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Knowing me, knowing you: perspectives on awareness in autism

Nicola Yuill^{1*}, Sarah Parsons², Judith Good³ and Mark Brosnan⁴

*For correspondence: nicolay@sussex.ac.uk

¹ School of Psychology, University of Sussex, UK

² Southampton Education School, University of Southampton, UK

³ School of Engineering and Informatics, University of Sussex, UK

⁴ Department of Psychology, University of Bath, UK

Abstract

Purpose: This paper raises important questions from the different perspectives on autism research that arose from a seminar on autism and technology, held as part of an ESRC-funded series on innovative technologies for autism.

Design/methodology/approach: The paper focuses on the roles of technology in understanding questions about different perspectives on autism: how do people on the spectrum see neurotypicals (people without autism) and vice versa?; how do we use eye-gaze differently from each other?; how might technology influence what is looked at and how we measure this?; what differences might there be in how people use imitation of others?; and finally, how should we study and treat any differences?

Findings: We synthesise common themes from invited talks and responses. The audience discussions highlighted the ways in which we take account of human variation, how we can understand the perspective of another, particularly across third-person and second-person approaches in research, and how researchers and stakeholders engage with each other.

Originality/value: We argue that the question of perspectives is important for considering how people with autism and neurotypical people interact in everyday contexts, and how researchers frame their research questions and methods. We propose that stakeholders and researchers can fruitfully engage directly in discussions of research, in ways that benefit both research and practice.

Introduction

Parsons, Yuill, Brosnan and Good (2015) discussed questions arising from the first of an ESRC-funded seminar series (2014-16) that is focusing on the development, application and evaluation of technologies for children and adults on the autism spectrum, and their families, entitled: 'Innovative technologies for autism: critical reflections on digital bubbles' ('Digital Bubbles' for short). The first seminar in the series explored some of the social considerations of technology development, for example, whether there are negative effects of technology use and whether maintaining a distinction between the idea of 'real' and 'digital' worlds is appropriate (Parsons et al., 2015). This paper debates questions arising from the main themes of the second seminar in the series, which focused on developmental aspects of technology research and application, specifically addressing the questions: Are aspects of development in autism best seen as delayed or different? How can developmental psychology inform understanding and intervention?

Exploring differences in perspective

The second Digital Bubbles seminar, held in March 2015, at the University of Sussex brought together academics, people working in the field in education, health and charitable sectors, parent groups and people with ASC to focus on the role of technology in understanding and supporting the development of social interaction in autism. A common theme in the talks concerned perspective, that is, how we understand ourselves as the objects of other people's attention, the different ways that technology enters into this relationship and how we might bridge gaps in understanding across the very broad spectrum from neurotypical to autistic. We use these terms to reflect those used in the positive reframing of autistic identities through the neurodiversity movement (e.g. Kapp, Gillespie-Lynch, Sherman & Hutman, 2013). The introductory address by Richard Brown, CEO of Autism Sussex, put into relief some stark figures on access to employment and services for adults with autism. For example, there are 10,000 people with autism in Sussex; and 80% of adults on the autism spectrum in Sussex are unemployed. This was an important reminder of the wider context in

which the discussion of research takes place and why research into the things that really matter to people with autism is so vital (Pellicano, Dinsmore & Charman, 2014).

Indeed, reminders about the different perspectives on autism, and on autism research, were a main feature of the day, not least in raising questions about from whose perspective research is initiated, designed and discussed. This was especially the case for our second speaker, Mark Bushby, an autistic self-advocate and member of Autism Sussex, who provided an insightful account of what 'neurotypicals' look like from the perspective of someone with autism. He described the possible diagnostic criteria for 'neurotypical disorder' such as excessive concern about what other people think of them and a delusional belief in the ability to read others' minds

(<https://neurotypicalsyndrome.wordpress.com/2011/08/04/nt-syndrome-diagnostic-criteria>). While producing good-natured humour, Mark's analysis was also a thought-provoking way of highlighting the pejorative nature of deficit-focused labelling of characteristics that many (though by no means all) consider part of natural human variation (Kapp et al., 2013).

These two talks from Autism Sussex framed the following three talks from academic researchers, who each took very different approaches to studying autism, illustrating the very diverse directions from which researchers start, both personally and in terms of theory. These different perspectives very rarely collide: papers are published in very different journals and audiences across conferences may seldom overlap, so this was a chance to compare different perspectives, one of the main aims of the seminar series.

Using virtual agents to explore eye-gaze in autism

Ouriel Grynszpan from the Université Pierre et Marie Curie in Paris, situates his research at the intersection between computer science, clinical psychology and affective and cognitive neuroscience, a developing field that seeks to use new techniques of investigating patterns of brain activity to throw light on emotional and thinking processes. He has used virtual and physical agents to assess and support social interaction in people with autism. Grynszpan's research has detected

that, when watching social scenes in a film, the eye movements of people with ASC are very different from neurotypical people, with the former showing less of a focus on the eye region of faces (Grynszpan et al., 2009). The researchers used eye-tracking information to provide immediate feedback to people with ASC about the potential effects that lack of eye gaze might have on the people with whom they interact. This was done by giving people continuous visual feedback, imposed on the image of an avatar, showing the direction of the participant's gaze towards the avatar. Grynszpan et al. (2012) suggest these virtual reality techniques might be used for training gaze. This talk naturally led to questions and comments from the audience about different perspectives on eye gaze. Firstly, there are large individual differences in eye gaze within the ASC population and people may actively choose to focus on different parts of a scene, sometimes as a way to manage visual hypersensitivities or information overload. Secondly, there is also a question about whose lead is followed: interventions such as Intensive Interaction (Caldwell, 2006) involve a therapist following the lead of a person with autism, whereas other interventions seek to teach neurotypical patterns of behaviour to people with ASC.

Using technology for exploring imitation in autism

The question of who leads and who follows was taken up in a different way by Antonia Hamilton from the Institute of Cognitive Neuroscience at University College London, whose research sits more squarely within experimental cognitive neuroscience and a formal cognitive model of social cognition, Social Topdown Response Modulation (STORM; Wang & Hamilton, 2012). Hamilton focused on the topic of social imitation in children, and on differences that occur in children with autism. There is huge current interest in psychology in how children develop the capacity to imitate for learning, e.g. to learn about the physical world, but this talk focused on social imitation – and in particular mimicry, when we copy the way someone does something, making a social connection between the mimic and the mimicked. It is an intriguing finding that even toddlers show over-imitation i.e. copying the style of an action even when it is not needed to reach the goal of an action. Children with autism showed a much lower tendency to over-imitate (Marsh et al, 2013) and

Hamilton's studies suggested complex differences in the way that children with ASC control their imitation behaviour, with links to different patterns of brain development (Hamilton, 2013). As the discussion showed, the talk was a useful reminder that we should be aware of common strengths in autism – imitating more rationally and less slavishly than in typical development -- and of the important questions it raises about what over-imitation is for, and why neurotypical people might do so much of it even when it seems irrational to do so.

Our audience were keen to see the relation between these tightly-controlled lab studies, often using virtual agents, and everyday behaviour with flesh-and-blood people. Hamilton highlighted the power of virtual reality tools to test theories in well-controlled and replicable ways, triangulated with data from more naturalistic settings. Practically speaking, virtual reality might provide a safe space in which to try out new social behaviours without offending anyone, but might not provide the social realism of the everyday world. A person with autism may often like to have a set of structured rules, but questions from the audience challenged whether this is always possible or helpful. An example was provided about reciting a joke you have heard someone else tell to great laughter, but having it fall flat. What are the subtle differences that mean a joke might work in one situation when someone else tells it, but not in another? Rules might differ between cultures and subcultures, and real interactions might fluctuate in very fluid and subtle ways. This raises questions for technology research, including: who is to determine what the 'correct' way to behave is, and can technology offer experimental control while also providing authentic and subtle (ecologically valid) contexts in which responses can be studied?

The value of researching interpersonal engagement in autism

This brought us to the distinctive cultural approach pioneered by Vasu Reddy, Professor of Developmental and Cultural Psychology and Director of the Centre for Situated Action and Communication at the University of Portsmouth. She described the long history of the concept of 'engagement', the way that living beings connect with each other: something that is hard to define

but easy to recognise. It works at all levels, interacting with things or with people –so when babies first start stepping movements, the precise dynamics of how they do this interacts with the properties of the surface they step on, and the interaction is even more powerful when it is disrupted. Parent and child show an intricate connected system of behaviour when the child anticipates being lifted from the floor. Reddy, Markova and Wallot (2013) and Trevarthen's work (Trevarthen & Reddy, 2007) woke psychologists up to the intricate 'dance' between mothers and babies in early proto-conversations, using the 'still face' paradigm, where mothers let their faces go blank during an interaction, which produces real distress in babies, and, as Reddy noted, in their mothers too. This brought us right back to Grynspan's very hi-tech approach to studying how gaze makes us self-aware, from the very different perspective of what it means to be an object of another's gaze. Reddy was keen to emphasise that being aware of oneself as an object of gaze is shown in behaviour well before psychologists have traditionally attributed 'self-awareness' to infants, and she traced the expansion of this awareness through the first two years of life. Despite this very different approach, the idea chimes with Grynspan's studies of people's responses to being an object of regard, suggesting that children with autism differ in their awareness of self.

Interviews with parents of children with autism and with Down's syndrome show that the latter engage in much more clowning and teasing in the first year of life compared to the former (Reddy, Williams & Vaughan, 2002). This raises a crucial question about intervention: Do differences in engagement mean we ought to teach people with autism how to connect or does it mean we should engage people in a wholly different manner – perhaps by engaging a bit less directly? Bushby's talk suggested that there might be a desire both for clear explicit rules, but also for allowing some space and stepping back from (neurotypical expectations of) social interaction. Comments from participants highlighted questions about how much adaptation each 'side' of the spectrum should make –why should we be asking people with ASC to look at eyes of others if they find this unsettling? How can research make use of a first-person perspective of ASC, and the second-person perspective of being in engagement, proposed by Reddy? More broadly, how should researchers,

service-providers and service-users engage with each other? Who sets the agenda and how do we communicate with each other? (cf. Pellicano et al., 2014).

From cognitivism to embodiment: a spectrum of approaches

Finally, our plenary discussant Hanne de Jaegher, from the University of the Basque Country, articulated some of the many different spectra illustrated in the talks. She highlighted new 'embodied' approaches in psychology – taking into account that thinking is not just a function of disembodied minds (a cognitive perspective), but involves the body and the environment –as in the stepping babies, whose limbs react to the surfaces they encounter (Ulrich, Ulrich & Kinzler, 1998). The closely related approach of dynamical systems, derived from mathematical theory and driven by the seminal work of Maturana and Varela (1987), treats humans as self-organising systems whose interactions with each other need to be studied dynamically within their environments, rather than in terms of static dispositions – looking at coordination of organism with environment rather than looking within the head. De Jaegher presented an enactivist approach to autism, arguing that this overcomes piecemeal individualistic approaches that separate thinking, feeling, perceiving and interacting (de Jaegher, 2013) and described a spectrum running between enactivism at one end and cognitivism at the other. The methodological implications of studying interactions rather than individuals need to be taken seriously by researchers (Yuill, 2014). This plenary talk raised questions about how this methodological range might apply to the spectrum we were here to discuss, between autism and 'neurotypical'. This question also relates to intervention, specifically: Should we 'teach autistic people non-autistic rules' or should each of us alter how we engage with the 'other', based on a more informed understanding of cultural identities and differences (cf. Davidson, 2008)? There was no resolution to these questions on the day (nor would we expect there to be) but the themes of whether and how research is meaningful for people with autism and their families, and the starting points we use in deciding what is meaningful, were clear, and echoed discussion from the first seminar (Parsons et al., 2015).

Another spectrum that became clear on the day was between the individual, with mindreading scripts in the head, and the dyadic engagement of a pair in interactional synchrony. This spectrum was reflected in each of the talks: Reddy's interviews on how parents engage with their children as objects of attention; Grynspan's work on presenting dynamic information about one's own gaze; and Hamilton's focus on styles of social imitation behaviour – copying for the sake of being the same. An additional crucial underlying spectrum is between practitioner and researcher, which was cogently expressed by practitioners in the audience, contrasting the seeking of funding for a major 3-year research programme with the everyday struggle to fund a laptop for someone with autism as assistive technology. This was another reminder about how we justify and discuss what is meaningful and useful in supporting autistic people and their families.

Importantly, De Jaegher showed us how the spectra need not be as alienating or as irreconcilable as they seemed: so Grynspan's work helps neurotypical people to see through the eyes of a person with ASC, while Bushby's explanation of what it is like to be overwhelmed by sensory information might be, for neurotypical people, imagining themselves being lost in a busy airport in a foreign country. This was described as 'thinking in autistic' (Vermeulen, 2001): taking another perspective requires considering what is relevant to this person in this moment. These themes raise questions for research: What are the useful strategies as well as challenges that have been found in developing, researching and evaluating technologies for autism? In what ways have 'users' been involved in the design, development and evaluation of the technologies? These questions were the focus of the third seminar at the University of Bath in July 2015, which examined the methodological aspects of technology research and autism.

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