Jorik Mol

BREAKING THE BOUNDARIES

On Lived-Experience Mentorship for Autistic Students in Higher Education

Disability Studies

Collection Editor
DAMIAN MELLIFONT

LIVED PLACES
PUBLISHING

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This book is dedicated to everyone who has had a Jorik, will be a Jorik, or has always needed a Jorik and never had one.

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Abstract

Universities can sometimes exclude Autistic students from getting the most out of their experience. As one of the few Actually Autistic Higher Education mentors for Autistic students in the UK, Jorik Mol seeks to improve the educational experience of neurodivergent students by encouraging breaking boundaries, challenging the system and providing places where students can be themselves.

Drawing from his own lived experience, and with stories from his own mentees, Mol offers guidance on how to best support students, emphasising the need to teach radical empathy, values-driven motivation, and self-advocacy.

Exploring topics including community, boundaries, and burnout, while pushing hard against the status quo, this book is ideal reading for students of Education, Disability Studies, Sociology, Psychology, and Queer and LGBT+ Studies, as well as education practitioners and policymakers, autistic people, and allies who want to be part of a movement for neuroqueer liberation within the education sector.

Key words

Disability; neurodiversity; University; DEIB; empathy; values-driven motivation; self-advocacy; communities; boundaries; burnout; autism; neuroqueerness; friendship; work-life balance; LGBTQIA+; gender; sexuality; race and ethnicity; class; activism

Preface

This book is based on my practice as a community organiser and autistic professional. I operate from the social model of disability, understanding barriers to disabled people to be socially and politically expedient for the majoritarian group in society. Therefore, my practice includes supporting those who have not (yet) been diagnosed as autistic. Likewise, I consider the terms 'autism', 'ADHD' and other diagnostic terms to be historically contingent and created from deficit-frames based on an imaginary behavioural norm at a specific historical moment, for specific historical purposes, influenced by Edward Said and his book ***Orientalism***.

I am deeply influenced by Damian Milton's Double Empathy Problem, a basic understanding of which I take as read in this book. In my other book, ***Feeling Fast and Slow***, I put the Double Empathy Problem to work, analysing the iniquities faced by autistic people versus our neurotypical peers. This I call 'neuro-chauvinism': the mainstream idea that there's only one way to have a brain, and whatever that way is, it's not ours.

Furthermore, I take the 'neurodiversity paradigm' as a given, as well as understanding the challenges faced by non-white, queer and otherwise disabled autistics to access community and healthcare in a way that matches their needs.

I am committed not just to equality of opportunity (which is usually a weasel word for upholding existing iniquities in society) but to equality of outcomes. This will hopefully explain my somewhat idiosyncratic view of higher education.

The term ‘neuroqueer’ originates with Nick Walker, and I have found it increasingly useful in understanding what being autistic actually means to autistic people. We are ‘queered’ by the way our brains are distinct from those around us. That ‘queering’ is a Butlerian concept, but basically, it means that our society positions us in certain roles, due to characteristics we already possess. In the case of neuroqueers, as I understand it, this makes us distinct from our peers in specific, socially constructed ways. To be neuroqueer is to be ‘disabled’ socially, due to our identities essentially being constructed around us, from the outside in, to be a certain **kind of person**.

Lastly, I am an activist against conversion therapy, which includes its brand names ABA, PBS, Teamteach and TEACCH. These systems intend to make us ‘indistinguishable from our peers’, according to their originator, Ole Ivar Lovaas, who, after inventing ABA, used it as a basis to create modern conversion therapy for queer people, which is now freely available on the open market. I take it as read that ABA is conversion therapy, since conversion therapy is the direct consequence of ABA.

Contents

Warning

This book contains explicit references to, and descriptions of, situations which may cause distress. This includes references to and descriptions of:

- Suicidal thoughts, intentions, and actions
- Psychotic delusions and hallucinations
- Violent assault
    - Ableism, discrimination, and microaggressions
    - Homophobia, biphobia, transphobia and acephobia
    - Sexual violence and misogyny
    - Eugenics, racism and systemic abuse
    - Trauma and PTSD
    - Frequent use of strong language throughout

References to potentially distressing topics occur frequently and throughout the book. Lastly, Jorik is a very opinionated activist. The views expressed in this work do not necessarily represent the views of Lived Places Publishing Ltd., or of the autistic community in general or of wider liberation movements.

About the author

Jorik Mol (he/him) is an autistic mentor, advocate, educator, writer and community organiser. Born in the Netherlands, Jorik moved to the United Kingdom in 2010, settling permanently in 2013. Qualifying as a teacher in 2017, Jorik has been an autistic mentor since 2021, the practice of which is the subject of this book. In addition, Jorik runs the QND Network, a queer neurodivergent writers' group, which creates a space for neuroqueer writers to connect, create and collaborate. He also runs the Autistic Wellbeing Group at Bath Spa University. He has spoken at Oxford University, the Association of University Presses (2021) and Autscape (2023), as well as providing training and consultancy to businesses, schools and other organisations on inclusion and equity for neurodivergent people in wider society. On his website, Jorik writes a regular blog, which you can find at: https://www.jorikmol.com. Besides all this, Jorik writes autistic fiction, aims to create neurodivergent theatre, and aims to neuroqueer research. Together with his autistic fiancé, Luke, dozens of cuddly toys, and hundreds of books, Jorik lives in Bath, UK.

Introduction

I kind of fell into being an autistic advocate. It wasn't something I sought out, but I was, rather, picked. This makes it sound like an Oprah Winfrey moment: "and *you* get a cause, and *you* get a cause, and *you* get a cause…" It really wasn't as fancy as that, though utterly, utterly life-changing. I was at an Autism Oxford event in early 2018, purportedly doing some 'continued professional development' (which is how I explained it to my line manager at the school I was teaching for), but really doing research for my own autistic novel I had started 18 months before. That book had already changed my life before I'd even finished it, allowing me to think of myself as part of a wider movement, pretty much for the first time. I never thought I had a community, especially since I had a track record of failed attempts to find one, best described by US comedian Maria Bamford as 'the Burning Bridges Tour'. I met the man who is now my partner and a significant number of people committed to what I was trying to do.

A few weeks before this conference, I left a form of therapy I'd been expected to complete, consequent to a misdiagnosis of personality disorder. In this NHS group therapy course, we were expected to mentalise. Now, mentalisation is a psychological term for gaining an awareness of the feelings we are feeling and the sensations our bodies undergo. This course had a different view of mentalisation: if you experience overwhelming emotions, you need to stop yourself, figure out what you're feeling, assess the emotion, change it, and go on your merry way. Yeah, we were supposed to modify our emotions at will. Obviously, autistic meltdowns occur because of a surfeit of emotions and sensory information; that's why they're meltdowns – they're a loss of control. When I pointed that out to the therapist, he started shouting at me. I have a talent for making people show their true colours around me, which is a blessing and a curse.

The speaker at the conference was Tony Attwood, a well-known British-Australian researcher and practitioner on autism spectrum conditions. Like other non-autistic researchers in the autism field who have been around for a long time, he is not uncontroversial or unproblematic, but he's never not been kind to me. This is where his kindness started. When I asked my question about this therapeutic barrier imposed on autistic people, he was actually a bit upset on my behalf and said that I should never have had to experience this. Quite accidentally – or not – a member of staff from a nearby NHS trust left me a message, if I was interested in coming in for a conversation. That conversation turned into a job, which turned into running an autistic experience group, which I did alongside being a teacher and a personal tutor. I worked there until early 2020, when Covid and national politics came together to stamp out the group and our plans to improve autistic people's lives. I made a lot of friends through my work and connected with a tonne of autistic activists, who all encouraged me to keep going. If you do not like what you read in this book, blame them. I jest of course: anything in this book is me, as a mentor, thinking through my own practice, making a few jokes, and allowing you to connect with this work, how it has revolutionary potential and what it says about the way autistic people can find connections and self-organisation.

This book is not going to rehash what you should already know about autism. Yes, we may show certain behaviours, like selective mutism, stimming, hyperfocus on our interests and/or difficulties in processing the sensory world. We can have meltdowns, sensory overloads, shutdowns, stick out like a sore thumb or fade into the background. No, we do have a sense of humour. No, we do have empathy. Yes, we're equally likely to be male or female, from every ethnicity or heritage, with or without learning disabilities. We are, however, a lot more likely to be LGBTQIA+. All that is true, more or less. This book takes that knowledge, in whatever shape it was passed down to you, culturally, as a given. This book is written for actually autistic people who wish to become mentors, who live that experience every day. In it, I show the cases of 14 autistic people I have supported over the past three-and-a-half years to stretch, question and think through what best practice would look like for other autistic people who want to do this particular job. I am highly opinionated and have a very specific outlook on neurodiversity politics, coming at it from a liberation-focused, anti-capitalist perspective. My perspectives on empathy, in particular, are quite the opposite of what is, embarrassingly, *still* the medical mainstream view. I will not go into this, or other theory too deeply, please read *Feeling Fast and Slow* for that. Still, when relevant, I will outline theoretical positions within these case studies, state my perspective and show how my practice is influenced by the values that I bring to this work. As I said to my PA the other week when he asked about how to present me and what I do to the world, I said: "my values are my brand", and was a little bit sick at the back of my mouth. As much as it pained me to say it at the time – so much awkward! – I do believe they are. I do what I do because of my values, which are against the status quo, against capitalist extraction from the lives of queer and disabled people, against the norms of existence that hold us back. Only the very worst autistic people make it big: Elon Musk, for example, richest man in history, whose repellent views on disabled people, women and labour rights are well known (NB: this comment is not necessarily representative of the views of *Lived Places Publishing*).

As for the case studies, they make up the bulk of this book. They are not exhaustive; I still work with many of these young people and some topics we discussed were not relevant for what each case study ended up becoming. All mentees have given feedback on the chapters that pertain to their experiences, and I have adjusted and modified their narratives in accordance with their perspectives. As I do with all parts of my job, I assume that all autistic people are right about their own experience, with caveats. Sometimes, we are clearly acting against our own best interests. I know, I've been there. The final chapter is a series of questions, which I want you to think through. The first chapter, however, is about the biggest case of my career, i.e. me. How did I become a mentor exactly?

Learning objectives

- To explain the socially constructed nature of disability, queerness and neuroqueerness.
- To challenge mainstream perceptions of boundaries while working with neurodivergent students, while remaking those boundaries in collaboration with the students.
- To provide creative feedback on the topic of friendship within a mentor-mentee relationship and show the potential risks involved in this relationship.
- To recognise the distinctions between neurodivergent and neurotypical collaborations, to challenge mainstream perceptions of autistic people, and be mindful of the political basis of neurodivergent rights.
- To become a mentor for other autistic people.

1

Jorik

In 2021, towards the end of our tenancy in Reading, my partner and I decided to move to Bath. I had just started as an independent autistic activist and knew that I was good in this field. I'd recently been let go from a position as an actually autistic so-called 'Expert by Experience' at a local NHS trust. The money was gone, they said. They probably weren't wrong. My experiences, stuck in between NTs of various stripes, having to bridge the gap between neurotypes and systems were not great. Let's say that it started in a complicated way and just became more difficult as time went on. The best parts of my week were the Autism Experience Group, which I ran. There were no neurotypical people present in the room, which was made accessible in collaboration with the attendees, who were – as I insisted – paid for their time. These meetings were amazing. I was so impressed with everyone. We really made a difference, too.

However, I found that there were very severe problems, mostly to do with the people who were otherwise in charge. It was difficult to challenge the overriding sense that I was an unwelcome guest, who disagreed strongly with the way things were usually done in the system, such as the use of behaviour modification, which I will refer to as conversion therapy practices. For more on ABA and behaviourism, see *Neurotribes* (Silberman, 2015), *Neuroqueer*

Heresies (Walker, 2022) and *Feeling Fast and Slow* (Mol, 2026), as well as my 2023 talk for the University of Exeter, which you can find on my website. These are systems to restrain and retrain autistic people in distress to be more neurotypical – whether that imposition is stated directly or not, we cannot ignore the normative power that systems like ABA, PBS (ABA's passive-aggressive, *very British* cousin), Teamteach (restraint, like the kind used against Elijah McClain and George Floyd) and TEACCH (a system that uses common sense communication tools, so is not explicitly harmful, but it is still wildly expensive and funds conversion therapy practices in other ways) were performing upon the bodies of autistic people. When I challenged my colleague on their support for ABA, I was called anti-scientific. When I retorted that science is done by people and for particular political ends, my colleague told me the conversation was over. I have plenty more stories, but knowing that NHS trusts are happy to litigate against disabled people, I will not tell them here. You will find more stories in the dissertation of my friend Jo Minchin, member of the National Autistic Taskforce (Minchin, 2020). I asked Jo how she was getting on with the transcription of my interview. She said: "I'm getting on great! It's been a three fucks and a cunt day." I am a very sweary boy when I'm upset.

So it's 2021. I started as an independent activist and educator. I began doing talks when I was asked to, and I started making connections in the local area – first Oxford, then Reading. Now I was moving to Bath, and I needed to get started there. I found an advertisement for Specialist Mentor – Autism, funded not by the student personally but by Disability Student Allowance. This is a grant, from the Department for Education, that allows disabled students to access higher education in a more equal way than they otherwise would have. For a successful interview, I needed to show teaching qualifications and commitment to autistic people's welfare. I have a CELTA, which allows me to teach English as a Foreign Language, as well as having taken courses on being a teaching assistant during the pandemic, spending more time challenging the course leader than listening, to be honest. He seemed to appreciate it though! For the commitment part, I could show my work in the NHS, my website and my other connections which showed my profile was on the rise. I contacted local Bath-based universities. Both told me they worked with a large corporation that was responsible for the allocation of students for DSA-funded mentoring. I contacted this corporation. Since we were still mid-pandemic (arguably we still are!) and they were really struggling for staff, I got in with relative ease. Even I didn't doubt that I would be fit for this particular job. And I doubt everything! Not even Descartes can out-doubt me. Why didn't I get nervous? Because of all the jobs I'd done, working closely with autistic people has been the thing I felt most naturally talented at. It was easy; it was fun. I was able to exist, as myself, and do what I'm good at: providing reassurance, dealing with potential conflict situations and breaking down barriers for others by advocating. I would be doing what I ended up doing quite naturally within the Experience Group. I would organise people, listen to their concerns and seek to resolve painful situations. I would advocate for them, when systems and individuals had done them harm. I would connect with others, increasing our network of autistic people, who were all, increasingly, proud to be autistic. My greatest memories of this time include creating the first Autistic Pride Oxford, in 2019, as well as representing my local trust at the Oxford Pride 2019, Autistic UK, Autistica and Autscape conferences. As someone who essentially fell ass-backwards into activism, I appeared to suddenly possess skills for organising people around me, and my specific set of values. When I left the NHS Trust, my community was clear: you need to continue doing this. So I did. Being a mentor is nothing if not a natural combination of my work as an activist and as a teacher/tutor.

I start from the perspective that autistic people's experience of the world is correct. That is already a huge job, given that I grew up being told that my brain didn't work right and I wouldn't be able to grasp reality as a consequence. I was pathologised as, well, 'wrong'. I was the kind of person who was wrong about life – that's what the world at least understood about me. My emotional responses, my hyperfixations, my connections with other people and the world around me, my sensory sensitivities, my sense of humour and my talent for languages and imitation: all of that was wrong. Working as an activist, I realised, meant that my increased political awareness grew and I combined my outlook with the work I could actually do in the world. No longer was I someone disabled by being wrong-in-the-world; my empathy and capacity to agitate were fundamental to my politics: as a queer neurodivergent activist. So imagine my shock when the company sent me an online training module that advertised conversion therapy. Things got sweary, I'll tell you that much.

When I got the job, I wouldn't see mentees until September 2021, by which time I would have finished moving to Bath and teaching a course of English for Academic Purposes. First, I had to pay out of pocket for online training created by the National Autistic Society, the UK's most important autism charity, though its audience is, first of all, neurotypical parents of autistic children. I baulked at that, since my training work covers nearly exactly the same ground as those trainings on autism. I enjoyed seeing some of my friends appear in the videos, but I finished them within barely two hours. The next training modules were self-created by the company. Initially, this was nothing I hadn't seen before – mostly old-fashioned terminology, combined with adherence to the now functionally retracted (by its own co-author) Triad of Impairments. Autistic people, to meet the now-discredited diagnosis of Asperger's Syndrome (which I was diagnosed with back in 1996), are deficient in social interaction, social communication and imagination. I am an actual novelist – what the hell you guys?

The Triad of Impairments was created by autism researchers Lorna Wing and Judith Gould. They were only funded to conduct studies on autism if they were to create a brand new diagnostic criterion. Therefore, they created Asperger's Syndrome, named after the then recently deceased Hans Asperger. Anglo-German autism researcher Uta Frith had just translated some of Asperger's work from the 1930s and 1940s, in what turned out to be a highly sympathetic, yet inauthentic portrayal of Asperger's character. In 2018, the American researcher Edith Scheffer wrote *Asperger's Children*, based on archive research she had done on Asperger's role at Spiegelgrund children's hospital in Vienna (Thomson, 2018). In the book, Scheffer, in meticulous detail, smashes Asperger's previous reputation as a kindly 'Oskar Schindler-figure', instead understanding him as a committed Nazi and eugenicist. Eugenics was the apolitical norm across psychiatry and children's healthcare in the first half of the twentieth century. But Asperger was committed not to saving the children he deemed worthy from those who were to be murdered in the T4 destruction programme, but was an active, enthusiastic participant in this system. For Asperger, there was something fascinating about us autistic people, mostly by how far we seemed to pervertedly deviate from the expected norm or *Volksgeist*. Here is where I depart from Scheffer, whose liberal anti-authoritarianism seems to hinge on a fear of otherness in the first place – 'What is the purpose of a diagnosis if we are all the same?' she seems to say, and her autistic son actually says in the afterword. What I find most disturbing instead is the creation of a fascist society based on colonialism, extraction and destruction of those it deems unworthy of lives. That's what I find upsetting about fascism, not the uniforms. I do believe we are fundamentally different from non-autistic people on some as yet impossible-to-define basis to do with our brains, but that this difference is only made a force of exclusion by the choice of the neuro-majority to disempower us.

I base this force on empathy, a ghostly concept that attaches social value judgements to an action as simple as recognising another human being as a human being. Damian Milton (2012) has written extensively on the Double Empathy Problem, where the empathy systems between two groups are meaningfully distinct to such an extent that automatic empathetic responses are not guaranteed across group identities. Instead, each group has to learn to empathise with the other group in a cognitive, controlled manner. That is indeed the goal, but we don't live in a world where those intergroup relations are in any way equal. Instead, autistic people are recognised as highly empathetic within their own group and quite empathetic with non-autistic people, at least within the first second of being exposed to their image and/or voice. Non-autistic people, in turn, are quite naturally empathetic to people who are also non-autistic, but comparatively do not show empathetic responses to autistic people anywhere near to people within their neurotype (Sasson et al., 2017). This has caused a huge discrepancy between autistic people and non-autistics, leaving an empathy gap, where the minoritised group is expected to empathise with the majoritarian one, while that majority neurotype defines the minority as uniquely lacking in empathy. Ouch. I call this cultural self-propelling machine neurochauvinism. As Nick Walker quotes in her book *Neuroqueer Heresies*, "power is to have the ability not to have to learn" (Walker, 135).

Clearly, the creators of these training modules had not had to learn about autism for a very long time. For starters, they looked old. Think mid-2000s. Clearly, they hadn't been updated in years, potentially decades. They were full of advertisements for chemical, nutritional and medical 'cures', strange conspiratorial statements about a lack of vitamin D during pregnancy "causing" autism, wheat-free diets and secretin; a linear "spectrum" of autism from "high-functioning" to "classic, or Kanner's autism", advertisements for ABA and early-intervention conversion "therapies", liberal use of the Autism Speaks puzzle piece logo, deep misgivings of our capacity to be human beings, a pro-treatment attitude that included ABA but also CBT: cognitive behavioural therapy, which many autistics, including myself, have had atrocious experiences with. One of the questions in the test, for which one had to score 95% or more on to pass, was: "Which one of these famous people did NOT have autistic tendencies? Diana Ross, Albert Einstein or Sir Isaac Newton?" Wow. We don't know about Diana Ross, but the subtext is that a Black female artist is always going to be less autistic than two dead white men, one of whom died 300 years ago (the answer was, apparently, Diana Ross). This was not the only example of implicit racism in the module, including an optical illusion that required one to assess whether the person presented was 'an Indian or an Eskimo'. They meant First Nations Americans and Inuit, which are both to be seen in the cartoon. The intention was to allow people to consider 'two ways of looking at things'. Okay, that's fine, I suppose!

My 'favourite' of all the questions was: "Which of these below statements would be unlikely to be said by someone with autism, considering the way they comprehend you, me and I?" "I would like a cup of tea please", "Joe would like a cup of tea", or "Would Jim like to watch TV with David?"

I am still baffled by this question. I really don't know what's expected here. Answer A. implies that we're not supposed to have a sense of self, so we refer to ourselves in the third person. Answer B. implies that other people don't matter to us, so we wouldn't refer to another person having any needs or desires since we're inherently selfish. Answer C. does the same as B again, but the idea is that we wouldn't be polite or be able to speak about third parties, or something, I don't know. And I'm 'a person with autism', according to this training module.

By the way, *never* refer to an autistic person as a 'person with autism' unless they, for their own reasons, request that you do so. If you insist on 'person-first language' that implies you perceive 'autism' as distinct from the person's identity when, in fact, 'I am autistic' is an identity-statement. The entire training module used person-first language like this.

I was, quite literally, shocked and appalled. I got on the phone with the company, which didn't have any autistic people working for them, nor had they ever heard a complaint about these modules. In fact, I later found out that the UK Department for Education – under Conservative leadership since 2010 – had approved these modules in 2020. I tried to raise a complaint with the Disability Student Allowance in 2022, but got nowhere. Since the DfE was run by Conservative Party appointees and the only external oversight body (the Equality and Human Rights Commission) was ruling in favour of allowing conversion therapy for queer people, I did not feel confident that there was anywhere else to go. Meanwhile, I never received full confirmation that the modules were ever meaningfully changed, including the racist language and attitudes, just a verbal assurance that the company would engage with external bodies to make sure that "language" is "up-to-date". Of course, you can use the most inclusive, focus-group-tested language in the world, but if what you're doing is still eugenics, then that doesn't change the outcome one bit.

This. This is how mentors for autistic people are trained, then. Mentors, who have a huge responsibility towards their students, will find them at their most vulnerable in a new environment with huge social and emotional expectations, as well as a shift in what is expected from them academically. As you will see, to be a mentor means to actively push back against the system that causes autistic students to drop out before they finish their degrees and to have a lower quality of life alongside a higher likelihood of traumatic incidents in an environment seemingly *built* to exclude us.

How else are mentors trained? Well, in the majority of cases, prospective mentors have postgraduate certificates in teaching and education. In the UK, these are called PGCEs – Postgraduate Certificates in Education. This means that they are qualified teachers, who may have specialised in special educational needs during their training. Still, SEND is not mandatory for PGCE programmes, so the vast majority will simply not. Ironically, 'behaviour management', and other systems based on cognitive behavioural psychology to punish 'bad' behaviour and reward 'good', IS mandatory for all PGCE candidates. Guess which kids end up in behaviour management classes, or are classed as problems? Yup, it's us, especially if we are also non-white or not native English speakers.

The other way that people qualify to become autism mentors, paid via DSA, is membership of professional organisations, such as the Dyslexia Guild. These are, naturally, expensive members' clubs, which autistic people might not have access to because we are less likely to have the money to buy ourselves in. That is a natural consequence of the shockingly low numbers of autistic people in paid employment in the UK. Plus, when you have difficulties in school because of who you are, fighting to stay afloat in that environment might mean never even getting to university, let alone postgraduate study.

It's important to address the innate difficulties actually autistic people face even getting so-called appropriate qualifications.