

Tensions between autistic sociality, communication and social skills research: a response to Bambara (2022) and Camarata (2022)

Nathan Keates¹, Krysia Emily Waldock¹ and Eleanor Dewar¹

¹Tizard Centre, University of Kent

Nathan Keates <https://orcid.org/0000-0003-3070-1580>

Krysia Emily Waldock <https://orcid.org/0000-0001-9631-3930>

Eleanor Dewar

The authors have no conflicts of interest to declare.

This study was unfunded.

Correspondence concerning this paper should be addressed to Nathan Keates, Tizard Centre, University of Kent, Cornwallis East, Giles Lane, Canterbury, Kent CT2 7NF. Email: nk411@kent.ac.uk

Abstract

Purpose: The purpose of this letter to the editor is to further elucidate the arguments Keates (2022) and Beechey (2022) stated in their commentaries. Both Bambara (2022) and Camarata (2022) pose comments which require clarifying the original arguments, in particular regarding power and autistic sociality, which we feel will provide further clarity to this highly significant and growing topic within autism research.

Conclusion: We recommend not teaching autistic people, but rather non-autistic individuals about autistic sociality, in order to lower the burden on autistic interlocutors in cross-neurotype interactions and socialisation (as per previous literature, Bottema-Beutel et al., 2018). We provide recommendations to address difficulties in cross-neurotype interactions; for example, bridging the neurotype gap through practices or psychosocial interventions for acceptance of autistic people and their system of interpretation, as per Jones et al., 2021).

Introduction

We thank Bambara (2022) and Camarata (2022) for their lively engagement with commentaries by Keates (2022) and Beechey (2022). The purpose of this letter to the editor is to further elucidate the arguments that Keates (2022) and Beechey (2022) introduced. Both Bambara (2022) and Camarata (2022) pose comments which require clarifying the original arguments, in particular regarding power, and autistic sociality, which we feel will provide further clarity to this highly significant topic within autism research.

The pathologisation of autistic social skills is in its own right the identification of the difference in neurotype¹ (Milton, 2014). In the last commentaries by Keates (2022) and Beechey (2022), it is believed that evidence through citation has been provided that autistic sociality exists as inherent to being autistic.

¹ Neurotype: category of different types of brain at a broad conceptual level, including how information and social cues are processed

Power Imbalance and Harm

Firstly, as stated by Bambara (2022) and Camarata (2022), ensuring ethical responsibility for participants we work with and collect data from is imperative. Whilst we understand this can be seen as going beyond the scope of their study, discussions on the ethics of studies are relevant to all empirical work, especially when collecting data from and with other people. Doing no harm is a central aspect of many ethical dilemmas, and beneficence (as reported in the Belmont Report; National Commission for the Protection of Human Subjects of Biomedical, & Behavioral Research, 1978) must outweigh any potential harm. We indicate important considerations in relation to the APA discussion on justice, that researchers should take precautions to avoid poor practice. Moreover, in our context in the UK, this is the same with the British Psychological Society (BPS) (Oates et al., 2021) stating that researchers should ‘...maximise potential benefits and avoid potential risks to psychological well-being, mental health, personal values, privacy or dignity’ (p. 9). Whilst it is understood that evidence bases should guide best practice, it is also the case that the quality of some evidence bases is ever more increasing - notably in the case of autistic people and people with intellectual disabilities (ID) through participatory and inclusive research (e.g., Nicolaidis & Raymaker, 2015; Pellicano, 2017). Furthermore, Hailes et al. (2020) extend the APA ethical code with consideration of power dynamics, empowerment, and individual and community well-being. Similarly, the BPS recommends that “normally, the risk of harm should be no greater than that encountered in ordinary life” (p. 9). Although teaching social skills with a non-autistic partner may appear beneficial, an increasing body of research suggests the implicit harm this can cause (e.g., Bottema-Beutel et al., 2018; Hull et al., 2017; Monahan et al., 2021). There remains a lack of differentiation between long- and short-term harm in the evidence bases, ethical guidance documents (e.g., BPS, Belmont Report) and autism research. Much of the harm which has been elicited through research studies in relation to autistic people is long-term - happening many months or years after participation in a study (e.g., Bottema-Beutel et al., 2020; Dawson & Fletcher-Watson, 2022). We understand why such studies are

likely to gain an ethically favourable opinion, and that studies may appear to have short-term merit for some autistic individuals, but we believe this is a broader problem which needs to be addressed within autism research (as echoed by Dawson & Fletcher-Watson, 2022; Papaioannou et al., 2021; McGill & Robinson, 2020).

Furthermore, considering power dynamics at play between autistic and non-autistic peers is of vital importance. We agree with Bambara's (2022) assertion that skills can be useful; however, we believe that further clarification is needed in relation to autistic sociality within a world based on non-autistic norms. It is true that many autistic people experience social anxiety (Spain et al., 2018) and may need support with socialisation. However, such support should not be imposing non-autistic norms upon autistic people. The issue of whom do interventions benefit, raises the question of the autistic being and the concept of observing power. Using Foucault's (2019) idea of a regime of power, autistic people are constrained through not meeting non-autistic norms, embodying preference for non-autistic being and compliance. For social validity, interventions should be acceptable to both autistic and non-autistic populations. Whilst it is understood that for some individual autistic people this may be 'socially valid', wider discussions identify a tension with this at theoretical (e.g., Milton, 2012) and practical levels (e.g., Bottema-Beutel et al., 2018).

The interaction between harm and ableism is central to assessing the power dynamics and the empowered typicality of an intervention. We recognise and accept Camarata's (2022) assertion that there was no evidence of coercion or disrespect. Physical harm and disrespectful behaviour generally are easier to observe than implicit attitudes, underpinning perceptions of disability and subsequent dehumanisation (Dawson & Fletcher-Watson, 2022; Papaioannou et al., 2021; McGill & Robinson, 2020).

The presence of potential willing participants alone does not suggest a study carries no long-term harm. The promotion of neurotypical (NT) behaviours through self-reflection and self-motivation for this change does not remove the prospect of self-stigmatising identity but may compound, disempowering individuals (e.g., Bradley et al., 2021; Cage & Troxell-Whitman, 2019; Miller et al., 2021). Interventions should not disempower autistic people, and should

allow for autonomy and agency. The tension remains between promoting choice and control with autistic sociality, and teaching skills to 'function' and adapt to NT norms.

Autistic Sociality and System of Interpretation

Fundamentally, Keates (2022) and Beechey (2022) both suggested that autistic sociality and system of interpretation have a growing evidence-base. Bambara (2022) remarked that their study was not about autistic people, yet their sample consisted of three autistic adolescents. When using autistic participants, the growing evidence bases surrounding autistic sociality and systems of interpretation should be consulted in terms of designing interventions and arguing their significance. Furthermore, the suggestion that an intervention could never change thoughts, personality, or traits, is disputed (e.g., it is unknowable whether interventions cannot change personality; Lai, 2022), ignores the history of education (e.g., Socrates' methods and discourse) (see Batista, 2015; Mulhern, 1959) and how a person can be shaped by others (e.g., Vygotsky, 1978, on social learning theory). In regard to autistic people, being shaped by the world around them, including a higher rate of adverse events (e.g., Hoover & Kaufman, 2018; Kerns et al., 2015), may lead to passing and masking (Cage & Troxell-Whitman, 2019). Consequently, the potential for harm could be resulting from self-stigma² and ableism³. One particular example from Camarata (2022) is when stating autistic people can achieve 'sufficient' social and communication skills, which clearly suggests authority over autistic people deemed to not have 'sufficient skills'. Suggesting that some autistic people are not deemed to have sufficient skills, in this case neuronormative⁴ communicative skills, is a further example of pathologisation, which is inherently harmful to autistic people's agency and autonomy. Neuronormative communication skills are based on the empowered typicality and is nescient to the autistic system of interpretation. Therefore, it

² Self-stigma: negative attitudes which have been internalised in regards to disabilities and/or medical conditions

³ Ableism: discrimination in favour of non-disabled people. Often in autism research, this includes discrimination in favour of non-autistic people.

⁴ Neuronormative: the privileging of neurotypical over neurodivergent expression and processing.

must be asked why neuronormative communication skills, notably enshrined through NT social communication, are more important than autistic people's way of being and socialising.

We agree that little is known in regard to autistic sociality and systems of interpretation, especially when co-occurring ID is present. However, Camarata (2022) comments on masking, stating "to generate social pressure to mask autism characteristics and/or who would otherwise be harmed by forcing conformity for the comfort of neurotypical 'norms.'" This implies that people with ID do not mask, which is currently under explored within the academic literature (Sedgewick et al., 2021). Nonetheless, Bambara (2022) agrees that communication is relational and interactional. This relational and interactional understanding of communication would suggest an agreement with teaching non-autistic participants to bridge the gap by an intervention promoting positive interactions with autistic people would be better (as per Jones et al., 2021), rather than any social or communication training for autistic people regarding engagement with non-autistic peers. Furthermore, Bambara (2022) noted the possibility of lopsided conversations between neurotypes, which indicates a need to teach NTs about autistic sociality and systems of communication. Likewise, Camarata (2022) agrees that there is a need for shared communication, which also implies the recommendation for psychosocial training for bridging the neurotype gap.

Bambara (2022) suggested that their intervention showed the autistic adolescents could learn NT communication to enhance their social relationships. However, autistic people may not express themselves according to the neuronormative methods (e.g., Cole, 2021; Heasman & Gillespie, 2018; Walker, 2021). By complying to these neuronormative standards, interventions requiring this of autistic people are promoting passing which leads to various issues, such as mental distress (Cook et al., 2021).

Further reasoning that sought to validate the intervention was promoted: Bambara (2022) discussed the imbalanced interaction between neurotypes that could lead to social isolation because non-autistic individuals would be burdened by maintaining conversational interactions. The burden falls currently on the autistic person (McCracken, 2021), as

noticeable through social skills training's focus on autistic people's development (and as more generally noted, Mullen, 2015). Therefore, a change to psycho-social education for NTs to not maintain negative social judgement of autistic people is required, for example, bridging the gap (a recommendation also given in a previous commentary on social skills training, Bottema-Beutel et al., 2018). Hence, to address Camarata (2022) comment that "... it may be difficult to altogether avoid interventions based on "neuro-typical" communication ... when an autistic individual is unable to communicate effectively and is, from a developmental perspective, at the initial stages of acquiring speech, language, and social skills." This merely vindicates the argument of the empowered typicality holding authority over what is "sufficient". It is imperative to teach NTs about autistic people, and how autistic people communicate (see our recommendations which includes an approach), rather than replace autistic communication in order to pass as NT. We agree with Camarata (2022) that non-speaking autistic people have used strategies and tools for speech and communication (i.e., Alternative and Augmentative Communication or AAC), but this does not avoid the need for non-autistic individuals to understand, accept autistic people and bridge the communication gap (over teaching autistic people NT communication). More research is needed, however, focus would be better served to be focused on autistic communication.

Camarata (2022) states our commentary is only valid upon certain conditions, one being "the goal of the intervention is to induce 'social conformity' rather than to establish foundational speech, language, and/or social skills." Keates (2022) and Beechey (2022) suggested using an autistic communication style. As such, we speak to the issue of the latter part, teaching NT social skills. Camarata (2022) discusses that interventions must match abilities with social interactions. Further suggesting that any initial training should be deemed acceptable as apparently this means the intervention does not focus on social conformity. Importantly, neither Keates (2022) or Beechey (2022) comments on teaching and learning communication as per natural, individual growth and maturation which would require a

discussion regarding spikey profiles and the non-normative learning trajectory of autistic people.

Recommendations and conclusion

Bambara (2022) reported that Theory of Mind framed their research; in a similar manner, one of the central foci of Keates' (2022) and Beechey's (2022) commentaries was a framing communication through the lens of the double empathy problem⁵ (Milton, 2012), along with other theories (such as monotropism⁶, Murray et al., 2005). Therefore, the Double Empathy Problem (and similar concepts, e.g., in neuroscience, Bolis et al., 2017, or cross-neurological theory of mind, Beardon, 2017) should be used to frame research on autistic sociality and systems of interpretation.

Camarata (2022) rightly introduces the commentaries suggesting that the need is to be ethical in practice, and that autistic people should be at the centre of all decisions made about them, and further identifies harm in past interventions. The paucity of research focused on the autistic system of interpretation needs addressing. Therefore, studies need to explore what the autistic system of interpretation includes and how it differs to enable non-autistic individuals to communicate in a manner that lowers the burden on autistic people, notably having to perform to NT standards (e.g., Rifai et al., 2022; Casartelli et al., 2020). In relation to future steps, Bambara (2022) called for a 'shared understanding' in order to "improve supports that are helpful, desirable, and acceptable." Supports for autistic people should be acceptable to autistic people, and we believe they can be guided by autistic people and autistic-led knowledge (Milton, 2014; Pickard et al., 2022; Poulsen et al., 2022). Researchers would gain from listening to, and working alongside autistic people in

⁵ Double empathy problem: an interactional theory of autism that postulates that there is a mutual mismatch of reciprocity and understanding between autistic and non-autistic people. See Milton, 2012 for further information.

⁶ Monotropism: A theory of autism and cognitive strategy of autistic people that argues that autistic people have monotropic minds - minds which focus on a small number of interests and stimuli at any one time. Stimuli outside the attention tunnel are missed. See Murray et al., 2005 for further information.

meaningful partnership in further knowledge generation, as autistic voices should be central in autism research (Waldock & Keates, 2022), given the impact of epistemic injustice (Fricker, 2007) upon autistic livelihoods.

We do not suggest all interventions or strategies are pathologising, but meeting an autistic individual's needs and not for non-autistic benefit. The contents of interventions and how they consider harm, epistemic injustice and agency indicate the degree to which an intervention is pathologising; for example, speech and language therapy is not inherently problematic, but if social skills are taught without consideration of autistic sociality and the oppression autistic people may face in wider society (see the social model of disability, Oliver, 1983) when using autistic sociality, this becomes problematic.

We recommend not teaching autistic people, but rather non-autistic individuals about autistic sociality, in order to lower the burden on autistic interlocutors in cross-neurotype interactions and socialisation. This particular recommendation has also been mentioned in previous literature outlining concerns on social skills training (e.g., Bottema-Beutel et al., 2018). Notably, Bambara (2022) discusses the significant level of social isolation that autistic people may face. We recommend the above to address this (e.g., bridging the neurotype gap through practices or psychosocial interventions for acceptance of autistic people and their system of interpretation, as per Jones et al., 2021).

References

- Bambara, L. M. (2022). Appreciating individual differences: A response to Beechey and Keates. *Journal of Speech, Language, and Hearing Research*, 65(4), 1604-1606.
- Bambara, L. M., Cole, C. L., Telesford, A., Bauer, K., Bilgili-Karabacak, I., Weir, A., & Thomas, A. (2021). Using Peer Supports to Encourage Adolescents With Autism Spectrum Disorder to Show Interest in Their Conversation Partners. *Journal of Speech, Language, and Hearing Research*, 64(12), 4845-4860.

- Batista, G. A. (2015). Socrates: Philosophy applied to Education - Search for Virtue. *Athens Journal of Education*, 2(2), 149-156.
- Beardon L. (2017). *Autism and Asperger syndrome in adults*. Hachette UK.
- Beechey, T. (2022). On perspective taking in conversation and in research: A comment on Bambara et al. (2021). *Journal of Speech, Language, and Hearing Research*, 65(4), 1597-1599.
- Bolis, D., Balsters, J., Wenderoth, N., Becchio, C., & Schilbach, L. (2017). Beyond autism: Introducing the dialectical misattunement hypothesis and a Bayesian account of intersubjectivity. *Psychopathology*, 50(6), 355-372.
- Bottema-Beutel, K., Crowley, S., Sandbank, M., & Woynaroski, T. G. (2020). Adverse event reporting in intervention research for young autistic children. *Autism*, 25, 322–335.
- Bottema-Beutel, K., Park, H., & Kim, S. Y. (2018). Commentary on social skills training curricula for individuals with ASD: Social interaction, authenticity, and stigma. *Journal of autism and developmental disorders*, 48(3), 953-964.
- Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2021). Autistic adults' experiences of camouflaging and its perceived impact on mental health. *Autism in Adulthood*, 3(4), 320-329.
- Cage, E., & Troxell-Whitman, Z. (2019). Understanding the reasons, contexts and costs of camouflaging for autistic adults. *Journal of Autism and Developmental Disorders*, 49(5), 1899-1911.
- Camarata, S. (2022). Balancing Respect for Individuals, Human Rights, Neurodiversity, and Positive Behavioral Support in Intervention Research for a Spectrum of Autistic People. *Journal of Speech, Language, and Hearing Research*, 65(4), 1607-1609.
- Casartelli, L., Federici, A., Fumagalli, L., Cesareo, A., Nicoli, M., Ronconi, L., ... & Sinigaglia, C. (2020). Neurotypical individuals fail to understand action vitality form in children with autism spectrum disorder. *Proceedings of the National Academy of Sciences*, 117(44), 27712-27718.

- Cole, K. L. (2021). Neuroqueering interpersonal communication theory: listening to autistic object-orientations. *Review of Communication, 21*(3), 187-205.
- Cook, J., Hull, L., Crane, L., & Mandy, W. (2021). Camouflaging in autism: A systematic review. *Clinical psychology review, 89*, 102080.
- Dawson, M., & Fletcher-Watson, S. (2022). When autism researchers disregard harms: A commentary. *Autism, 26*(2), 564-566.
- Foucault, M. (2019). *Power: the essential works of Michel Foucault 1954-1984*. Penguin UK.
- Fricker, M. (2007). *Epistemic injustice: Power and the ethics of knowing*. Oxford University Press.
- Hailes, H. P., Ceccolini, C. J., Gutowski, E., & Liang, B. (2021). Ethical guidelines for social justice in psychology. *Professional Psychology: Research and Practice, 52*(1), 1.
- Heasman, B., & Gillespie, A. (2019). Neurodivergent intersubjectivity: Distinctive features of how autistic people create shared understanding. *Autism, 23*(4), 910-921.
- Hoover, D. W., & Kaufman, J. (2018). Adverse childhood experiences in children with autism spectrum disorder. *Current Opinion in Psychiatry, 31*(2), 128-132.
<https://doi.org/10.1097/YCO.0000000000000390>
- Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M. C., & Mandy, W. (2017). "Putting on my best normal": Social camouflaging in adults with autism spectrum conditions. *Journal of autism and developmental disorders, 47*(8), 2519-2534.
- Jones, D. R., Morrison, K. E., DeBrabander, K. M., Ackerman, R. A., Pinkham, A. E., & Sasson, N. J. (2021). Greater social interest between autistic and non-autistic conversation partners following autism acceptance training for non-autistic people. *Frontiers in Psychology, 4026*.
- Keates, N. (2022). A Letter to the Editor Regarding Bambara et al.(2021), "Using Peer Supports to Encourage Adolescents With Autism Spectrum Disorder to Show Interest in Their Conversation Partners". *Journal of Speech, Language, and Hearing Research, 65*(4), 1600-1603.

- Kerns, C. M., Newschaffer, C. J. & Berkowitz, S. J. (2015). Traumatic Childhood Events and Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 45, 3475–3486. <https://doi.org/10.1007/s10803-015-2392-y>
- McCracken, C. (2021). Autistic identity and language learning: Response to Kissine. *Language*, 97(3), e211-e217.
- McGill, O., & Robinson, A. (2020). “Recalling hidden harms”: autistic experiences of childhood applied behavioural analysis (ABA). *Advances in Autism*.
- Miller, D., Rees, J., & Pearson, A. (2021). “Masking Is Life”: Experiences of Masking in Autistic and Nonautistic Adults. *Autism in Adulthood*, 3(4), 330-338.
- Milton, D. E. (2012). On the ontological status of autism: the ‘double empathy problem’. *Disability & Society*, 27(6), 883-887.
- Milton, D. E. (2014). Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism*, 18(7), 794–802. <https://doi.org/10.1177/1362361314525281>
- Monahan, J., Freedman, B., Pini, K., & Lloyd, R. (2021). Autistic Input in Social Skills Interventions for Young Adults: a Systematic Review of the Literature. *Review Journal of Autism and Developmental Disorders*, 1-21.
<https://doi.org/10.1007/s40489-021-00280-9>
- Mulhern, J. (1959). *A history of education: A social interpretation*. Ronald Press.
- Mullen, G. (2015). The Discourse on Autism. *Review of Disability Studies: An International Journal*, 11(2).
- Murray, D., Lesser, M., & Lawson, W. (2005). Attention, monotropism and the diagnostic criteria for autism. *Autism*, 9(2), 139-156.
- National Commission for the Protection of Human Subjects of Biomedical, & Behavioral Research. (1978). *The Belmont report: ethical principles and guidelines for the protection of human subjects of research* (Vol. 2). Department of Health, Education, and Welfare, National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.

- Nicolaidis, C., & Raymaker, D. M. (2015). Community based participatory research with communities defined by race, ethnicity, and disability: Translating theory to practice. *The SAGE handbook of action research*, 167-178.
- Oates, J. Carpenter, D., Fisher, M., Goodson, S., Hannah, B., Kwiatkowski, R. Prutton, K., Reeves, D., & Wainwright, T. (2021). *BPS Code of Human Research Ethics*. The British Psychological Society.
- Oliver, M. (1983). *Social Work with Disabled People*. Macmillan.
- Papaioannou, D., Cooper, C., Mooney, C., Glover, R., & Coates, E. (2021). Adverse event recording failed to reflect potential harms: a review of trial protocols of behavioral, lifestyle and psychological therapy interventions. *Journal of Clinical Epidemiology*, 136, 64-76.
- Pellicano, E. (2017). Engaging 'seldom heard' individuals in participatory autism research. In D. Milton, & N. Martin (Eds.), *Autism and intellectual disability in adults* (Vol. 2, pp. 29-34). (Learning from success series). Pavilion.
- Pickard, H., Pellicano, E., den Houting, J., & Crane, L. (2022). Participatory autism research: Early career and established researchers' views and experiences. *Autism*, 26(1), 75-87.
- Poulsen, R., Brownlow, C., Lawson, W., & Pellicano, E. (2022). Meaningful research for autistic people? Ask autistics!. *Autism*, 26(1), 3-5.
- Rifai, O. M., Fletcher-Watson, S., Jiménez-Sánchez, L., & Crompton, C. J. (2022). Investigating markers of rapport in autistic and nonautistic interactions. *Autism in Adulthood*, 4(1), 3-11.
- Sedgewick, F., Hull, L., & Ellis, H. (2021). *Autism and masking: How and why people do it, and the impact it can have*. Jessica Kingsley Publishers.
- Spain, D., Sin, J., Linder, K. B., McMahon, J., & Happé, F. (2018). Social anxiety in autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders*, 52, 51-68.

Vygotsky, L. S. (1978). *Mind in society: Development of higher psychological processes*.
Harvard university press.

Waldock, K. E., & Keates, N. (2022). Autistic Voices in Autism Research: towards active citizenship in Autism research. In S. Ryan & D. E. M. Milton (eds.), *Routledge Handbook of Critical Autism Studies*. Routledge.

Walker, N. (2021). *Neuroqueer Heresies: Notes on the neurodiversity paradigm, Autistic empowerment, and postnormal possibilities*. Autonomous Press.