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How unsafe do Autistic and intersectionally marginalised people feel in your presence?



By Jorn Bettin

April 11, 2024












The biggest fears of Neurodivergent, LGBTQIA+ and Disabled people relate to unmet healthcare needs, their work environment, their parents, and disrespect by healthcare professionals. Data from our participatory research shows the large overlap and the intersectionality between Autistic communities, and the LGBTQIA+ and Disabled communities.

1. Safety of intersectionally marginalised people
2. Prevalence of trauma
3. Neurodivergent, LGBTQIA+ and Disabled patients
 1. What are the most important things you wish healthcare professionals to know, respect, and do, when engaging with you?
 2. Have you had any traumatising experiences in healthcare settings that no one should ever experience? Please outline.
4. Neurodivergent, LGBTQIA+ and Disabled professionals
5. Neurodivergent, LGBTQIA+ and Disabled healthcare professionals
6. Next steps
 1. Contribute to our Dr. B. Educated participatory research
 2. Regularly attend our Dr. B. Educated courses
 3. Regularly attend our education courses for educators

The vast majority of healthcare professionals are ignorant not only about Autistic culture and Autistic ways of being, they are also ignorant about the prevalence of complex trauma amongst



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intersectionally marginalised people.

This article presents insights from **Dr. B. Educated participatory research**.

If you would like to look at the detailed data in a visual format and understand the demographic context, please check out [the longer version of the article](#) published by the Autistic Collaboration Trust.

Safety of intersectionally marginalised people

Across the board, **many – if not most Neurodivergent, LGBTQIA+ and Disabled people do not feel safe within their families, amongst their friends, and at work.**

As to be expected, compared to other spheres of life, Neurodivergent, LGBTQIA+ and Disabled people tend to feel safest with their life partner.

Amongst our survey respondents, more than 40% of Neurodivergent, LGBTQIA+ and Disabled people do not have a life partner. Around half of these 40% likely don't have any accessible social sphere in which they can feel genuinely safe.

Prevalence of trauma

In our survey data, over 85% of Autistic and otherwise Neurodivergent, LGBTQIA+ and Disabled people often or always feel **misunderstood**, and the same number often or always feel **overwhelmed**. Over 60% of Neurodivergent, LGBTQIA+ and Disabled people often or always have at least five negative feelings, in addition to the above, feeling **unsafe**, **insecure**, and **disrespected**. Furthermore over 40% often or always feel **bullied/manipulated** and **abandoned**, and 32% indicate that they often or always feel **betrayed**.

93% of the Neurodivergent respondents to our [Feeling Safe](#) survey identify as Autistic. This means that the demographics of our data show the large overlap and the intersectionality between Autistic communities, and the LGBTQIA+ and Disabled communities.

In our survey data 56% of Autistic people also identify as Disabled, and 53% number identify as LGBTQIA+. This means **the majority of Autistic people are intersectionally marginalised**. We are part of an easily overlooked minority within the Disabled and LGBTQIA+ communities.

Given this context, it is no surprise that complex trauma is very common amongst Autistic people, and that this is reflected in our mental health statistics.

Our survey data indicated that 82% of Autistic and otherwise Neurodivergent people often or always experience **anxiety**. 63% often or always suffer from **burnout**, 57% often

or always suffer from **stress related health problems**, 52% often or always suffer from **insomnia**, and 45% often or always feel **depressed**.

Neurodivergent, LGBTQIA+ and Disabled patients

The vast majority of **healthcare professionals are ignorant not only about Autistic culture and Autistic ways of being, they are also ignorant about the prevalence of complex trauma amongst intersectionally marginalised people**, and this ignorance is reflected in the lived experience reports we are receiving from Autistic and otherwise Neurodivergent patients.

The biggest fears of Neurodivergent, LGBTQIA+ and Disabled people relate to:

1. unmet healthcare needs (65%)
2. their work environment (64%)
3. their parents (54%)
4. disrespect by healthcare professionals (46%)

In comparison, the numbers of those whose greatest fears relate to other social spheres are much lower:

1. friends (22%)
2. siblings (22%)
3. life partner (18%)
4. children (7%)

It is very clear that **healthcare settings are consistently experienced as highly unsafe** by Neurodivergent, LGBTQIA+ and Disabled patients.

This is also reflected in the experiences submitted in the qualitative parts of our surveys and in the in-depth lived experience reports we receive. Consistently, over 75% of the responses we receive to our ongoing **Feeling Safe** survey include examples of traumatising experiences in healthcare settings that no one should ever experience.

Below I have included a small number of examples of lived experiences from our growing anonymous **database of participatory research**.

What are the most important things you wish healthcare professionals to know, respect, and do, when engaging with you?

I wish they wouldn't make assumptions about autism. I have sensory challenges. Informed consent is a must. Do not order, push, or try to change my mind about treatment. I will decide what I can do and what I want. I believe in self advocacy and working as a team with healthcare providers. I don't do well with anyone who wants to tell me what to do. I haven't met many who understand the needs of autistic people.

Clarity and not get upset if I ask them to repeat the questions, and wait if I don't respond fast enough.

That autists can have higher sensitivities to life stressors, which affects every part of health.

That if I am bringing a problem to them, I have already spent a lot of time learning and thinking about it and they should be open to asking me questions instead of dismissing my concerns based on my history of depression/anxiety.

Don't lie to me, or lie by omission. Do not withhold information for fear I will be upset by it. Lay everything out as it is. I cannot make informed decisions if I am not properly informed. In the same vein; I will take everything you say at face value. If you mince words, if you exaggerate or hold back, I will not realise. I will not read between the lines and put together your puzzle. Just because I seem okay, it does not mean I am. I have had decades of practice at acting "normal". That mask doesn't drop just because I'm in pain, physical or mental.

I don't always feel pain or discomfort the same way as others, and I can take longer to process new information and formulate questions about it. Encouraging follow up emails would help.

Listen and believe my experience.

Our bodies are all holding so much trauma.

My experience of pain and responses to treatment in psychotherapy and medical settings (i.e., anesthesia does not work as expected in my body); and all mental health and medical treatment must be managed differently to prevent iatrogenic harm.

They need to understand when you upset someone with communication difficulties, it amplifies those difficulties. That it steals our words. I need them to listen to me when I talk and to believe what I have to say. To consider it at face value as I describe it, not twist and warp it with intent into something it is not. It is important to allow me to start where I need to in the process of medical history, starting in the middle can be hard. The forms should be more detailed; tell me if you want 2 years or all of my medical history.

Even though I am a grey haired middle aged autistic bisexual married woman, I am not stupid. I am often treated as if I am somehow low in intelligence. My IQ is around 146 +/- 10. People expect me not to be able to use my cell phone, not to understand simple medical explanations etc. The lightning in the doctor's often is very difficult, and all stimuli is overwhelming.

I hear you when you're talking about me even when I don't appear to be listening or capable of hearing. I'm afraid you will kill me. My personal experiences and the experiences of my family and the experiences of others taught me this fear. When I may be in need of medical attention I consider whether I am ready to die in your care. If you are engaging with me it will be because I think the risk of dying is higher without at least attempting to get medical help. If that happens: Please do not disparage me, or make fun of me, or laugh at me, or punish me with your power because you are angry at me. Please know that I am not trying to be difficult, ever. Please help me by asking me questions and listening to my answers. Please ask me if I have questions and reply respectfully to those questions if I do. Please let me offer solutions to your gown and other things that cause me distress while I am being treated. Please don't lie to me. Please know that I am terrified, even when I do not appear to be. I may not be able to speak or hear well. I may seem to be resistant to things that don't make any sense to you. I would need you to explain why you are doing what you are doing. I am very courageous and can put up with many painful and invasive things if necessary but I need to understand. I am slow processing but I can and do understand a lot. I'm capable. Please give me time, information, and choices. That said, please listen to what I am telling you about my body and my symptoms. I am listening to you. I am not lying. I understand that I can be wrong. I am not thinking I know better than you. If I did I wouldn't be there. Please do not force me or manipulate me physically or otherwise to do things you want me to do.

Have you had any traumatising experiences in healthcare settings that no

one should ever experience? Please outline.

Yes. Pushing of invasive screenings. Disrespect of my bodily autonomy and informed consent. Rough exam. I avoid going to the doctor at this point as no one is autism and trauma informed.

I was in the ER after my hip had dislocated for the 3rd time. The doctor never visited me prior and after my resetting of my hip. He also left the hospital to go to his private practice without giving an order to the discharging nurse to remove my catheter. I personally had to call his office. When I asked to personally speak to the doctor he refused and I was embarrassed to tell the receptionist that I needed to have him call the hospital and give the order to remove the catheter. I was so upset my words were mumbled, I shut down from anger, and cried all the way home. It took hours to regain my composure.

Yes. I have had a male doctor pretty much kick me out of the patient room. I had a female doctor misdiagnose me with a rare brain disorder and put me on the wrong medication; when I told her it wasn't working she upped my dose. She refused to hear any of my other symptoms or complications. Not many doctors understand the consequences of sensitivity on the body. My therapist didn't even recognize my autism until I got diagnoses through my psychiatrist.

Yes, too many and I'm going right now with a breast cancer diagnosis with 0 accommodation .

Yes, multiple. I respond differently to anesthesia and have had horrifically painful surgeries while fully conscious and feeling everything. I was repeatedly misdiagnosed with major depression, generalized anxiety, and borderline personality disorder and mistreated as a result in subsequent treatment settings. I am a mental health professional.

I am partially from a Muslim background- during my second appointment with a talk therapist, I mentioned a poor relationship with my father, and she immediately assumed that his poor attitude towards me was due to his religious background. She kept insisting on this even after I explained that the issues were clashes of personality between two people living in the same house (he is impatient and quite extroverted, I do tasks slowly and am almost asocial).

Yes. People not respecting my pronouns, my gender. Doctors not wanting to treat me for being trans. Having my illnesses minimized due to my mental health diagnosis.

My former psychologist used to invalidate me because I began to unmask my autistic traits. I left because she did not want to understand anything about my experience in the world.

Neurodivergent, LGBTQIA+ and Disabled professionals

Many Neurodivergent, LGBTQIA+ and Disabled professionals often or always feel unsafe amongst peers, superiors, and suppliers, **in some aspects of work more than 50% or more of Neurodivergent, LGBTQIA+ and Disabled professionals often or always feel unsafe.**

Across the board, the level of psychological safety amongst Neurodivergent, LGBTQIA+ and Disabled workers is much lower than the level of psychological safety amongst workers in general.

Neurodivergent, LGBTQIA+ and Disabled healthcare professionals

50% or more of Neurodivergent, LGBTQIA+ and Disabled healthcare professionals often or always feel **unsafe amongst peers, superiors, and patients**, noticeably more so than their non/less-marginalised colleagues.

Even though according to our survey data, the psychological safety experienced across all healthcare professionals is slightly lower than in many other industries, this lack of safety is consistently highest amongst Neurodivergent, LGBTQIA+ and Disabled healthcare professionals. In particular more Neurodivergent, LGBTQIA+ and Disabled healthcare professionals indicate that they are:

1. **always** afraid to be their authentic self at work
2. **always** afraid to make mistakes at work
3. **always** afraid to disagree with their peers and their patients

Next steps

Contribute to our Dr. B. Educated participatory research

Participate in our **anonymous surveys**, submit **lived experience reports**, and encourage your colleagues, families, and friends to participate.

Feeling Safe – This 5 minute anonymous survey (fourteen questions) is conducted by the Autistic Collaboration Trust and is sponsored by S23M.

Feeling Safe Growing Up – This 5 minute anonymous survey (fifteen questions) is conducted by the Autistic Collaboration Trust and is sponsored by S23M.

Regularly attend our Dr. B. Educated courses

If you are a medical doctor or allied healthcare professional, join our **Dr. B. Educated courses** as part of your Continuous Professional Development (CPD) efforts.

Our courses are taught by neurodivergent educators, allow you to learn from our unique database of lived experiences, and provide interactive opportunities to learn from and with members of the intersectional AutCollab community.

Regularly attend our education courses for educators

If you are a teacher or education professional, join our **education courses for educators** as part of your Continuous Professional Development (CPD) efforts.

Our courses are taught by neurodivergent educators and provide interactive opportunities to learn from and with members of the intersectional AutCollab community.

Onwards! – The AutCollab Education Team.



Jorn Bettin

Knowledge archaeologist by day and neurodivergent anthropologist by night at [S23M](#)



The more we help each other to question in ways we otherwise wouldn't – and correspondingly discover new insights about the world and ourselves, the more we are able to learn from each other, and the more we start to understand each other. The gift that we all bring to the world is the (re)generative potential of all the trusted relationships that we co-create.

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Content Catnip says:

April 12, 2024 at 05:50

Thank you so much for this. So much of what you say here about trauma and feeling unsafe has been true for me in the past however I have built myself to be much stronger now and I feel grateful everyday to have a life partner, also autistic

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Raphael Solomon says:

April 12, 2024 at 06:04

Articles like this fill me with impostor syndrome. I am a well-educated autistic (I hold a PhD in Economics). I have encountered autism-informed doctors and dentists. I have never had the trauma described above. And this makes me wonder, am I autistic enough? I struggle in various arenas, but the medical one is not one of them.

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Jorn Bettin says:

April 12, 2024 at 06:39

There are many variables involved, both amongst the Autistic patients in terms of specific sensitivity profiles and health conditions, and amongst healthcare professionals and their work environment.

Many of us start out with too much trust in the expertise of doctors and then learn the hard way. I have also not been traumatised by doctors, but for longer periods of time have had unexplainable symptoms that I now can trace back to complex trauma in other spheres of life. Thanks to amazing Autistic friends and peer support, I feel much more supported overall, and these symptoms have disappeared.

When I was a young adult my health deteriorated severely because a GP simply did not provide any useful advice on how to manage my allergies. I had to figure out what to do myself, and it did not involve any medication. I have learned the hard way that I need to do all my own research and only trust medical advice if it is coherent with what I know about my body and what my own research tells me.

Others are less fortunate. It only takes one or two major medical misadventures to accumulate chronic health conditions from which there is no full recovery.

We are keen to gather more data, so that we can compare experiences between countries, as the quality of care available can vary greatly.

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Andrea Brownridge says:

April 12, 2024 at 07:43

Bravo per usual Jorn 💜💜💜

I am sharing widely with my colleagues bc we will do better!

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Reply



Andrea Brownridge says:

April 12, 2024 at 07:49

Jorn— As always, you hit the ball out of the park and ensure my life's journey is richer every single time I read your works and dang it, borrow from your soul. Thank you for sharing your gifts and talents and bringing us along for your life ride.

I literally have a Dropbox folder named Jorn Bettin Life Wisdom times 3 years now. 💜💜💜

And I am sharing widely with my colleagues in psychiatry along with the links for them to learn and understand autism as it is— just another way of being PERIOD!

Andrea

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Jorn Bettin says:

April 12, 2024 at 18:34

Andrea, many thanks for your encouraging words. Oh yes, life is a journey of omni-directional learning. What I am sharing are the insights and experiences that I am gaining from de-powered dialogues within my evolving ecology of care.

So you are reading not my insights, but the insights from an ecology beyond the human, and the timeless wisdom people in healthy ecological contexts have known for thousands of years. I only discovered Daoist philosophy last year, a whole treasure trove of wisdom. It feels so familiar, it somehow reflects the culture that is emerging within Autistic communities. I am trying to be a knowledge archaeologist and scribe in this context.

Autistic ways of being are part of a culture that deserves the same respect as any other culture. I think this is a really important message for medical professionals who have been trained to look at humans as individuals, at best within a context of an atomised family, but not as precious human beings within an ecological context.

The numbers and experience reports in this article highlight deficits in the education of medical doctors, related to understanding the human condition and human ecologies. Our education team is keen to work with medical colleges and medical schools to expand the sphere of discourse to ecological diseases and disorders, and to shift away from pathologising individual ways of being. All assistance in this space is appreciated.

We are learning every day <https://autcollab.org/2024/04/01/therapy-and-beyond-in-a-post-weird-world/>. I can recommend the 57th chapter of the Dao De Ching <https://autcollab.org/tools/>. 😊 Here is a wonderful dialogue on that note: <https://youtu.be/OYZZRdFJg5Q>.

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Andrea Brownridge says:

April 12, 2024 at 21:11

🍷💜💜🍷 me fan allying over here. THANK YOU Jorn...more once I digest and process all the goodness in your direct reply. 🙌🙌🙌

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Jorn Bettin says:

April 13, 2024 at 18:13

🙏 More material for your colleagues: <https://autcollab.org/2024/04/13/trust-in-human-scale/>. Can we get our education into the college of psychiatrists?

The WHO's framework for meaningful engagement with marginalised groups and communities has not (yet!) been

written in the language of the neurodiversity paradigm, but it provides strong and explicit guidelines on the pivotal role and the value of lived experience <https://iris.who.int/bitstream/handle/10665/367340/9789240073074-eng.pdf>.

In jurisdictions where support from the college of psychiatrists is in the “too hard” basket, supportive psychiatrists can support our efforts globally, by helping us to get professional education courses based on lived experience into other medical professions, for example into the colleges of paediatricians and GPs. In Aotearoa and Australia we do have a public health system, but our departments of health are primarily looking to the professional “experts” for advice, or to parent led organisations (like in the US...), rather than to communities with lived experience. The more psychiatrists explicitly speak out and publicly endorse the importance of our education based on lived experience, ideally referencing the above WHO’s framework, the better we are equipped to engage with medical colleges, medical schools, and departments of health.

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Andrea Brownridge says:

May 6, 2024 at 10:46


Catching up on what you shared...thanks so much Jorn! 💜💜💜

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