

Handout for Presentation
“Autistics, Autism Awareness Campaigns, and the Mental Health Care System”
Association for Autistic Community Conference 2016
by Kit Mead

ACCESSIBILITY STATEMENT

Please let me know if you have any access needs with this document. Access needs could include a different format, large print, be easier-to-read, and more.

CONTENT OF HANDOUT:

- Rough Transcript*
- Sources and Resources
- Contact Kit

ROUGH TRANSCRIPT

TITLE SLIDE

I'm Kit Mead. I'm also a writer on autism and mental health.

I'll be talking about how autism awareness campaigns affect autistic people and how all of that interacts with the mental health care system. The presentation focuses on the United States.

SLIDE: Presentation Structure 1/2

There are several sections to this presentation. There are three fifteen minute discussion periods. Please hold your questions and comments until parts I have planned for that. I will get thrown off track otherwise.

The first half covers the introduction - what we know about autistics' mental health, what awareness campaigns consist of, and the mental health care system. I'll go over my theories and arguments - what I think we can draw connections between. I'll describe what what information we're missing. Then we will have our first discussion period.

SLIDE: Presentation Structure 2/2

The second half talks about informal information I collected via Google Forms. The information is to better highlight the intersection of awareness campaigns and autistics' mental health. Then we'll have our second discussion period. I'll talk about what I think the survey results mean and why they matter. I'll discuss what steps can we take moving forward. Then there will be a final discussion period.

Also, this presentation will talk extensively about suicide, hospitals, and abuse.

SLIDE: Our mental health, autism awareness campaigns & mental health care

Let's get started with what we know about autistics' mental health, autism awareness campaigns, and the mental health care system.

SLIDE: Our Mental Health (1/2)

Autistics have high rates of co-occurring psychiatric disabilities. 70% of autistics have at least one mental health diagnosis. 40% of autistics have at least two mental health diagnoses.

Studies show autistic children are at least as likely to experience trauma as their non-autistic peers. Traumatic experiences as defined by one article are abuse, bullying, death and separation from loved ones, exposure to violence, exposure to disasters, and painful medical interventions.

SLIDE: Our Mental Health (2/2)

Many autistic people report social isolation and bullying. One survey said 63% of autistics have been bullied, but that one only surveyed parents.

Autistic adults without an intellectual disability are nine times more likely to die by suicide than non-autistic adults. 0.5% of non-autistic children experience suicidal thoughts, but 14% of autistic children experience suicidal thoughts. Studies have shown that 30-50% of autistic adults have considered suicide.

SLIDE: Autism Awareness Campaigns

Most awareness campaigns spread harmful messages. This is not new. This starts way back in the 1940s and 50s with Kanner and Bettelheim. It goes on to the current day - think Ransom Notes Campaign in 2006, think Autism Speaks' rhetoric.

These awareness campaigns argue that autism is a national public health crisis to be solved. These campaigns contribute to cure culture and the spread of dangerous "miracle cures." They also contribute to abusive "normalization therapies."

SLIDE: Mental Health Care System (1/2)

The mental health crisis system does not really treat anyone like a person. The system is to take a person away from what they know best, and put them in a hospital. For autistic people, this can be really traumatizing. We may face additional ableism when in hospital settings. This may include pressure to "treat" autism, being punished for autistic traits, or other abuse.

SLIDE: Mental Health Care System (2/2)

In non-crisis settings, we also often face pressure to "treat" autism. Professionals may also prescribe heavy psychotropic drugs, to autistic people, including young children. These drugs don't even always work for the people they're designed for. One 2008 study indicated that 29% of autistic people age 24 and under were on psychotropic drugs. Of those, the most used were sleeping medications, psychostimulants, and anti-psychotics.

Or professionals may not believe autistic people about being autistic. They may not adjust to different communication styles and needs.

They may also deny autistics what they need like transition related medical care. An example is hormone replacement therapy (HRT) for transgender people.

SLIDE: Arguments and Theories

I argue that autism awareness campaigns can increase the effects of our long-term psychiatric disabilities. I further contend that they can be linked to developing psychiatric disabilities such as PTSD. The reason is encouraging "cure culture" and abusive "therapies" which result in trauma and/or PTSD.

I also believe they can be linked to many people having short-term or situational mental health incidents. These messages wear people down over time, or spark intense reactions.

Finally, I say they contribute to social isolation and bullying. Both of those can lead to mental health incidents. And because the bullying survey only interviewed parents, the number is likely much higher.

All of these - increasing the effects of existing psychiatric disabilities, along with trauma, PTSD, and other mental health incidents - can result in entering the mental health care system.

SLIDE: The Formal Data We Lack

We're also missing a lot of information. What information is it? Why does it matter?

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

We are missing information on suicide rates for those of us with known long-term psychiatric disabilities versus those without. We lack data on suicide rates for those of us with different backgrounds, such as race, gender, and sexuality. We don't have psychiatric disability rates for those of us with different backgrounds. Nor do we have exact rates of trauma and/or PTSD for us, and best approaches. One study did note that "Further research is needed to clarify the symptom presentation and frequency of PTSD."

We don't have studies on whether things like ABA cause trauma and/or PTSD, which is because normalization "therapies" are so mainstream. Any further studies might not count things like ABA as traumatizing. Not counting ABA would cause problems trying to figure out trauma rates.

SLIDE: The Data We Lack: Effects of Awareness Campaigns

There is also no data on what autism awareness campaigns *do* to us. There is a lot of anecdotal evidence that says, "This hurts us." But there haven't been any studies on these awareness campaigns, mental health, and self-image.

We also don't know the wide range of interactions in the mental health care system for all of us. An example is the rate of psychiatric hospitalizations in adults. Another example is if mental health professionals treat us differently.

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

It matters because we are a diverse group of people. Different identities influence and change a person's experience, and how they see the world. They don't necessarily define a person, but they influence. Without information on mental health for different backgrounds, we can't address things like mental health care gaps among different autistics. We also can't target things to specific communities.

We also don't have best practices to address our trauma and/or PTSD. We are all different. But more research could help professionals have more tools for a person seeking help. They could have a toolbox of options to work with when working with us. The autistic community doesn't have any best practices on helping traumatized community members - from the perspective of fellow community members. We would be able to help each other more with trauma.

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

Lots of people think that social isolation and so on happen only because of autism itself. Many people do not take into account that awareness campaigns reach and hurt us. Or that they can make people think awful things about autism - leading to things like us going through traumatic "therapies."

So if we had research that said it hurts us, more people might realize that it's not just the effects of autism. Then they might think about better ways to educate people on autism.

SLIDE: The Data We Lack: Why it Matters (3/3)

We should be able to access mental health care if we want to without fear, ableism, and pressure to "treat" autism. If we had data talking about how mental health professionals treated autistic people, changes could be made.

We also only know rates of having a co-occurring psychiatric disability. Professionals still don't have tools to better serve autistics in mental health crises and in non-crisis settings. They don't have that kind of toolbox for addressing an autistic person seeking help. And there's not really a great set of standards for anyone in a mental health crisis. There could be more research into more community-based crisis services. Locking people away isn't the best solution.

SLIDE: Q&A, Discussion Period

Here is the question and answer plus discussion period. It's going to be 15 minutes.

SLIDE: Q&A, Discussion Period

The discussion will likely take the form of people going off each other's questions. But I do have one starter question. What other data are we missing and why does it matter?

SLIDE: Informal Data Collection Through Google Forms Survey: Results

I made a Google Forms Survey for people to take. I collected various identities (demographics). I asked about life experiences, how autism awareness campaigns affected people, and experiences in the mental health care system.

SLIDE: Identities (demographics): Age range

The age range was 18-60.

SLIDE: Identities (demographics): Gender Identities

People said they had the following gender identities:

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

SLIDE: Identities (demographics): Sexual and romantic identities

People said they had the following romantic and sexual identities:

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

SLIDE: Identities (demographics): Racial identities

People said they had the following 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

SLIDE: Identities (demographics): Ethnic identities

People said they had the following ethnic identities:

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

SLIDE: Identities (demographics): Religious identities

People said they had the following ethnic 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/neurodivergence besides autism

Various people had some combination of the following:

- generalized anxiety disorder
- traumatic brain injury and complications
- major depressive disorder
- nonverbal learning disorder (NVLD)
- OCD
- social anxiety disorder
- ADHD
- PTSD

SLIDE: Diagnoses besides autism, continued

- dysthymia/depression
- dermatillomania
- verbal dyspraxia
- dyscalculia
- depersonalization-derealization disorder (DPDR)
- complex PTSD
- anorexia
- various learning disabilities

SLIDE: Diagnoses besides autism, continued

- schizoaffective disorder
- dyspraxia
- prosopagnosia
- agoraphobia
- dissociative identity disorder
- sensory processing disorder
- psychosis
- borderline personality disorder

SLIDE: Life Experiences: Rates of Trauma and PTSD

For life experiences, I first asked about trauma and PTSD. According to the results, over 75% of us have experienced trauma. Almost a quarter have a PTSD diagnosis from the trauma. A minority have no trauma or PTSD diagnosis. These results may be skewed due to not being able to access a diagnosis or no one recognizing the PTSD.

SLIDE: Life Experiences: Bullying and Social Exclusion

I next asked about bullying and social exclusion. When I asked about having ever been bullied, the vast majority said yes. A small fraction said no. When it came to social exclusion, the majority said yes to being excluded. A small fraction said no to being excluded. "Other" responses included not really noticing.

SLIDE: Effects of Autism Awareness Campaigns

For the effects of awareness campaigns, I first asked if the campaigns had ever harmed mental health or self-image. For mental health, over 50% said yes. Just over 25% said "not sure." Only 14% said no.

For self image, over 50% said yes. 31% said no. 9.9% of people said "not sure."

SLIDE: Effects of Autism Awareness Campaigns

Next I asked about if autism awareness campaigns had ever triggered a mental health episode.

Then I asked if anyone had ever considered/attempted suicide and linked messages of being a burden to themselves.

SLIDE: 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."

SLIDE: In Mental Health Care (Therapy)

I asked: Did you want to? 66.7% said yes. 33.3% of those wanted a better fit. 18.2% said no.

I also asked: 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.

SLIDE: In Mental Health Care (Psychiatric Hospitalizations)

I asked about psych ward stays. 70.4% said no, 29.6% said yes.

I also asked, "If yes, reaction to being autistic?": 50% said not sure, 45.5% said negatively, 4.5% said it did not affect anything, and 0% said positively.

SLIDE: In Mental Health Care (Other)

I asked, "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."

SLIDE: 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."

SLIDE: 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.”

SLIDE: Q&A, Discussion Period (15 minutes)

15 minute Q&A/discussion period.

SLIDE: What Do the Results Mean? Why Do They Matter?

Lots of data. What do the results mean? Why do they matter?

SLIDE: What Do These Results Mean?

The results support the idea that awareness campaigns can trigger mental health episodes, and harm our mental health and self-image. Some of us have linked autism as burden messages to themselves and considered or attempted suicide as a result.

The results also suggest rates of bullying and social isolation are higher than formal data says.

Finally, the results say that our trauma rates are really high. There seem to be a lot of reasons for that. There also seem to be many factors affecting our mental health.

SLIDE: Why Do They Matter?

They highlight the need for:

- policy and research changes on autism and mental health
- changing the conversation on us in a general way,
- changing how mental health professionals see us.
- for our community to work on mental health and self-care.

SLIDE: Moving Forward

Here are some next steps in how we can change policy and research efforts. Then there are some ways that our community can work on mental health. I don't have all the solutions. But here are some ideas.

SLIDE: Moving Forward: Next Steps In Policy and Research (1/2)

For reforming mental health, integrated health care models could be useful. Integrated models of health care basically mean that your health care get linked if you want it to be. That way it's easier for your doctors to know the same things. You also don't have to explain things over and over again.

Another aspect of mental health reform would be community-based resources. Community-based resources are things like 24-hour drop-in centers. They're peer respite centers, too - these are places people can go to take a break. Peer respite centers have staff with mental health needs. They're also ways of addressing crises that don't take you away from the community.

Mental health hotlines that connect you to resources based on your needs should exist. The services would reflect other aspects of yourself like gender, sexuality, or having other disabilities.

For research into autism and mental health, research needs to focus on autistics with psychiatric disabilities and how they can get self-directed community-based supports. We need to find out the rates of trauma and PTSD in our community, so best practices can be created. Finally, reforming the Autism C.A.R.E.S. Act and the Interagency Autism Coordinating Committee or IACC's research agendas could be a method for that - including such research in their priorities.

SLIDE: Moving Forward: Next Steps in Policy and Research (2/2)

The last couple of steps that we can take in this area are general stigma studies and training mental health professionals about us.

General stigma studies, like those in the mental health community, look at popular attitudes about certain disabilities and how those affect the groups. It would be good to get a sense of how popular attitudes about autism affect us. The studies could include media coverage and awareness aspects.

Then, there is training mental health professionals to understand us. This is tricky because if the training is bad, then that makes everything worse. So it'd have to be done carefully. Another way to do this would be to work with the the UCEDD LEND programs. The programs could increase outreach to include mental health professionals. They already provide education and training for many specialists.

We could also get the help of autistic-friendly mental health professionals. They could help change the way others in their field see us. We could then establish a network of autistic-friendly mental health professionals. We could even have them gather in conferences that are autistic-run. We could provide them with guides on having autistic patients.

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

What can our community can start doing?

First, here are some general ways to talk about suicide:

- Discuss the suicide like other deaths.
- Don't make it seem appealing.
- Respect the person who died.
- Avoid details like method or photos of where it was.

Then there's suicide in our community. Use the general guidelines above. Some other good strategies are to talk to others who seem to be struggling if you feel able to. Don't let people blame autism for a suicide if you can. Reach out after a suicide in the community if you can. Reaching out can help both yourself and others.

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

Some general self-care and sustainability tips are to set boundaries for yourself and others. Responding to your own needs and to others' needs can be hard.

Take general breaks from doing intense things or work if you can. Some people don't have control over when they can take a break or can't due to other reasons, so this is only if you can.

Also make plans for if things get bad due to events or brain things. The plans can include what others

should do for you and self-care methods. Share the plan with other people. It can also help to work on plans with a group and think together.

Recognize signs of burnout. Burnout leaves you drained and empty. The signs include

- Anxiety
- Guilt
- Isolation
- Irritability
- Anger
- Sadness
- Pessimism
- Disappointment
- Numbness
- Fatigue/Insomnia
- Lack of motivation
- Physical pain/Sickness

These aren't universal signs but they can be a start. Especially if you have mental health needs, think on burnout's effects. It can interact with other things to push people into dangerous places.

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

Self-care is also a problem for advocates and activists. Some self-care and sustainability tips specifically for advocates and activists are to:

- find community both in and out of advocacy circles.
- Get advice from people good at stepping back on taking breaks - these people might not be advocates, so they can provide perspective.
- take breaks from advocacy, even if it's just a couple of days every month or two.
- talk about potential burnout in advocacy circles so other advocates can practice self-care.

**Transcript does not include the slides on sources, the final discussion period, or contact info.*

SOURCES and RESOURCES

Autistica, "Personal Tragedies and Public Crisis,"

<http://www.autistica.org.uk/wp-content/uploads/2016/03/Personal-tragedies-public-crisis.pdf>

Awareness language: Autism Speaks website and YouTube version of "I am Autism" video

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>

Various articles and the like by Leo Kanner, Bruno Bettelheim

"Pharmacological treatments prescribed to people with autism spectrum disorder (ASD) in primary health care," <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3932167/>

"The Effects of Psychological Trauma on Autistic Children,"
<http://link.springer.com/article/10.1007/s40489-015-0052-y>

"Psychiatric hospital treatment of children with autism and severe behavioral disturbance,"
<http://www.ncbi.nlm.nih.gov/pubmed/24231172>

"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 "Ransom Notes" Affair: When the Neurodiversity Movement Came of Age," Joseph F. Kras,
Disability Studies Quarterly: <http://dsq-sds.org/article/view/1065/1254>

Burnout in Social Justice and Human Rights Activists: Symptoms, Causes and Implications:
<http://www.edchange.org/publications/Activist-Burnout-Chen-Gorski.pdf>

Survival Strategies for Activists: <http://www.kathylabriola.com/articles/survival-strategies-for-activists>

When Activism Meets Anxiety and Depression:
<http://www.truth-out.org/speakout/item/17308-when-activist-burnout-meets-anxiety-and-depression>

Dealing with Activist Burnout and Self-Care:
<http://knowyourix.org/dealing-with/dealing-with-activist-burn-out-and-self-care/>

On Compassion Fatigue, Vicarious Trauma, and Burn-out
<http://akhilak.com/blog/2011/10/11/on-compassion-fatigue-vicarious-trauma-burn-out/>

How To Avoid Burnout when You're Saving the World:
<https://www.themuse.com/advice/how-to-avoid-burnout-when-youre-saving-the-world>

CONTACT KIT

This is for if you want to get in touch for any reason. I am also happy to send a PDF of the presentation.

If you want to get in touch through email:

kit.p.mead@gmail.com

If you want to get in touch through social media:

Main blog:
<https://kpagination.wordpress.com>

Facebook:
<https://www.facebook.com/paginatedthoughts/>

Twitter:
<https://twitter.com/kpagination> (@kpagination)