

Six ideas about how to address the autism mental health crisis

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The autism mental health crisis can be described with the following paradox: autistic people have a high chance of developing mental health problems, but a low chance of receiving effective help. In this editorial, I outline the mental health challenges that autistic people experience under current systems of care and share some ideas about how clinicians, researchers and members of the autism community can work together to address this situation.

The extent of the mental health challenges that autistic people face became clear to me more than a decade ago with the publication of a landmark paper, *Psychiatric Disorders in Children with Autism Spectrum Disorders: Prevalence, Comorbidity, and Associated Features in a Population-Derived Sample* (Simonoff et al., 2008). Its findings were compelling and shocking: 70% of autistic children met criteria for at least one psychiatric disorder and 41% had two or more. These very high rates of mental health difficulties were all the more striking because they were observed in a community-based sample rather than a clinic-based sample, where we might expect those with co-occurring mental health problems to be over-represented.

Since then, many studies have confirmed that autistic people experience high rates of mental health challenges, substantially higher than those found in non-autistic comparison groups in both clinical and general population samples (see Lai et al., 2019 for a systematic review and meta-analysis). This elevated risk is for the full gamut of conditions, including anxiety, depression, bipolar disorder, psychotic disorders, obsessive-compulsive disorder, sleep disorders and conduct problems. These difficulties are found across the lifespan and affect autistic people of all genders. The consequences for autistic people with untreated mental health problems include lower quality of life (Mason et al., 2019), worse employment prospects (Scheeren et al., 2021) and greater risk of premature mortality (Hirvikoski et al., 2018).

Support systems for autistic mental health are, currently, not fit for purpose. I am not criticising the individuals delivering mental health services who, in my experience, are usually highly dedicated to their complex and challenging work. Rather, the lack of support for autistic mental health reflects longstanding systemic problems that result in professionals lacking the required resources and training to provide effective support to their autistic clients. In a USA-based online questionnaire, a third of autistic adult participants reported having unmet mental health needs, which was twice the rate found in the non-autistic comparison sample (Nicolaidis et al., 2013). In the UK, a survey of post-diagnostic experiences of autistic adults found that 45% wanted psychological therapy for their mental health challenges, but only 22% were offered it (Jones et al., 2014). There are other indicators that mental health needs of autistic people are not well supported. Rates of psychotropic medication use are high for autistic people (Nylander et al., 2018), with the possible implication that some problems are being treated at the symptoms level, with insufficient in-depth formulation of underlying difficulties and the sources contributing to these (e.g., the mismatch of individual characteristics and environmental demands). The growing qualitative literature on the experiences of autistic people in mental health services highlights that autistic people often struggle to access care and face multiple barriers to benefitting from treatment (e.g., Babb et al., 2021; Camm-Crosbie et al., 2019).

Thankfully, there is growing consensus that this situation cannot persist – that services must do more to include and help autistic clients. Recently, the James Lind Alliance conducted a priority-setting exercise with more than 1,000 members of the autism community (Cusack & Sterry, 2016). The exercise identified improving mental health interventions for autistic people as the number one priority for autism research. In the UK, the National Health Service (NHS) Long-Term Plan, a highly influential document that provides strategic direction to the NHS over a 10-year period, highlighted better care for autistic people, including a focus on mental health, as a priority (NHS, 2019). The World Health Organisation published a resolution (WHA67.8) recognising the stigma and discrimination that autistic people face and explicitly calls out the need for better mental health care.

So, there is the will to improve mental health care for autistic people. But how can this be accomplished? Here, I put forward six suggestions to contribute to debates about this crucial task.

First, we need continued improvements in autism screening and assessment. Autistic people who grow up without the support and understanding that can come from an autism diagnosis are at especially high risk of having experiences that lead to mental health problems. Too many autistic people are diagnosed in adolescence or adulthood, often after they have developed mental health difficulties. Efforts should be targeted at those in primary education to address this problem. We will also need flexible mechanisms for identifying people requiring autism assessment as adolescents and adults. One way to do this is to focus on populations where we know there are especially high rates of undiagnosed autism, for example, women with eating disorders (Huke et al., 2013), men who are homeless (Churchard et al., 2019) and those with treatment-resistant OCD (Wikramanayake et al., 2018).

Second, we need standardised and evidence-based post-diagnostic supports that educate and empower autistic people, and could thereby prevent mental health problems. Initial investigations suggest that psychoeducation that emphasises the strengths, not just the difficulties, associated with autism, can have a beneficial effect (e.g., Beresford et al., 2020; Gordon et al., 2015). In my view, this post-diagnostic support should involve peer-to-peer support, with autistic people coming together to share experiences and knowledge (e.g., Crane et al., 2020). The pandemic has shown some potential advantages from using telehealth in autism services, as long as this is done flexibly and in consultation with individual clients (Bundy et al., 2021). Post-diagnostic support could be delivered, at least in part, remotely to improve accessibility, cost effectiveness and scalability.

Third, we need more acknowledgement of the role the environment plays in causing mental health problems in autistic people. This will require movement away from a medically oriented paradigm that assumes that the mental health difficulties of autistic people arise simply from their individual characteristics. Instead, we need greater acknowledgement that autistic people are often expected to live in environments that are profoundly

unaccommodating to them, and that this has consequences for their mental health (Milton & Sims, 2016; Mitchell et al., 2021). Research and clinical practice should focus on person-environment fit – looking at the environments that autistic people live in, understanding how these often a misaligned with their capacities and values, and finding ways to make them more accommodating (Lai et al., 2020). Such work can then inform interventions that seek to improve autistic mental health, not merely by asking the individual to change, but rather by making adaptations to the environment, to give its autistic inhabitants more chance to live well.

Fourth, a systematic and evidence-based programme of training for mental health professionals is needed, so they better understand the characteristics and needs of their autistic clients. In almost all general mental health settings, autistic people present for help. Yet clinicians often feel lacking in confidence and knowledge about how to work with their autistic clients (e.g., Crane et al., 2019; Hu & Chandrasekhar, 2021). When a clinician starts work at a service, it is common for them to receive routine training on such matters as how to handle data safely and anti-discrimination policies. Why not also include mandatory training about neurodiversity, including autism? This can give clinicians a much better chance of forming productive partnerships with their autistic clients, based on mutual understanding.

Fifth, we should be working towards the design of evidence-based specialist autism pathways in general mental health settings. The alternative would be to set up autism-specific mental health services, but I think this is unlikely to become a widespread model, largely for financial reasons. Also, it is not clear that specialist services would even be desirable - those working in general mental health settings have much expertise to offer, so long as they can be helped to adjust their practice to accommodate their autistic clients (e.g., Russell et al., 2020). I appreciate that the development of such pathways will require work over the next decade and more; but this should not prevent the provision of adapted support for autistic people in mental health services in the meantime. There is already some knowledge which can be drawn on to inform the adaptation of mental health services for autistic clients (e.g., Russell et al., 2019; Tchanturia et al., 2020), and we must aim to broaden and deepen this in the coming years.

Sixth, more research is needed on autism-informed mechanisms that cause or perpetuate mental health problems. We should not assume that mental health problems of autistic people will always have the same underlying mechanisms as those of non-autistic people; and nor can we assume that treatments designed for non-autistic people will necessarily work for autistic patients. For example, there is emerging evidence that general anxiety (e.g., Neil et al., 2016), eating disorders (e.g., Brede et al., 2019), post-traumatic stress (e.g., Rumball et al., 2021) and obsessive-compulsive disorder (e.g., Hellriegel et al., 2017) might each be driven by autism-specific risk factors. Such work can ultimately bear fruit in suggesting interventions that target autism-specific risk mechanisms.

I support an approach that emphasises prevention as much as treatment, and which harnesses the mental health benefits of creating social and physical environments that are more accommodating for autistic people. I am under no illusion that turning such rhetoric into reality will be anything other than difficult, and success is not guaranteed. To have a chance of making good progress, it will be essential that the current trend towards autistic voices having greater influence on research and practice continues (e.g., Fletcher-Watson et al., 2019). The current autism mental health crisis will only be addressed with the forging of authentic partnerships between researchers, clinicians and the autism community.

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