

Community discussion:

Autism and the LGBTQ+ community



Hosted by LGBT Health and Wellbeing with guests Scottish Autism and our LGBT Autism Community Group, on Tuesday 4th September 2018 at Terrence Higgins Trust, Glasgow.

Background

Proposed Question: 'A community discussion to raise awareness of Autism, with a focus on Autistic LGBTQ+ people. How does autism and LGBTQ+ identities intersect? What impact does this have? How can the LGBTQ+ community better support Autistic LGBTQ+ people?

Glasgow Community Project holds a community discussion each quarter. They take the format of a panel discussion and allow our community members to engage with questions that are directly related to their LGBTQ+ identities and therefore are central to their lives.

This quarter's Community Discussion was titled 'Autism and the LGBTQ+ Community'. LGBT Health and Wellbeing support a LGBT Autism Community Group and we wanted to better understand how to support both this group and Autistic LGBT community members who use our services.

About the event

Panel members on the day were from our LGBT Autism Community Group and Scottish Autism. The event was attended by 28 of our community members and lasted 2 hours.

We implemented a series of suggestions from Scottish Autism to make the space more accessible for autistic community members and a review of this is included at the end of this report.

After a short introduction by Ian, Rachel from Scottish Autism and Emily from the LGBT Autism Community Group spoke, followed by a Q&A with community members.

Overview of Discussion

Ian: Why this topic?

While we have an LGBT Autism Community Group and community members who are both LGBT and autistic, we've not had events focused on autism before and we want to make our events as accessible as possible.

Short presentation by Rachel from Scottish Autism on being LGBT and autistic:

This presentation will focus on the autism-side more than the LGBT side although it will address the intersectionality of the two.

What is autism?

First of all, it is a collective term. No one particular behaviour is autistic. It's a collection of certain traits that can mean a person is autistic.

Here are some aspects of autism that can occur:

Neuro development differences

Autistic people's brains develop differently

Sensory and information processing differences

This is a common one for many autistic people. Sensory differences can manifest as sensitivity to light for example, but it can also affect all or any senses. Sensory seeking behaviour is often common, such as looking for sensory input. Another instance of sensory differences is related to sensory filtering, for example inability to filter out sounds.

Social communication differences

These can be oral or verbal. This can lead to social anxiety for individuals, or can contribute to some being non-verbal. Another instance is that some autistic people might struggle to pick up social cues or body language.

Social understanding and awareness differences

This can lead to inappropriate behaviour or comments, done with the best intentions.

Stress and emotional regulation differences

Some autistic people can experience emotions quite strongly, have difficulty expressing emotions or can experience breakdowns or

meltdowns. This leads to autism often being incorrectly thought of as a behavioural problem.

Some autistic people might benefit from extra processing time.

Differences in the area of executive functioning: Autistic people often have differing skills from non-autistic people in areas such as planning or prioritising.

Autism and LGBTQ+ Identity

- At least 1% of the population has autism.
- There is an increased prevalence of gender identity variance in autistic people.
- It is suspected that autistic people are more likely to have LGBT sexualities, although not enough research has been conducted in this area.

Autistic people are at risk of:

- Mental ill health
- Social isolation
- Abuse and bullying
- Poverty and barriers to accessing education and employment

These issues are all prevalent among LGBTQ+ communities as well. If you are at the intersection of both identities, there is added difficulty.

Specific issues which affect people with both identities:

- Problems accessing Pride and other LGBTQ+ events; Pride is extremely difficult for people with sensory processing differences.
- Gender transition problems; Pre transition, an individual might not be sure whether sensory issues are due to autism or due to experiencing gender dysphoria.
- Exploring, identifying and expressing LGBT identity; Exploring your emotions can be very difficult if you struggle communicating. A lot of autistic people don't fit into societal norms and also struggle fitting in with others of LGBTQ+ identities.
- Problems around romantic and sexual relationships.

How can LGBTQ+ projects and communities better support LGBTQ+ autistic people?

- Increase in accessible quality information, visibility and positive messages; Positive messages are very important, it is very difficult to hear negative things about your LGBT identity and then further hear negative things about your autistic identity. Positive messages can emphasise the value your identities have.
- Plan events with autistic people in mind.
- Listen to autistic LGBTQ+ people; lived experience is better than any theories.
- Be accepting and mindful of differences.
- Provide social opportunities and support.
- Organise wellbeing events and projects.
- Do more research.
- Provide person centred support, every person is different.
- Communicate clearly and allow time for processing.

- Remember there's no fix all, every person is different.

For more information and support, email Rachel and check out the leaflets in the hall.

Ian: suggestions from Rachel as to how we can be more inclusive

- In terms of accessibility at events, provide a quiet space outside of the main room where community members can come and go as they please.
- Wave instead of clapping when applauding.

The LGBT Autism Community group meets every second Saturday of the month at the LGBT Health Offices at 12 Queen's Crescent from 1pm until 3pm. The community group leaders are Emily and Aileen.

[15 minute break]

Introducing the community group leaders, Emily:

- Emily identifies as both LGBTQ+ and as autistic and has been part of the LGBTQ+ community for about 3 years.
- Why start the community group? Due to problems with accessibility and ableism at LGBTQ+ spaces. There is no support for people on the autistic spectrum who are also transgender.
- According to Stonewall UK, 26% disabled people have been discriminated against in LGBTQ+ spaces. LGBTQ+ people are in denial

of this when speaking to them, they don't accept it's true because they haven't seen it happening personally. This is one of the reasons Emily wanted this community group to happen, to begin a new conversation.

- Research shows that 1 in 7 or 1 in 8 people who are autistic are also transgender. There is a high degree of transphobia in autistic circles. Having an autistic transgender identity is very different from having only a transgender identity.
- Emily was fed up of being alone, and felt more scared to come out as autistic than to come out as transgender.
- She has found that people do not know what autism is – when she had this initial conversation with Ian from the community project she found that even he didn't know exactly.

Questions and Answers

1. Is it possible to study/have a career while autistic?

100% yes (*answered by Rachel – she said she has done both*).

There are barriers, issues and struggles which are harder than for non-autistic people. For example, interviews can be very difficult. However, there are very successful people who are autistic out there. People on the autistic spectrum can work in diverse roles and industries. There are certain traits common in autistic people which can be massive positives in the workplace.

2. Is there any protocol in the NHS around getting an autism diagnosis and getting access to the gender identity clinic? (Question asked by Benn). Is there an NHS wide policy or is it doctor dependent?

Scotland follows a particular guideline. This is based on the stability of the condition, so it depends on the criteria used to determine whether a condition is stable enough. Of course, there is a problem if your LGBTQ+ identity is fluid; you might be dismissed from the gender identity clinic due to being deemed as uncertain due to being autistic in this case. There have been examples of doctors trying to convince their patients that transitioning is not good for them. It also depends on what age you are and how binary your identity is. If you identify as non-binary, it is more difficult. There is not much of a standard across Scotland.

3. At an autistic centre in Edinburgh, two people came out as publicly as transgender; the rest of the community members of the centre lacked understanding of other identities, and the diversity and complexity of LGBTQ+ identities, so there was conflict.

Emily answered that as an autistic person, it is difficult to explore your own emotions. You might not understand what you're feeling when coming out as transgender, and having the public response be dismissive can be very dangerous. It is a lot easier to transition with support.

The community member who had made the above comment, continued explaining the situation; that for him, it is difficult to put closure to one form of identity and to accept and understand that this person has always felt differently when you've always known them a certain way. His friend won't accept that it takes time and wants full acceptance and understanding from everyone immediately.

At this point, Rachel introduced the concept of theory of mind in autism research (they are not a big fan of this theory, but there are relevant things about it). This theory poses that autistic people struggle to put themselves in other people's shoes. There are counter theories which emphasise the existence of double empathy in autistic people. Although the theory of mind cannot be generalised in Rachel's opinion, there are autistic people who struggle to guess what others' are thinking. In this case, open communication is the key, by their preferred method of communication.

4. Are there resources for people who have been recently diagnosed?

There are online communities who can provide peer to peer support. This can be helpful as it will provide a space for the individual to mull it over and maybe by understanding others better, one can understand themselves better too. This should ideally be a space free of negativity, where the recently diagnosed individual can understand that they are not broken, just different.

There is also an Autism Resource Centre in Glasgow in Partick, and the Scottish Autism organisation has an Advice Line.

5. Is the LGBT autism community group an open group? Do you have to have a diagnosis to attend?

Anyone can come, a diagnosis is not necessary. Family and friends can come too. At the moment, it's a space for having a tea, coffee and chat and for getting peer to peer support.

6. Are there any resources on bisexuality and autism?

The site from the infographic in the presentation is called Twainbow, which is an organisation that promotes advocacy for people who are both on the autistic spectrum and the LGBTQ+ spectrum.

There is generally not a lot of resources on bisexuality and autism, just whatever you can find on google. Otherwise, contacting the Scottish Autism advice line could be potentially helpful.

There has been more research and work in the area of gender and autism, rather than sexuality and autism. There was recently an Autism and Gender conference in the UK, the resources of which can be found online, as well as other gender and autism conferences around the world which can be found online. There is an online webinar from Australia on this topic too.

7. A community member, who had asked a question earlier, commented that he has noticed online that there are a lot of people who are self-diagnosing, and are able to access services as a result. He was not able to access services until he was formally diagnosed, so he felt that it's unfair and not right that people can self-identify as autistic without a medical diagnosis.

Rachel explained that this is a personal choice. There are pros and cons to both self-diagnosis and to formal diagnosis. A pro of self-diagnosis is that some people are just happy self-diagnosing and stopping there and they don't feel like they need more than that. A pro of formal diagnoses is that you can access services and get legal support.

In addition, some people cannot access diagnosis, as this is not centralised (for example, in Scotland, people who live in East Ayrshire cannot access diagnosis as there is no adult diagnostic services in that area. In other places, there are huge waiting lists.)

Diagnosis method also has a problem of being gender biased. There are two types of assessment you can undergo to get an autism diagnosis: ADOS (Autism Diagnostic Observation Schedule) and DISCO (Diagnostic Interview for Social and Communication Disorders). If you are assessed through ADOS and you're a woman, you are less likely to be diagnosed than if you were diagnosed through DISCO.

Another issue is that in the UK, if you pay for private diagnosis, it does not count towards getting support. You need to get an official NHS diagnosis if you want it to be formally recognised.

Unfortunately, there is no base for mental health services, it is very ad hoc still.

8. Can you ask to get re-diagnosed?

Yes, you can keep trying, you can get a second opinion from a different doctor, you are entitled to this.

Unfortunately, it is very likely to get diagnosed with bipolar disorder or borderline personality disorder if you have a meltdown. It is very difficult to get away from this diagnosis once you've been assigned it.

The Royal College of General Practitioners has created an Autism toolkit which GPs use, this is however useful to anyone with autism or who thinks they might be on the spectrum.

- 9. Comment from community member in the audience that the DSM 5 standard currently used has made leaps in terms of diagnostics. This diagnostic criteria recognises that adults have no development history available and thus only require the patient's current history.**

Community member Emily from the audience disagreed with this and said that it's not the DSM 5, but the ICD which is currently used in the UK (the DSM 5 is the standard in the US), and the ICD does not recognise sensory process differences as a symptom of autism.

The community member who made the above comment said that in Greater Glasgow & Clyde, both DSM5 and ICD are used. Individuals can also get two different diagnoses, one of autism and one of social communication disorder (which can be argued is at the core of autism).

Impact of new accessibility actions

A range of new measures we could take to make events more accessible for Autistic community members was suggested by Scottish Autism. Below is a review of the actions we took of the day:

Suggestion 1

Have directions to, and photographs of the venue available prior to the event.

We added photos of the venue on our Facebook event and had a detailed description of how to get to the venue, and how community members

access the venue once they've arrived. The photos and description were liked by community members on Facebook and some attendees mentioned at the event that they found this helpful.

Suggestion 2

Have a brief description of the event itself available prior to the event so that people know what will be happening once they get there.

A more detailed description of the event was added on social media than is standard. However we did not add a detailed timetable of the event, which was the emphasis of Scottish Autism's suggestion. This was due to uncertainty about whether one of the speakers would attend and we felt it was better to have a less detailed timetable than one that would change at the event. Overall we would aim to have as explicit a description of events as possible in future and where possible including a timetable of event.

Suggestion 3

Provide a quiet space, like a room close by, where people can go if they want/need.

We had a separate room at the event that community members could use if they needed a quiet space. The space was used at different times by two community members at the event and one commented that they were grateful the space was available. Quiet spaces are useful for accessibility for other access issues such as community members who attend our Mental Wellbeing Project events, and we have used them in the past. We would aim to have quiet spaces for community members. An extra suggestion post-

event was that we could add objects into the quiet space for community members to use.

Suggestion 4

Be mindful of the sensory environment of the room.

The room we used at the Terrence Higgins Trust has quite harsh fluorescent lighting. We requested lamps instead which provided a more comfortable space for community members. As with quiet spaces, it is useful to take the sensory environment into consideration for a range of access reasons. A community member and Scottish Autism commented positively on the lighting changes we had made.

Suggestion 5

Offer communication badges to community members on arrival at the event.

This was the first event that LGBT Health and Wellbeing has offered communication badges. The impact of this wasn't clear, as the event was a panel discussion rather than a social event. However we would assume in the future, at a social event that communication badges could prove to be very useful of community members. We had communication badges available at the sign in desk but it may have been easier to have a separate table for this to better explain the system to community members.

Suggestion 6

Be accepting of people leaving mid talk as they may be overwhelmed and need to step out.

Additional signage was added to doors at the event to make it clear that community members to enter/leave the space as they needed to. We also made an announcement at the start to let attendees know this and where the quiet space was. A few community members took advantage of this and the quiet space.

Suggestion 7

Be accepting of people making noises or moving provided it is not causing a significant and reoccurring/long-term disruption.

Again this was mentioned at the start of the event to make people more comfortable if they may be moving/making noises and to make other community members aware this may happen. It was useful to mention this as there was some movement at the event.

Suggestion 8

Ask audience members to wave, instead of clapping, to limit auditory stress.

We requested that audience members refrain from clapping at the start of the event. Although we stated they could wave instead, no one used this system, however everyone did refrain from clapping.

Suggestion 9

Have staff clearly identifiable.

All staff wore LGBT Health and Wellbeing badges at the event and everyone was introduced at the start of the event. Wearing badges is standard

practice already. It was helpful to introduce staff members at the event so community members knew who to ask if they had questions.

Suggestion 10

Clear signs to toilets, exit, quiet room etc.

Additional signage was used for the event to make it clear where all facilities were. This was helpful for community members who had to leave the space during the discussion.

Suggestion 11

Try not to have seats too close together.

We did have extra space between the chairs however a community member still stated they felt the chairs were too close together. Perhaps we need to consider a different setup for the space during community discussions.

Extra suggestions going forward:

- Community members may find objects in the quiet room/ discussion space useful if they stim (Self-stimulatory behaviour, also known as **stimming** is the repetition of physical movements, sounds, or words, or the repetitive movement of objects) during events
- Access to headphones/ear defenders
- We used a bucket to submit questions for community members who didn't want to or couldn't ask questions verbally – this was used and useful and could be useful for a range of accessibility reasons

Key themes

- Scottish Autism mentioned that there was standard procedures for Scotland when diagnosing autism. However during the discussion how this was implemented, and what diagnostic tools were used seemed to vary dependent on area. Therefore there was a lot of confusion about NHS services procedures/processes. If there are difference in practice in different areas, this could be particular access problem for autistic community members,
- There was a focus on autistic people and gender identity. Although there are gender clinics in Scotland, the way in which individuals GP's and clinics deal with the intersection of gender identity and autism varied a lot, again dependent on location/ individual doctor.
- A lot of the discussion was taken up between discussing the advantages of NHS diagnosis versus self-diagnosis – Scottish autism noted this was a personal choice.

Conclusion

It was clear from the community discussion that there is still a lot for the LGBT Community to learn about Autism and this community discussion was a useful start. In addition to the impact of the extra accessibility actions and key themes from the discussion, as a facilitator I would note that we may also need to consider new facilitator methods when running an event of autistic community members to help include everyone in the discussion.

LGBT Health and Wellbeing are currently arranging a date with Scottish Autism for autism awareness training for staff and volunteers. Facilitation methods, accessibility and the key themes will be a useful starting point for us as an organisation going into the training, and also when planning events for autistic community members.

Selection of Community Feedback from the event (taken from social media and feedback forms)

‘Very interesting’

‘[I enjoyed] Learning more about the LGBT+ Community’

‘An educative discussion’

‘Very informative, friendly people and space- Helped me feel better about my own situation’

‘I liked the question bucket. I was able to ask my question but it was a good option’

Useful Links



LGBT Health and Wellbeing

LGBT Health delivers a varied programme of services, projects, groups, courses and events in Edinburgh and Glasgow for people aged 16+. We welcome people with a diverse range of identities.

Website: www.lgbthealth.org.uk

Edinburgh: 0131 523 1100

Glasgow: 0141 271 2330



Scottish Autism

In 2018, Scottish Autism will mark 50 years since its founding. Established in 1968 by a group of parents, we are now the largest provider of autism-specific services in Scotland and a leading authority and advocate for good autism practice.

Facebook: www.facebook.com/scottishautism

Website: www.scottishautism.org



LGBT Autism Community Group

A safe inclusive space for people who identify as Autistic/Aspergic people. This is a community led group that provides a social space to campaign on relevant issues and to raise awareness with mainstream Autistic organisations and LGBT organisations to reduce social isolation, increase confidence, self-esteem and to empower individuals to become active within their communities.

This group is for 16+only.

Email: glasgowlgbtautism@gmail.com

