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# Autism should be considered in the assessment and delivery of mental health services for children and young people

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**ABSTRACT**

Autistic Children and young people (CYP) experience higher rates of mental health problems, including anxiety and depression, than their neurotypical peers. Yet, often mental health assessment and support is lacking for autistic CYP as assessment tools and evidence-based interventions have typically been developed with neurotypical population needs in mind. Following a narrative matters style, this article outlines the lack of recognition given in mental health services towards autistic CYP attempting to access support, highlighting some future priorities in service delivery. Issues relating to health professionals misinterpreting and mis-labelling autistic CYP experiences, the impact that this has upon those attempting to gain mental health support and possible changes that can be implemented at minimal cost both financially and to service delivery design and implementation are highlighted.

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Autism; children and young people; mental health; service delivery; CAMHS

## Autism and mental health

The mental health of autistic children and young people (CYP) must be prioritised. Autistic CYP experience higher prevalence of co-occurring mental health problems, including anxiety and depression, compared to their neurotypical peers. Around 70% of autistic CYP experience one mental health condition, while 41% experience two or more mental health diagnoses (Simonoff et al., 2008). Yet, neurotypical strategies in the assessment and intervention of mental health needs of autistic CYP continue to dominate, and there can be disregard of autistic CYP's experience. Here, we outline the lack of understanding of autism afforded towards autistic CYP attempting

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to access support from mental health services, highlighting some future priorities in service delivery.

## Autism matters

Autism presents with differences in social-cognitive processing styles. Yet, deficit-based models of autism (e.g. the theory of mind) dominate societal and medical arenas. Subsequently, it is widely perceived that social-cognitive and emotional processing impairments account for any social, emotional, and cognitive difficulties autistic people may experience during social interaction. In turn, these assumptions may lead health professionals to disregard variation in neurocognition, as they attempt to redress these perceived impairments by aligning the autistic individual to a neurotypical profile of socio-cognition and sensory processing. Framing autism in this way neglects the inherent role a neurotypical individual has when socially interacting with a neurodivergent individual, and the influence their perceptions have during this interaction. In other words, the deficits *they* may experience interpreting the autistic individual.

An alternative approach, coined as the double empathy problem (Milton, 2012), strives to redress a deficit-based approach to autism. Accordingly, a reciprocal lack of empathy among non-autistic and autistic individuals towards each other results from a mis-matched understanding of how differing neurotypes perceive and experience the world. Arguably, prominence of deficit views of autism creates barriers that prevents access to, and delivery of, effective mental health services that support autistic CYP. Indeed, it has been reported that therapists delivering mental health support to autistic CYP in community settings found this to be 'challenging' and 'frustrating' due to a lack of training and autistic-specific 'tools' to deliver effective strategies (Brookman-Frazee et al., 2012). Similar frustrations have been reported by parents and autistic CYP. These findings suggest there is a disconnect between neurodivergent and neurotypical people in terms of how to perceive support, yet a connection in that support is needed. This disconnect may impact clinical practice. First, it may be challenging for mental health practitioners lacking the relevant understanding, training and/or experience of autism to disentangle features commonly related to autism from signs of mental health problems. Secondly, it may bias accurate mental health assessment among autistic CYP and lead to missed opportunities to deliver effective mental health support. Moreover, this may account for the further widening of existing mental health inequalities experienced by autistic CYP attempting to access mental health services, resulting in their needs not being met.

## Autism: a coat-hanger for systemic shortfalls

The recent COVID pandemic has further underlined difficulties in availability and access to NHS mental health services attributable to the effects of

austerity, insufficient funding, and staff shortages. However, problems existed prior to the COVID pandemic that exposed autistic CYP to avoidable health inequalities. A 2016 report by Christou, 'A spectrum of obstacles: An inquiry into access for healthcare for autistic people', highlighted barriers to poorer healthcare access and outcomes for autistic individuals, such as a lack of autism training and understanding among healthcare staff. These problems continue to persist, with individuals' autism seemingly consistently overlooked in the diagnosis of, and therapeutic support offered, for mental health difficulties, despite the value that early identification of autism spectrum condition may have in mental health support management.

A key mental health priority is early assessment, identification, and intervention to promote better outcomes. Autistic CYP face a myriad of obstacles hindering access to mental health services. In the first instance, the pathway to obtaining a diagnosis is notoriously protracted, with females often experiencing greater diagnostic delays than males. Diagnostic delays may be harmful to the mental health of autistic CYP as they attempt to camouflage innate social behaviours to 'fit in' with their peers and social norms. Moreover, late diagnosis is associated with increased isolation and lack of belonging during childhood (Stagg and Belcher, 2019). Relatedly, significant co-occurring mental health problems among autistic CYP may be dismissed and ascribed to autism rather than mental health difficulties. Symptoms commonly associated with anxiety and depression, such as avoidance, loss of motivation, and sleep disturbance may not be expressed in the same way as in neurotypical individuals and may be related to autistic-specific experiences, such as autistic inertia and/or autistic burnout (Buckle et al., 2021; Raymaker et al., 2020).

Outcomes for autistic girls are worsened further by poor understanding of the differences in autism presentation between girls and boys, including greater levels of camouflaging or masking behaviour to conceal autistic characteristics, as well as greater socialisation and societal expectation regarding social communication and interaction in girls and women. This gender bias is further exasperated by ill-informed diagnostic criteria and the development and validation of assessment tools that fail to tap into female autistic characteristics, due to a preponderance with male samples that continue to dominate. Resultantly, vital opportunities to diagnose autistic girls are missed, leading to under- and late diagnosis, particularly for those without intellectual disability.

## Change takes time, what can we do now?

The recently published UK 'National Strategy for autistic children, young people and adults: 2021 to 2026' in 2021 by the DHSC and DfE proposed some ambitious, albeit necessary, strategies to improve the lives of autistic people. Relatedly, 'Five-year NHS autism research strategy for England' (NHS,

2022) sets out a strategy to build research capacity within autism services to improve mental and physical health of autistic people in England through the development of evidence-based clinical practice. If properly implemented, this should raise autism awareness and help 'level up' accessibility to health services, including mental health. Also, research evidence aiming to elucidate the mechanisms underpinning mental health problems among autistic CYP, such as alexithymia and intolerance to uncertainty is emerging. This may inform the design and implementation of effective mental health assessment and interventions for autistic CYP. However, implementation of the strategies proposed and translation of research findings to real-world practice will take time, money, and commitment to see the changes come to fruition; thus, negatively impacting autistic CYP currently accessing mental health services, or those who may need to do so soon. Affirmative changes are needed now to affect positive change to avoid perpetuating barriers and harms to autistic CYP seeking help.

Mental health services have the capacity to implement small yet smart adaptations within the parameters of their current policies and procedures that may improve service experience for autistic CYP. Firstly, rapid access has consistently been shown to promote better mental health. Co-occurrence of mental health problems among autistic CYP, such as anxiety, are evident across the lifespan. As a society we repeatedly emphasise to our CYP to talk about their mental health and to seek help when needed. Autistic CYP face greater barriers gaining support for mental health problems than their neurotypical peers, as communicative differences may mean health professionals fail to recognise underlying mental health problems. Facilitating rapid access to mental health services and consideration of communicative differences would allow the voices and concerns of autistic CYP to be heard and addressed promptly, potentially averting deterioration or crisis.

Secondly, autism reflects a spectrum such that one autistic CYP's experiences of mental health is individual to them, and is not a universal template applicable to other autistic CYP. Subscribing to a neurotypical, 'one size fits all' approach in mental health assessment and intervention invalidates not only the challenges autistic CYP experience, but undermines autistic CYP's strengths. Furthermore, sensory processing sensitivities (e.g. noise and light) among autistic CYP are common. Sensory overload may make it harder for the autistic CYP to engage, therefore approaches that promote therapeutic settings, which consider their sensory processing requirements, are needed. Critically, co-production with stakeholders (including autistic CYP and their families) could facilitate delivery of tailored mental health interventions and allow assessment and exploration of underlying mental health problems, and adaptation of strategies to suit the autistic individual. For too long neurotypical ideas of good outcomes have pervaded treatment for autistic people, leading to therapy which has resulted in masking of autistic

behaviours and potential mental health risks. Treatment methods need to better target sources of distress experienced by the individual rather than those around them.

Lastly, while an autistic CYP is an expert in their own mental health and autism, they may not be able to communicate this within a therapeutic setting which often includes neurotypical biases. For example, around 50% of autistic people experience difficulties recognising and understanding their emotions (Kinnaird, Stewart and Tchanturria, 2019) and autistic inertia may make help-seeking and engagement more difficult for autistic CYP (Buckle et al., 2021). Moreover, a lack of appropriate help and adaptation within the therapeutic setting could contribute to autistic burnout and further exacerbate autistic CYP's mental health problems (Raymaker et al., 2020). It is important to listen to the parents/caregivers of autistic CYP who may be best positioned to advocate for their children, at least until they feel able to do so themselves. Yet, parents have reported a lack of trust in the healthcare system and felt blamed for their concerns surrounding the mental health of their autistic child (Jackson, Keville, and Ludlow, 2020). Arguably, such assumptions levied towards parents are done so by neurotypical biased services and clinicians who fail to account for neurodiversity in the first instance, which further perpetuate autistic biases and health inequalities. Shifting from parental blaming could foster a more open dialogue between clinicians and promote understanding of the autistic CYP's mental health needs. Additionally, employing autistic therapists, who themselves understand what it is like to be neurodivergent in a neurotypical dominated society, could overcome issues such as double empathy that may hinder effective mental health assessment.

It would be remiss to suggest the changes outlined above can remediate the problems related to autistic CYP mental health service experiences. To do so requires long-term investment in research that aims to understand the role of autism in mental health for autistic CYP. In turn, translation of such findings will inform service provider staff training and the design of assessment tools and interventions which accurately capture the autistic CYP mental health problems; and allow for their needs and priorities to be central to the implementation of service delivery. Nevertheless, in the interim enacting these changes may at the very least promote discussion between the autistic CYP and the mental health service provider.

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This study did not need ethical approval as it is a narrative matters article.

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## Contributorships

Authors CH, EA & PS conceived the article. CH, EA, PS, DM & BD drafted and revised the manuscript. All authors read and approved the final manuscript.

## Disclosure statement

No potential conflict of interest was reported by the authors.

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