

## Shifting stigma about autistic young people

Jacquiline den Houting<sup>1, 2</sup>, Monique Botha<sup>3</sup>, Eilidh Cage<sup>3</sup>, Desiree R. Jones<sup>4</sup>, & So Yoon Kim<sup>5</sup>

<sup>1</sup>Macquarie School of Education, Macquarie University, Sydney, Australia

<sup>2</sup>Cooperative Research Centre for Living with Autism (Autism CRC), Brisbane, Queensland, Australia

<sup>3</sup>Department of Psychology, Faculty of Natural Sciences, University of Stirling, Stirling, Scotland

<sup>4</sup>School of Behavioral and Brain Sciences, University of Texas at Dallas, Richardson, Texas, United States

<sup>5</sup>Department of Teacher Education, Duksung Women's University, Seoul, South Korea

Corresponding author:

Jacquiline den Houting

Macquarie School of Education

Macquarie University

Sydney, Australia

[jac.denhouting@mq.edu.au](mailto:jac.denhouting@mq.edu.au)

*Commentary accepted for publication in The Lancet Child and Adolescent Health, 14<sup>th</sup>*

*September 2021*

Accepted refereed manuscript of: Den Houting J, Botha M, Cage E, Jones DR & Kim SY (2021) Shifting stigma about autistic young people. *The Lancet Child and Adolescent Health*, 5 (12), pp. 839-841.

[https://doi.org/10.1016/S2352-4642\(21\)00309-6](https://doi.org/10.1016/S2352-4642(21)00309-6)

© 2021, Elsevier. Licensed under the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International

<http://creativecommons.org/licenses/by-nc-nd/4.0/>

Who do you think of when you hear “autism” mentioned? Maybe a familiar trope comes to mind: an eccentric white male, perhaps in the vein of *The Big Bang Theory*’s socially naïve genius Dr Sheldon Cooper, or savant Raymond Babbitt of *Rainman* fame. Endearing though they may be, characters like these reflect outdated and stereotypical understandings of autism that can have harmful consequences for autistic young people. Indeed, for many autistic people, these stereotypes and the stigma that they reinforce may be a greater barrier to wellbeing than the characteristics of autism itself.<sup>1</sup>

Link and Phelan<sup>2</sup> define stigma as comprising four component parts: 1) labelling of human differences; 2) associating labelled groups with negative stereotypes; 3) separating labelled groups from the majority in an “us” and “them” dynamic; and 4) status loss and discrimination against labelled groups. Importantly, stigmatization can only occur within the context of a social power imbalance – to enact stigma, a dominant group (the “us”) must hold enough power to engage in individual and/or structural discrimination against a labelled group (the “them”).

Autistic people are vulnerable to each of the four component processes by which stigmatization occurs,<sup>1</sup> and research to date has found considerable evidence of the stigmatization of autistic people and their families. Parents of autistic children, for example, consistently report that they and their children are subject to negative stereotyping and judgement; social isolation and rejection; and discrimination.<sup>3</sup> Non-autistic people can hold dehumanizing attitudes, viewing autistic people as child-like, even though autistic children inevitably grow up to become autistic adults.<sup>4</sup> Non-autistic people are less willing to engage socially with autistic (versus non-autistic) people, and make negative judgements about autistic children and adults after just seconds of exposure.<sup>5</sup>

Unsurprisingly, the experience of stigmatization can have considerable negative impacts for autistic people. Exposure to stigmatizing events, repeated rejection, and discrimination can result in internalized stigma.<sup>1</sup> Internalized stigma refers to the process of applying negative societal beliefs to one's personal identity. Internalized stigma has been described as the most insidious form of minority stress because, although it stems from negative external attitudes, it can become "self-generating", persisting even in the absence of direct external judgement.<sup>6</sup> For autistic adults, greater internalized stigma is associated with significantly poorer social, emotional, and psychological wellbeing, as well as higher levels of psychological distress.<sup>1</sup> Although research on autistic young people's experiences of internalized stigma is limited, in interviews about their time at school and views of being autistic, autistic adolescents often talk negatively - wishing to be 'normal' or thinking they have a 'bad brain',<sup>7</sup> suggesting that young people are indeed vulnerable to internalized stigma. To counter this, we must avoid exposing autistic young people to negative attitudes about autism, instead adopting a strengths-based approach to their care.

Stigma presents an even greater barrier for those autistic young people who do not conform to the pop-culture cliché of autism. While we might be forgiven for believing that autism is the exclusive realm of white men and boys, the autistic community largely mirrors the diversity of the broader community in terms of race, ethnicity, gender, sexuality, and so on. Many of these identities carry their own forms of stigmatization, compounding the stigma faced by autistic people. A Black autistic child, for example, faces not only the stigma associated with their race and that associated with being autistic, but also specific stigma that arises from being *simultaneously* Black and autistic.<sup>8</sup> It is imperative, therefore, that we understand autistic young people's experiences not only in light of their identity as autistic, but also in relation to the many and varied intersectional identities they may inhabit.

The Sheldon Cooper archetype, reinforced by media portrayals of autistic characters, emerged in part as a result of deeply ingrained biases within the autism research and practice establishment. For example, one highly influential theory of autism described autistic people as having Theory of Mind deficits and, by extension, lacking empathy. This idea was later extended to become the Extreme Male Brain theory of autism, which posits that autistic people have hypermasculine patterns of cognitive processing. Arguably, these concepts, which have been dominant in autism research and practice for decades despite questionable empirical support,<sup>9</sup> have likely propagated and maintained the damaging stereotype that all autistic people are unempathetic boys. In practical terms, such theories have led to interventions that aim to teach autistic young people conventional social skills, sending the message that autistic people must suppress their authentic ways of being in order to conform to normative expectations.<sup>10</sup> This conformity, termed ‘camouflaging’, carries potentially significant consequences to the young person’s mental health and sense of identity. More recently, there have been calls for a shift in intervention targets, with a focus on fostering autism acceptance in the general community and thereby reducing the burden of conformity for autistic young people.<sup>10</sup>

Preliminary efforts to reduce autism stigma have occurred in the form of autism acceptance training programs, which aim to increase participants’ knowledge of autism and provide insight into autistic people’s lives, with promising results. For example, school-based interventions can improve non-autistic school students’ autism knowledge, and online training can reduce autism stigma in university students.<sup>11</sup> Such programs, however, are limited in their scope, aiming to shift attitudes at the individual level only. To fully address the stigmatization of autistic people, multifaceted and multilevel approaches are required.<sup>2</sup> Stigma arises from a complex interplay of individual and structural factors, and reducing stigma requires addressing both. Two key elements are needed if we are to eradicate autism

stigma. First, we must change the deep-seated negative beliefs and stereotypes about autism that are so common, within autism science, medicine, and the broader community. We can begin this process by reflecting on our own assumptions and biases when working with autistic young people, and learning from the experiences of autistic adults – who were once, after all, autistic children. Autistic advocates have been working to promote autism acceptance for decades, with some success; but collectively, autistic people lack the social power to engender wide-scale social change. This brings us to the second key point: we must work to break down the systemic and structural barriers that oppress autistic young people and, in doing so, counter the social power imbalance that facilitates the enacting of stigma. It is only through widespread change at both the individual and systemic levels that we can shift attitudes about autism and counter the harmful effects of stigma.

### **Contributors**

All authors contributed to conceptualization of this manuscript. JdH wrote the original draft of the manuscript, with contributions from MB. All authors contributed to reviewing and editing the manuscript.

### **Declaration of interests**

JdH is supported by a Macquarie University Research Fellowship. MB is supported by Economic and Social Research Council grant ES/V012347/1.

The views expressed are the views of the authors alone and do not necessarily represent the views of their organizations or funding sources.

## References

1. Botha M, Frost D. Extending the minority stress model to understand mental health problems experienced by the autistic population. *Society and Mental Health* 2018;**10(1)**:20–34.
2. Link B, Phelan J. Conceptualizing stigma. *Annu Rev Sociol* 2001;**27**:363–85.
3. Mazumder R, Thompson-Hodgetts S. Stigmatization of children and adolescents with autism spectrum disorders and their families: A scoping study. *Rev J Autism Dev Disord* 2019;**6(1)**:96–107.
4. Cage E, Di Monaco J, Newell V. Understanding attitudes and dehumanisation towards autistic people. *Autism* 2019;**23(6)**:1373–83.
5. Sasson N, Faso D, Nugent J, Lovell S, Kennedy D, Grossman R. Neurotypical peers are less willing to interact with those with autism based on thin slice judgments. *Sci Rep* 2017;**7**:40700.
6. Frost D, Meyer I. Internalized homophobia and relationship quality among lesbians, gay men, and bisexuals. *J Couns Psychol* 2009;**56(1)**:97–109.
7. Humphrey N, Lewis S. ‘Make me normal’: The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism* 2008; **12(1)**:23–46.
8. Jones D, Nicolaidis C, Ellwood L, et al. An expert discussion on structural racism in autism research and practice. *Autism Adulthood* 2020;**2(4)**:273–81.
9. Gernsbacher MA, Yergeau M. Empirical failures of the claim that autistic people lack a theory of mind. *Arch Sci Psychol* 2019;**7(1)**:102–18.
10. Bottema-Beutel K, Park H, Kim SY. Commentary on social skills training curricula for individuals with ASD: Social interaction, authenticity, and stigma. *J Autism Dev Disord* 2018;**48(3)**:953–64.

11. Cremin K, Healy O, Spirtos M, Quinn S. Autism awareness interventions for children and adolescents: A scoping review. *J Dev Phys Disabil* 2021; **33(1)**: 27-50.

Accepted version