

Debate: Responses to commentaries – neurodiversity, autism and healthcare

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I am grateful to my respondents for their varied and thoughtful responses to my article – and also to CAMH for the opportunity to respond to some of their points.

I thank **Rhiannon Hawkins**, as a neurodiverse person and service user, for her challenges as well as supportive comments. Dialogue including clear feedback from the experiences of autistic people has been a key part of how we have evolved in clinical thinking, language and practice over recent years; I am sure we all continue to fall short of satisfactory and many have echoed Rhiannon's point about the lack of service adaptation to autistic peoples' needs. I agree that co-production in knowledge development can be tokenistic or late on in the design process ('consultation' rather than 'co-development'), but I do believe that this is now changing, with much more writing and attention to detailed procedures for co-design, both in healthcare generally (Donetto, Pierri, Tsianakas, & Robert, 2015; Moll et al., 2020) and in autism (Fletcher-Watson et al., 2019). Rhiannon supports the call I made conceptually to separate autism from ID and give more research focus to ID. Her point on cultural expression and understanding of autism is surely relevant as we enter an era of globalised healthcare, as well as the need to respond well to the intersection of autism and cultural diversity in the UK and similar countries. My own experience of working in autism across the UK, South Asia and other countries suggests to me that there are key cultural universals in neurodiversity and autism development across cultures, but indeed the pattern of awareness and health beliefs varies greatly and needs to be understood and engaged with if we are to truly be clinically acceptable and to make a difference.

I thank **Andrew Whitehouse** for his clarity and support of the model I have proposed – and his tremendous achievement in advocating successfully for the state-wide Western Australia implementation of a pre-emptive care pathway that flows from both the model and the intervention evidence built up over two decades of trials work, including our collaboration. Implementing evidenced changes into already stretched health systems – moving from a primarily 'wait and see' or a later reactive stance, to one that is on the front foot, pre-emptive and developmentally focused – is hard! But our own experience with the pathway over the last several years, with both CAMHS and developmental community services colleagues in Manchester, is that with patience and determination such change can come, and we plan soon to report on our early outcomes from this implementation. Andrew's state-wide implementation is on a substantially larger scale and we look forward to reports of

his experience. It is also worth noting that, over the next 5 years, my group and colleagues in South Asia are also leading an NIHR-funded implementation scale-up of this kind of detection-care pathway, adapted for low-resource settings in Nepal, Sri Lanka and India (<https://sites.manchester.ac.uk/namaste/>; <https://sangath.in/namaste/>). We hope and expect that learnings from this will also be useful in our wider implementation of this pathway in the UK NHS. Colleagues who wish to partner with us in wider UK implementation of this kind are very welcome to be in touch.

Laurent Mottron and **David Gagnon** agree with much of the 'emergence' part of the model I propose but valuably push at some potential limitations or partialities. They wish firstly to balance my focus on the environmental aspects of early autistic development with an emphasis on intrinsic processes within the child's biology and brain development. This is helpful in case my paper at all gave the impression of underestimating this (which I do not). For sure there are ongoing processes of biological development, as in any infant; and an unfolding of biological difference in neurodiversity is not at all ruled out by the model I have described. This has been well described by others. The question is about the model of this biological development and how to demonstrate or test it.

Similarly, I agree with their emphasis on the role and importance of the physical environment. We have increasing awareness and understanding of differences in autistic experience of the non-social environment (and also of space and time). I referred to this in my paper with the term 'Sensorium' as indicating a fundamental quality of neurodiverse development, on which there is now an emerging literature, with, for instance, evidence of differences in auditory and visual perceptual organisation extending back into the first year. Later in development, autistic colleagues and I explored this in our own phenomenology study (Murray et al., 2023). And yes, there are important transactions here too – in the way that autistic people will wish to adjust their own environments to make them more manageable (something that can illuminate some behaviours), and in the increasing awareness of the value of adapting physical environments for well-being, whether through 'sensory diets' or sensory management in everyday life, or adapted public or office spaces for older individuals. In my own clinical work, we would pay complimentary attention to these alongside other interpersonal work.

But, accepting Mottron and Gagnon's point on the often distinctive patterns of perceptual orientation and ability in neurodiversity, their theory of a

social/non-social 'bifurcation' is more binary than I would understand it and I think underplays the continuing interplay between 'social' and 'non-social' in all development. As well as an awareness of difference, our own work and others' in phenomenology (Murray et al., 2023; Williams, Gleeson, & Jones, 2019) have highlighted the equivalent value for autistic and neurodivergent people – as anyone – of acceptance, understanding, trust and relationship. For instance, our intervention model in PACT and iBASIS aims to create a more neurodiversity-adapted early environment for infants and children, using video-feedback work with parents to help them attend to and understand their neurodiverse child's verbal and non-verbal communication intent and attune their parental dyadic responses. We do not work in this model with the child at all, but our trials show that they spontaneously respond to this adapted environment with increased social initiation with the parent – something that suggests to me an intrinsic motivation towards inter-personal engagement when the environment is right. Moreover, our mediation studies show that this social engagement is sustained after the end of intervention and is the key thing that leads to increased engagement in other social contexts as well as sustained adaptive benefits in both social and non-social domains of later development (Carruthers et al., 2023). This is a core developmental benefit I would suggest for the neurodiverse child. But it is a matter of balance; there is no evidence that core aspects of perceptual organisation within neurodiversity, referred to above within the idea of sensorium, are affected (Green, 2022).

With regard to phenomenology, I agree with Mottron and Gagnon that identifying consciousness and phenomenology before 3 years poses perhaps insuperable challenges; our only route is the traditional one of retrospective recall and building up convergent inferences through triangulating such recall with behavioural and perhaps neurophysiological observations. For older pre-school and school age children, adapted play techniques in the context of neurotypical development can begin reliably to reliably access more directly children's 'internal representations' of relationships (e.g., Allen, Bendixsen, Fenerci, & Green, 2018), and equivalent techniques could be adapted for autism. Of course as age increases, direct experience gets more accessible and adult recall gets more reliable. More attention needs to be given in addition to innovative ways of accessing experience in children with intellectual disability or complex needs. Mottron makes an important point that the phenomenology of clinician experience is also relevant here.

Regarding language acquisition, Mottron and Gagnon makes some provocative and interesting points. It has long been a clinical observation that autistic children can develop linguistic competence in idiosyncratic ways which are independent of social learning; the excellent review of Kissine et al he cites provides depth to this thought. Some aspects of the PACT and iBASIS trial results are consistent with this idea. In them, we consistently show significant impact on parent-reported language use and the social use (*pragmatics*) of communication, but less on objectively measured vocabulary and grammar. This may partly be a measurement sensitivity issue, but the results could also support a notion that joint-attention/social learning may not be

the only route into language for many autistic children (alternative routes could include statistical learning). Mottron and Gagnon's idea of adding in a specific language acquisition therapy based on non-social models (they do not detail what this would entail) is one that we have proposed ourselves as complementary (and undertake clinically in some cases) and synergistic (and we include clinically currently ourselves in many cases). What remains to be done is to test scientifically in an adaptive trial the efficacy of adding such synergistic approaches to currently evidenced early care.

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Ethical information

No ethical approval was required for this article.

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