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Editorial: Intersectionality and Autism

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At the time I am writing this editorial, we seem to be living in edgy post-pandemic times and a panmorphic crisis (Simon 2021), with the risk of escalating war at the doors of Europe and with the effects of climate change already impacting us and the planet.

At home in the UK, we have a new national autism strategy since last summer that includes children for the first time (UK Government, 2021). In the introduction of the strategy, the Secretary of State of Health and Social Care says that he “hopes" that employers across the country, including the public sector "will help more autistic people get into work” (UK Government, 2021, p. 4). Perhaps he is referring to the fact that only 1% of autistic people feel well supported by health, social care, education, and employment services according to a survey that helped to formulate that strategy (UK Government, 2022).

With the mission to “transform lives and change attitudes”, the National Autistic Society and the All-Party Parliamentary Group on Autism continue to raise awareness about autism. Since 2019, they have delivered “Understanding Autism” training sessions to 150 members of parliament and their staff (All-Party Parliamentary Group on Autism, 2021).

Shortly before the Covid pandemic started, the Equality and the Human Rights Commission (EHRC) launched a legal challenge against the government over the “repeated failure to move people with learning disabilities and autism into appropriate accommodation” (Equality and Human Rights Commission, 2020). EHRC claims that more than 2,000 people with learning disabilities and autism are detained in secure hospitals, often far away from home and for many years. EHRC denounces a "systemic failure to protect the right to a private and family life, and right to live free from inhuman or degrading treatment or punishment” (Equality and Human Rights Commission, 2020).

Whilst politicians “hope” and go to training on understanding autism, and human rights organisations raise their voices, autistic people on Twitter talk about a popular combination of keywords called hashtags, such as #autismpride and #actuallyautistic. As user @joshsusser explains, "We share our stories of autistic life, so other autistic folks can recognize themselves in their own stories". And this seems to be also what internet users are looking for. If we search web queries for the terms “autism” using the Google Trends tool (Google, 2022), we find that during the last 12 months, the top search associated with autism was the diagnosis of top model Christine McGuiness (White, 2021).

Perhaps we are looking for stories that can be meaningful to us because they represent us, or an aspect of ourselves somehow. This special issue of Murmurations is the result of the collective work of the steering group at the Autism and Systemic Practice Hub and presenters of the 3rd Autism and Systemic Practice Conference. An eclectic group that first functioned under the umbrella of the University of Bedfordshire and later as part of Lenticular Futures, a new organisation that some of us helped to give birth to in early 2022 with the aim of depathologising and decolonising the mental health professions.

In July 2021, we organised the 3rd Systemic Practice and Autism Conference. It was an insightful and exciting 2-day Conference in which we shared ideas, experiences, ways of working and ways of being with each other with people participating from the UK, Ireland, the rest of Europe, and the United States.

In February 2022, we participated in the European Congress of Qualitative Inquiry. We designed an interactive poster (in this issue) in which we wanted to share our learning from organising an online conference for a neurodiverse conference. Our main point was that good practice for neurodiverse attuned online conferences could be generalisable as good conference practice. In July 2022, we meet to plan the next Systemic Practice & Autism conference that is scheduled for July 2023.

In this special issue, we write from our lived experience of mothers, service users, activists, employees of the NHS and social care, private psychotherapists, psychologists, at work and retired. We also write about intersectionality (Crenshaw, 1991) from our intersections of being Autistic, LGBTQI+, Black, Global Majority, white, immigrant, transgender, female, male, and many more descriptions. What strikes me is that I feel we write mainly as people, as human beings who want to change the world, or at least our closest territories of influence and make it better for everybody.

Felix Moore offers us an intimate piece of writing from the intersection of being an autistic trans man. Felix argues that he faced the same issues that many girls face in obtaining an autism diagnosis and how his pleas for help were ignored and dismissed by health professionals. Felix also explores a growing body of evidence about the overlap between autism and LGBTQI+ identity. Felix also shares the horrendous experiences that hundreds of trans people go through whilst trying to obtain medical transition treatment in the NHS, and urges a radical reform to this service as over 60% of patients contemplate suicide during the years it takes to obtain treatment. Felix speaks for many autistic trans people when he says, “Listen to us. Believe that we are who we say we are. Grant us the dignity to think for ourselves and to speak on our own behalf”.

Rachel Morgan-Trimmer writes from her lived experience and denounces how autistic women are suffering from being under-diagnosed, under-served, and under-represented because they don't like to "make a fuss" and because professionals are often not looking for autism in women. Rachel writes about the autism diagnostic gap, in which males are much more likely to be diagnosed than women. Rachel also explains how the diagnostic process uses forms directed towards traditionally masculine interests and behaviour, and in some cases even uses male pronouns. Rachel also points out a set of actions, such as putting oneself forward as examples of autistic women, sharing what their lives are like and helping people understand the rich variety of individuals across the autistic spectrum. Rachel urges us to address the issues facing autistic women, to explain, educate, to ask difficult questions about why autistic women aren't being considered, and why their needs aren't being met yet.

Mairi Wickens offers us experiences from her personal and professional life in insightful research into the lived experience of mothers of autistic girls. Mairi explores how constraints to diagnosis can be fuelled by societal myths and stereotypes, resulting in variable levels of support and the negative focus of the diagnostic process. Mairi also explores how diagnoses can be useful for understanding needs, reframing behaviours in the context of autism, and reframing autism itself. The mothers who participated in Mairi's study emphasised that diagnosis also facilitated new awareness that informed a change in expectations, tolerance, and understanding. Mairi explains how mothers adopted new parenting strategies, transforming their parenting and relationships with their daughters. Finally, Mairi also explores how diagnosis brought support from others, including schools, although the amount of support is questioned for not being what was needed and deserved.

Dawn Thibert shares her path into working in child and adolescent mental health as a family therapist and how she started to learn about working with autistic people. Dawn highlights the intersection of autism, gender identity and sexuality, and the complexities regarding racism, culture, and religious beliefs. In places, Dawn writes in poetic form, a way that she finds ethical and that honours the therapeutic relationship with her clients as she hears and shares a wider range of responses than prose or outer talk allows. In one intimate piece of writing, Dawn explores her dilemmas in coming out as an employee in a health organisation and she illustrates what a collaborative, ethical and helpful journey might look like for clients, their families, and the therapist. Through her courage in listening to and sharing her inner dialogue and observations in stanza form with clients, Dawn inspires us to find ways of communicating with clients in ways which honour their and our voices.

David Steare invites us to consider how "we are more than others can say" in the sense of resisting language that seeks to colonise us. David's writing shows us how at times he is a systemic professional working with autistic clients in complex bureaucratic systems. In other places, his writing becomes more autobiographical and intimate when David decides to tell us about his life experiences and blurs the boundaries between the personal and the professional, as a psychiatric nurse, social worker and his current active work as a retired practitioner actively advocating for his clients. David also plays with the idea of a possible “neurodiversity scale” and I find it particularly interesting how David dares to talk about the L-word (love) in the context of a therapeutic relationship. David proposes a resistance that is playful rather than hostile, moving from “either/or” to “both/and”.

In my paper, **(Fran Urbistondo Cano)** I develop a relational-intersectional perspective in my work with autistics with learning disabilities and their paid care staff in social care in England. I illustrate what I call a shifting position from normalisation to depathologisation in autism as it has already occurred with LGBTQ+ people and the category of “homosexuality” in the 1970s. I also explore the performativity of “being LGBTQ+” as well as “being autistic” in a neurotypical-heteronormative-ableist-led society. I point to a possible confluence of intersectionality and the social graces model by digging into what research tells us about the lives of people with learning disabilities and autism, as well as the lives of care workers in social care. Finally, I emphasise the benefits of working from a relational-intersectional perspective in a relational approach that has social justice as some of its values.

In a jointly written paper, **Gail Simon** and I (**Fran Urbistondo Cano)** propose a deconstruction of the Autism Spectrum through the concept of Multi-Spectra Contextual Living. We expose the ideological roots of the Autism Spectrum in the historical development of autism theory, diagnostic practice and hopes of cure. We replace the single spectrum with an alternative model in which people with autism are understood as living fluid, intersectional lives with many axes and contexts in play. We warn that autism research in the UK has mainly focused on genetics and biological aspects of autism with the potential risk of a view of eradication of an entire section of the population through future preventative measures, following what can be framed as a eugenics agenda. In particular we discuss the importance of contextual layers as backdrops to the many spectra autistic people on and between to appreciate more fully who autistic people are when they are not with us in a professional context. Finally, we invite reflexive professionals to mind their language and to stay aware of which alliances they are joining and what the consequences are of the language they use and such alliances.

Freda McEwen shares with us two powerful poems. In "Psycho Terror", she writes about her experience as "a single mother of an Autistic big black male" in a world which foregrounds Black then Male then Big before appreciating her son as autistic. She describes how she navigates the professional system, the culture and the spirituality of her experiences. Freda describes how sometimes she and her son are like in a theatre trailer whilst “people watch and wait, curiously and judgmentally”. Freda's poem warns us about how people might feel when professionals learn by the book and generalise a person's needs. In the second poem, Freda explores how the COVID pandemic segregated and made it “obvious that some people are a minority” and "an insignificant part of the human race". Freda refers to the UK Government’s 2021 Covid-19 instruction to health services to DNR - "Do Not Resuscitate" – people with learning disabilities. Finally, Freda puts herself into the shoes of people called having "special needs" and shows us an emotional world that will not leave you indifferent.

This special issue also incorporates visual and interactive resources:

- An interactive board about "Neurodiverse Online Conferencing" which the Autism Steering Group presented online at ECQI 2022.
- A video wall with the presentations that were part of the 3rd Systemic Practice and Autism Conference as well as its website.
- An invitation to the next Autism and Systemic Practice Conference on 6th and 7th July 2023 which we will re-name the "Neurodiversity and Systemic Practice Conference".

Join our Autism and Systemic Practice Hub at Lenticular Futures for shared projects and inspiring conversations! Contact us: systemicautism@lenticularfutures.com

Many thanks to all the contributors and reviewers of this issue who have worked as a team in supporting this important subject of autism and intersectionality through a systemic set of lenses.

And on behalf of the journal, we issue a heartfelt welcome to a new Deputy Editor, Dr Marilena Karamatsouki, who has been an ambassador for the journal in social media and our writing projects.

References

All Party Parliamentary Group on Autism (2021). All Party Parliamentary Group on Autism 2021 Annual General Meeting Minutes. APPGA AGM 2021 Minutes.pdf (thirdlight.com)

Crenshaw, Kimberlé (1991). Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. *Stanford Law Review*, 43(6), 1241-1299. https://doi.org/10.2307/1229039

Equality and Human Rights Commission (2020). Health Secretary faces legal challenge for failing patients with learning disabilities and autism. Health Secretary faces legal challenge for failing patients with learning disabilities and autism | *Equality and Human Rights Commission* (equalityhumanrights.com)

Google (2022) Trends. https://trends.google.com/trends/explore?geo=GB&q=autism

Simon, Gail (2021). Panmorphic Crisis: Cultural Rupture and Systemic Change. *Murmurations: Journal of Transformative Systemic Practice,* 4(1), 87–101. https://doi.org/10.28963/4.1.7

UK Government (2021). National strategy for autistic children, young people and adults: 2021 to 2026. National strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK

UK Government (2022). Summary of findings from the government’s review of the National Autism Strategy 'Think Autism': call for evidence - GOV.UK

White, Vicky (2021). Christine McGuinness diagnosed with autism just like kids after Paddy's suspicions. Christine McGuinness diagnosed with autism just like kids after Paddy's suspicions. *Mirror Online*.

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Urbistondo Cano, Francisco (2022). Editorial. *Murmurations: Journal of Transformative Systemic Practice*, 4(2), i-v. https://doi.org/10.28963/4.2.1