Autism Training

For INSAR 2020
Developed by the 2020 INSAR Autistic Researchers Committee

What is autism?

https://youtu.be/RbwRrVw-CRo
Autism occurs in about 1 in 59 people (Centers for Disease Control and Prevention, 2019 – but different studies report different numbers, due to methodological shortcomings and/or differences in how autism is conceptualized and identified across regions).

Often but not always observed in people with autism (Remember each autistic person is different):

- Hyper-focus on special interest
- Hyper-observant of details
- Sensory differences to light, sound, touch, smell, etc.
- Difficulty communicating needs, particularly when overwhelmed
- Co-occurring medical challenges which may include severe allergies, food intolerances, asthma, anxiety, migraine, eczema, etc.

Safe, quiet, low-sensory spaces are important especially where large numbers of people are gathered.
Often but not Always Observed in Autistic Individuals (remember each autistic person is different)

- Difficulty reading emotions/body language
- Laughs unexpectedly
- Odd facial expressions, speech tone, or wording
- High levels of honesty
- Very literal language
- Socially isolated
- Highly intuitive
- Keeps talking when others aren’t interested
- Avoids touch/eye-contact
- Delayed responses

AUTISM IS A SPECTRUM...OR EVEN A CONSTELLATION WITH MANY DIFFERENT DIMENSIONS...WE ARE ALL DIFFERENT
Researchers and clinicians used to think that being on the autism spectrum meant just being autistic. Clinicians used to be told that they shouldn’t diagnose autism alongside other neurotypes like ADHD.

We now recognize that autistic people are more likely than typically-developing individuals to qualify for many other diagnoses, like ADHD, anxiety, depression, sleep problems, gastrointestinal problems, intellectual disability, and more (Croen et al., 2015; Lai et al., 2019; Rydzewska et al., 2018). Autism is not necessarily “pure”; it is often “plus” something else.

Autistic people might qualify for these co-occurring diagnoses because of shared biological factors that also cause autism, or because of stress from the negative life experiences autistic people often have.

These co-occurring challenges might also affect autistic people’s ability to function in conferences and meetings. For example, anxiety could be a major barrier in the overwhelming conference environment!
How do we describe ourselves?

- 🚨 Autism Spectrum Disorder (ASD): a clinical term to describe the autism spectrum
- ✅ Autism Spectrum Development: A cultural term that respects autistic perspectives and moves beyond the clinical
- ✅ Autism Spectrum Difference: A cultural term that respects autistic perspectives and moves beyond the clinical
- ✅ Autism: A simple and straightforward term that is highly appropriate for everyday conversation

“Words create worlds” Dr. David Cooperrider
How do we describe ourselves?

- Person-First (e.g., “I am a person with autism”): used by some in the community
- Identity-First (e.g., “I am autistic”): used by many in the community. There have been at least two studies showing that identity-first language is preferred by more individuals on the autism spectrum than person-first language, at least in online studies (Kapp et al., 2013; Kenny et al., 2016).
- The phrase “person on the autism spectrum” is used by many in the community, and according to an online study (Kenny et al., 2016), it attracts about the same level of support as identity-first language. Furthermore, this phrase may be relatively inoffensive to most supporters of either identity-first or person-first language.
- Please note that respectful terminology changes person-to-person and even within a society that is becoming more inclusive of all people. It is important to ask an actual autistic person what is acceptable to them.

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How do we describe ourselves?

- High Functioning: clinical term to describe those who pass as ‘normal’ in many aspects of their lives.
- Low Functioning: clinical term to describe those on the spectrum who appear to have more obvious differences such as differences in verbal ability, cognitive ability, etc.
- No Functioning words: Amethyst explains why functioning labels are problematic. This is a 10:24 video. If short on time, please watch to 2:18 (https://youtu.be/RLJXqlOPZ5U)
How do we view ourselves?

- We are a diverse group of people. We don’t just vary from one another along one dimension – a single spectrum – but along many different dimensions. We are part of a multidimensional autism constellation.

- We also vary in our opinions. Some of us identify strongly with our autism and view ourselves as part of a community of autistic people. Some of us disagree and choose not to identify with autism or an autistic community.
How do we view ourselves?

- Some of us see society as being disabled rather than us being disabled. This simply means that society often fails to accept and include us, and instead pushes us to the margins.
- Some of us view ourselves as disabled and want society to understand the struggles we may have on a daily basis, especially with co-occurring conditions that often accompany autism.
- Some of us accept parts of both perspectives, seeing the challenges we encounter as the result of an interaction between our own characteristics and aspects of society.
- Some of us have different perspectives.
Myth busting

Content Warning: autistic individuals being real, funny, and using some swear words

https://youtu.be/d69tTXOvRq4
Research shows that autistic people are rapidly judged in negative ways by others (Sasson et al., 2017). These negative judgements aren’t based on what autistic people say, but how we say it – they disappear when transcripts of our speech are shown instead of videos and pictures.

While researchers have long said autistic people struggle to understand other people’s thoughts and perspectives, the idea of the “double empathy problem” suggests that neurotypicals also struggle to see the autistic point of view (Milton, 2012). This claim has been supported by research (Edey et al., 2016; Heasman & Gillespie, 2017).

This is why it’s important to make a special effort to see things from the autistic point of view.
Are Autistic Individuals Disinterested in Engaging Socially with Others?

- It is a MYTH that people with autism lack interest in interacting with others.
- Many autistic people, children and adults alike, do want to interact socially with others, but lack the skills needed to interact effectively.
- Many autistic people have had experiences of social victimization or exploitation, or simply of being ignored, that can make us anxious or feel like giving up on social interaction.
- Many autistic people can become overwhelmed or anxious in unfamiliar environments, which may reduce interest in new social horizons.
How might we communicate at the meeting?

- Our communication abilities in social environments runs the spectrum
- Some of us may be very verbal
- Some of us may only hold short conversations
- Some of us may be very quiet
- Some of us may have trouble distinguishing speech in noisy environments
- Some of us may use eye contact differently when communicating
- Some of us may seem confused in a conversation when we become distracted by stimuli around us
- Some of us may have trouble finding the right time to break into a conversation
- Some of us may be loud or repeat our statements

_It is important to understand the differences in our communication so you don’t take it personally_
What are some stressors that we might encounter?

- Bright lights; vertical lights; bright colours; lights that wash out presentation slides; flickering movements; loud sounds; sudden sounds; soft but irritating sounds; smells; microphone feedback or distortion; the feel of items
- Long waits; close contact with others; feeling forced to have conversations with people around us
- Feeling left out or judged; inability to hear speaker; feeling rushed;
- Not knowing where to go; not having someone to answer questions; feeling overwhelmed
- Not being able to leave a space quickly
What might we do under stress?

◦ Shutdown: lose the ability to communicate temporarily until we can feel less overwhelmed
◦ Meltdown: react by crying, being verbal (e.g., shouting, screaming), and sometimes acting out physically
◦ Leave a room or conversation abruptly
◦ Look for a quiet space
How might you support us at the meeting?

- Be patient and compassionate
- Ask us if you can help us
- Wait until we approach you if we are wearing identifying badges that are yellow or red
- Don’t take our behaviour personally (remember the double empathy problem: the reason for our behaviour may not be what you think it is!)
- Guide us to a quiet space to answer our questions
- Show us where the sensory space or autistic social space is located
- If someone is having a meltdown, guide without touching. Use a soft voice. Do not bombard with many ideas or directions. Sit beside; get out of their face.
Does everyone wish autism could be cured?
No. The neurodiversity movement views autism as a minority identity that is an important part of human diversity like race or sexuality.

A 1:23 video

https://youtu.be/47jz97K4Uvs
Nothing about us without us

https://youtu.be/ocemhm6My5o
Nothing about us without us

- It is important moving forward to understand autism through the eyes of those of us who are actually autistic.
- Books, videos, lectures etc. should all be considered from the first-person perspective of the autistic individual and remember...
- Autism is a spectrum or constellation and therefore one person’s experience...is just one person’s experience.
References


