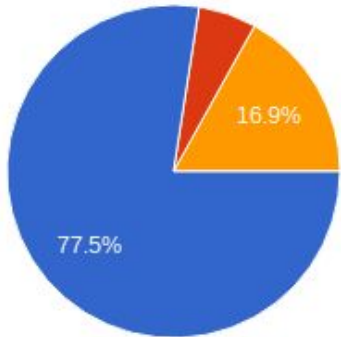
- **Bullied:** Vast majority said yes. Small fraction said no.
- **Socially excluded:** Majority said yes. Small fraction said no. "Other" responses included not really noticing.

Bullying



Social Exclusion

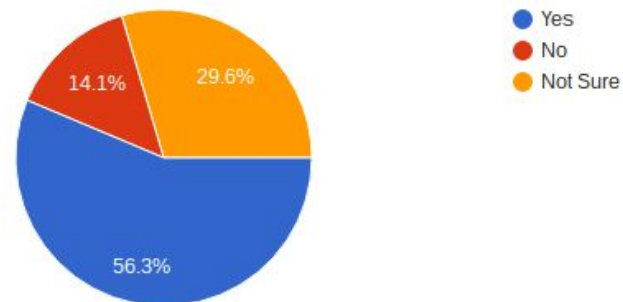
- Yes - people often do not include me
- No - people include me often
- Other



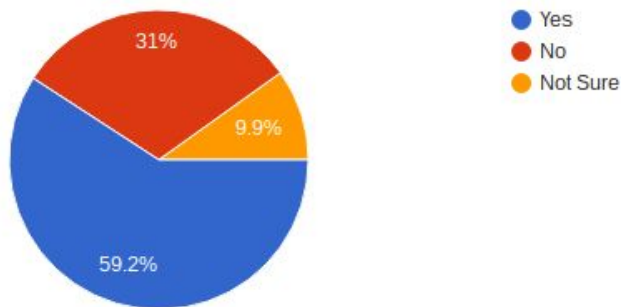
Effects of Autism Awareness Campaigns (1/2)

- **Harmed your mental health?**
56.3% yes, 29.6% not sure. Only 14.1% said no.
- **Lowered your self image?** 59.2% yes, 31% no, 9.9% not sure.

Have autism awareness campaigns harmed your mental health?



Have autism awareness campaigns lowered your self image?



Effects of Autism Awareness Campaigns (2/2)

- **Ever triggered a mental health episode?**

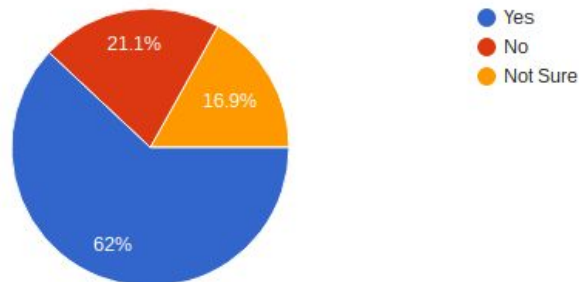
- 62% yes, 21.1% no, and 16.5% not sure.

- **Ever considered or attempted suicide - if so, did you link messages of being a burden to yourself?**

- 74.7% have considered or attempted suicide - 29.6% linked that to messages of being a burden. 18.3% had not considered or attempted suicide.

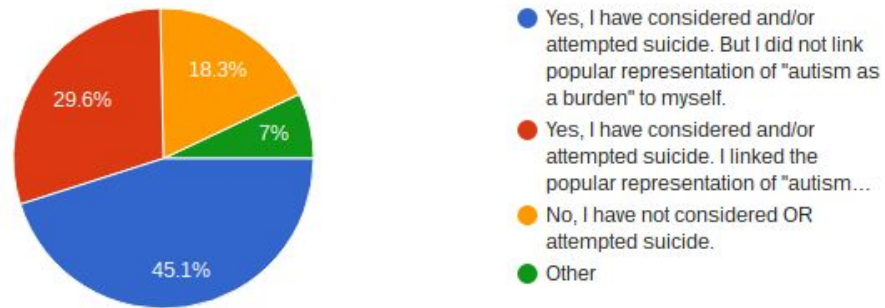
Have the messages of a being a burden ever set off mental health episodes?
(for example, depressive episodes)

(71 responses)



Have you ever considered or attempted suicide? If so, did or do you link the popular representation of "autism as a burden" to yourself?

(71 responses)



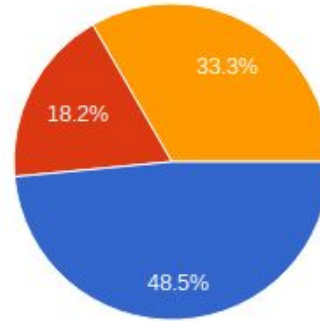
Effects of Awareness Campaigns: Selected Quotes

- “I have been suicidal... generally because of feeling worthless for having a disability and needing more help than other people or not being able to do the same things as other people; feeling hopeless because I needed help and wasn't getting it; and feeling judged by other people who might see me as lazy because of the things I couldn't do, and not believe I had a disability.”
- “Autism awareness makes me feel like I'll never amount to much.”
- “Every April is a particularly rough month for my mental health. I schedule extra psychiatrist visits during April because of the negative impact. "Autism Awareness" campaigns have on my mental health.”

In Mental Health Care: Therapy (1/2)

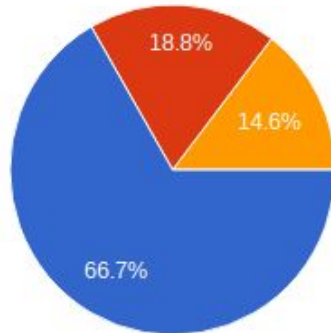
- **Did you want to?** 66.7% said yes. 33.3% of those wanted a better fit. 18.2% said no.
- **If you see one now, do you want to?** 81.3% said yes. 14.6% of those said they wanted another therapist. 8.8% said no.

If you have seen a therapist in the past, did you want to? (66 responses)



- Yes, I did want to
- No, I didn't want to
- I would have wanted to if it had been the right fit

If you see a therapist now, do you want to be in therapy? (48 responses)



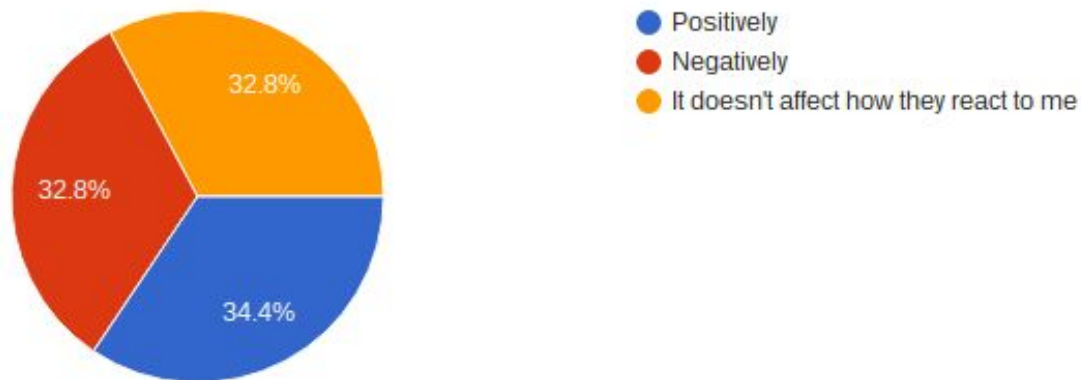
- Yes, I want to be in therapy.
- No, I do not want to be in therapy.
- Yes, I want to be in therapy, but with a different therapist.

In Mental Health Care: Therapy (2/2)

- **How have they reacted to you being autistic?** 34.4% said positively. 32.8% said negatively. 32.6% said it had no effect.

If you have seen one, how have therapists reacted to you being autistic?

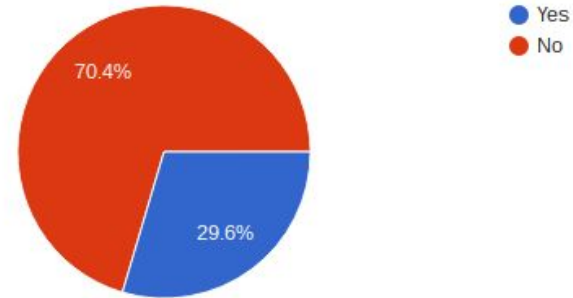
(61 responses)



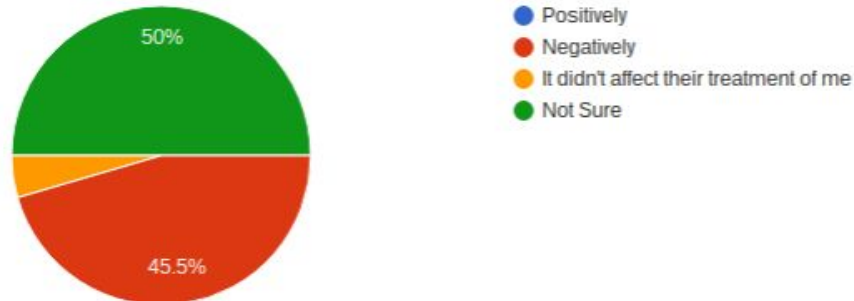
In Mental Health Care: Psychiatric Unit Stays

- **Ever stayed in a psych ward?**
70.4% no, 29.6% yes
- **If yes, reaction to being autistic?:** 50% not sure, 45.5% negatively, 4.5% it did not affect anything, and 0% positively.

Have you ever stayed in the psychiatric unit of a hospital, or anything similar?
(71 responses)

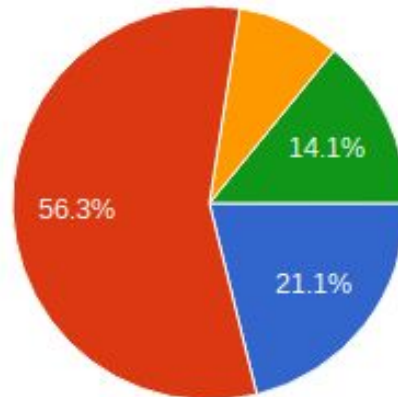


If you answered "yes" to having stayed in a psychiatric unit, how did staff react to you being autistic?
(22 responses)



In Mental Health Care: Other

- **Have you ever taken or been forced to take medications in an effort to “lessen” your autistic traits?**
 - About 56% said no.
 - About 44% have been asked to take or have taken medications in this regard.
 - Of those, 8.5% took them willingly. About 14% did not want them and did not have to take them. About 21% said they did not want to but had to.



- Yes, but I did not want to
- No, I have never been asked to take them
- Yes, and I took them willingly
- No, I was asked to take them, but I said no and did not have to

In Mental Health Care: Selected Quotes (1/2)

- “[The therapist] always jumped to these emotional explanations for my cognitive disabilities... My disability wasn't why I had wanted to go to therapy but it felt like we couldn't get past it. I stopped going to therapy... and feel somewhat hopeless about the idea of ever going to therapy because I've heard many other Autistic and learning disabled people have had the same problem.”
- “Mental health care and general health care providers extremely dismissive of autism.”
- “Long history of severe psychiatric abuse.”

In Mental Health Care: Selected Quotes (2/2)

- “The overall experience of being dragged around to dozens of doctors and put through dozens of different treatments (that constantly upturned my life and was sure to instill in me the feeling that I wasn't accepted the way I was, nor listened to about what treatments I wanted, I was perfectly happy going through regular talk therapy) was... traumatizing.”
- “Different therapists reacted differently to autism. Most did not treat me differently... But one therapist said I was faking it and just had social anxiety (I am not afraid of people), and said the same to my parents.”

Q&A, Discussion Period (15 minutes)

What Do the Results Mean? Why Do They Matter?



What Do These Results Mean?

- Awareness campaigns add to mental health incidents
- Many factors in autistic community, trauma, and mental health

Why Do They Matter?

- Highlight need for
 - policy/research changes on autism/mental health
 - changing conversation on us in a general sense
 - changing how mental health professionals see us
 - our community to address mental health and self-care

Moving Forward

Moving Forward: Policy, Research, & Changing Attitudes (1/2)

- **Mental health care reform:**
 - integrated health care models
 - community-based resources & peer respite centers
- **Research into autism and mental health:**
 - psych-disabled autistics and self-directed community supports
 - rates of trauma and PTSD for best practices
 - reform Autism CARES Act/IACC, include such research

Moving Forward: Policy, Research, & Changing Attitudes (2/2)

- **General stigma studies**
 - on popular attitudes about autism
 - would include media/awareness aspects
- **Train mental health professionals to understand us**
 - Done carefully to avoid trainings that do more harm
 - LEND program outreach to mental health professionals
 - Network of autistic-friendly mental health professionals

Moving Forward: Talking about Autism & Mental Health (1/3)

- **General Ways to Talk About Suicide**
 - Discuss like other deaths. Respect the person who died.
 - Avoid details like method or photos of where it was.
- **Suicide in Our Community**
 - If you feel able to, talk to others who seem to be struggling.
 - Refute others blaming autism for a suicide if you can.
 - If you can, reach out after a suicide, for yourself or others.

Moving Forward: Talking about Autism & Mental Health (2/3)

- **General Self-Care and Sustainability**

- Set boundaries for yourself and others. Take breaks if you can.
- Make plans for if things get bad due to events or brain things.
- Share the plan, and/or work on plans with a group.
- Recognize signs of burnout.
- Especially if you have mental health needs, think on burnout's effects.

Moving Forward: Talking about Autism & Mental Health (3/3)

- **Self-Care and Sustainability for Advocates**
 - Find community both in and out of advocacy circles.
 - Get advice from people good at stepping back on taking breaks.
 - Take breaks from advocacy.
 - Talk about potential burnout in advocacy circles so other advocates can practice self-care.

Sources

Main Sources (1/2)

- Autistica, “Personal Tragedies and Public Crisis,”
<http://www.autistica.org.uk/wp-content/uploads/2016/03/Personal-tragedies-public-crisis.pdf>
- For awareness language: Autism Speaks website and YouTube version of “I am Autism” video, things I’ve seen around the Web
- Informal data from autistic people via Google Forms survey
- Traveling Show, “Healthier Advocates,”
<http://iamthethunder.tumblr.com/post/140069828870/healthier-advocates>
- Traveling Show, “Talking About Suicide,”
<http://iamthethunder.tumblr.com/post/140060811720/talking-about-suicide>

Main Sources (2/2)

- “Pharmacological treatments prescribed to people with autism spectrum disorder (ASD) in primary health care,”
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3932167/> [very clinical]
- “The Effects of Psychological Trauma on Autistic Children,”
<http://link.springer.com/article/10.1007/s40489-015-0052-y> [medical model]
- “Psychiatric hospital treatment of children with autism and severe behavioral disturbance,” <http://www.ncbi.nlm.nih.gov/pubmed/24231172> [medical model]
- “Trapped Children: Popular Images of Children with Autism in the 1960s and 2000s,” Jennifer Sarrett, *The Journal of Medical Humanities* (vol 32, no 2, pub. 2011, pg 141-53)

THE END

Final Q&A, discussion period + how to contact Kit

- **Final Q&A and discussion period**
 - 15 minutes
- **Contact me through email**
 - kit.p.mead@gmail.com