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'Whose agenda? Who knows best? Whose voice?' Co-creating a technology research roadmap with autism stakeholders

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ABSTRACT

Technologies play vital roles in the learning and participation of autistic people and yet have mostly been conceptualised according to a medical model of disability. In this stakeholder review, the comments of 240 participants from a two-year seminar series focusing on autism and technology were analysed to co-construct an understanding of how research could develop more inclusively. Our socio-cultural analysis shows that stakeholders were very positive about the roles that technologies can play in many areas of life, but that these technologies need to be developed and evaluated according to the needs and preferences of autistic people and their families. We propose an inclusive common social framework for research based on the core themes of social inclusion, perspectives, and participation and agency. Such a framework requires the field to recognise that some current practices are exclusionary and that a commitment to action is needed in order to make positive changes.

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Autism; technology; participatory research; co-construction; stakeholders

Points of interest

- This article presents a new way of reviewing and producing evidence about autism and technology research.
- Over 240 people took part in a series of seminars over two years. The participants included autistic people, parents and families, teachers, business leaders, research students, research funders, and academics.
- This review is based on the comments of participants gathered using post-it notes at each of the seminars.

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- The analysis of the comments was done in a very careful and detailed way.
- Research in autism and technology needs to think differently by recognising and respecting a range of views from people with different perspectives and experiences.
- Thinking differently means doing research differently to work in more inclusive and participatory ways.

Introduction

> With computers a newly autism-compatible environment has emerged in the late twentieth century. People on the autistic spectrum have as much to contribute in this new environment as anyone. (Murray and Lesser 1999, n.p. as quoted in Davidson 2008, 801)

This quote encapsulates three big themes relating to the use of technology by children and adults on the autism spectrum, which contextualise the rationale for this article. The first big theme is the emergence of a field of research and practice that is interested in the uses and application of technologies by and with autistic people,[1] which really started to gain traction from the late 1990s onwards. Ploog et al.'s (2013, 302) review of computer-assisted technologies for supporting social communication in children on the autism spectrum shows that while there was some emergent interest in this area in the 1980s as personal computers first entered more mainstream use, there was an exponential increase in published research papers in the late 1990s/early 2000s focusing on 'autism + computers'. This strong trend shows no sign of diminishing, not least in the context of new and emerging technologies (Kientz et al. 2013). Against this backdrop, we reflect on what we have learned from the application of various technologies over the past few decades in order to understand how the field has evolved and the opportunities this affords for where it could develop next.

The second big theme is the notion that computers might be 'autism compatible'. This claim gives rise to legitimate questions about whether and why such compatibility might exist, and what this means for individuals, families, practice, and research. Certainly, and related to the strong surge in research interest identified by Ploog et al. (2013), there are often-repeated claims in the literature that some people on the autism spectrum have an 'affinity' for computers (and technology more broadly) (for example, Durkin 2010; Mineo et al. 2009), mainly because computers respond predictably to inputs in comparison to the unpredictability of human responses (for example, Swettenham 1996; Silver and Oakes 2001). Researchers in the autism field have regularly used this reported affinity as the basis for justifying technology as an appropriate medium through which to design and

implement targeted psychosocial and behavioural interventions (for overview, see Kientz et al. 2013). In other words, technology is typically construed as a tool that can be applied to ameliorate or reduce the problematic behaviours of some autistic participants (for example, Boucenna et al. 2014), or for addressing 'core deficits' related to diagnostic criteria; for example, social behaviours (for example, Grynszpan et al. 2014) and communication (for example, Boyd, Hart Barnett, and More 2015). It is important to examine whether this focus in research remains appropriate given the extensive literature available in the field, the evolution of technologies over time, and the more recent focus on neurodiversity and strengths rather than deficits in autism research (see later 'Digital bubbles' section).

Most of the many literature reviews tend to focus either on specific technologies, such as tablets, assistive devices, Virtual Reality, or social robots (for example, Schlosser and Koul 2015; Lorah et al. 2015; Parsons 2016; Pennisi et al. 2016), and/or on the rehabilitative efficacy or effectiveness of using technology to target specific areas of difficulty (for example, Den Brok and Sterkenburg 2015). In short, there tends to be a compartmentalised approach emphasising the technology itself or the kinds of skills that the technology is argued to support, rather than research that closely examines and critiques the integration of the two. Commonly, such reviews report that the applications of technology for addressing core difficulties in the social-communicative domains of autism show promise, but that there are methodological weaknesses in the evidence base (e.g. small samples, lack of comparison or control groups) and more research is required (for example, Wass and Porayska-Pomsta 2014; Kientz et al. 2013). Consequently, findings from the aforementioned reviews reveal that the field tends to be rather piecemeal, with a lack of follow-up studies or consideration of how emerging themes might be integrated. Therefore, rather than adding yet another review reporting similar findings and outcomes, our aim is to step back and reflect, with stakeholders, on ways to enable research to be more cumulative, integrated, and mutually informing of practice.

Following directly from this point is the third big theme introduced in the opening quote, which is that people on the autism spectrum have an equal role to play in the development of the autism and technology field. This is a very interesting and powerful proposition but, perhaps because of the rehabilitative focus on technology use and application highlighted earlier, one that has not yet been pursued to the same extent. In other words, the dominant approach is one in which research has been typically done 'on' autistic participants, rather than 'with' them (cf. Oliver 1992, 2013). This is a traditional knowledge transfer model of research (Guldberg 2017), which prioritises and values particular and formalised 'ways of knowing' from the academic community (Parsons et al. 2015). Consequently, the research evidence

base on the role and uses of technologies for autistic people is rather narrow and instrumental in nature, focusing mostly on improvements in skill acquisition or development based on positivist or post-positivist paradigms, and positioning technology mainly as a cognitive or behavioural prosthesis in mainstream contexts (Spiel, Frauenberger, and Fitzpatrick 2017). This is problematic because it means that there is a high risk of excluding the voices and experiences of those who, by definition, experience the world differently from those without autism (i.e. 'neurotypicals'; Silberman 2015). As Davidson notes:

> Performance in mainstream environments is restricted and restrictive by definition, and autistics have long felt pressure to study and copy majority social skills they do not 'naturally' possess. (2008, 795)

Indeed, Davidson (2008) discusses how communication online has created new opportunities and valuable spaces for the social inclusion and cultural expression and representation of at least some autistic people, thereby challenging the dominant rehabilitative or clinical thinking in relation to technology applications.

Within this context, we therefore sought to provide a different kind of review for the field, based on the participation and knowledge of a range of stakeholders, including autistic people, families, practitioners, and academic researchers from different disciplines. This knowledge was co-constructed through a seminar series that took place over two years in the United Kingdom and aimed to explore, and critically reflect on, the idea of 'digital bubbles' relating to the development, application and investigation of technology use for, and by, children, young people and adults on the autism spectrum. What is meant by 'digital bubbles' is discussed next, followed by our foci for the seminars where we addressed different 'bubbles' in turn. This article analyses the stakeholder perspectives on these 'bubbles' to provide a basis for future directions for the field.

'Digital bubbles'

We use the term 'digital bubbles' to describe the tendency for digital technology to become, or be perceived as, an isolating bubble that separates people from reality (consider the use of smartphones in everyday public spaces). We apply it here to refer to the ideas and practices that we have played roles in or witnessed as autism and technology researchers over many years (see Table 1 for a summary). First, media headlines have raised concerns about children's use of personal technologies including tablet PCs, smartphones, and games – for example:

> The five signs your child is addicted to their iPad – and how to give them a 'digital detox'. (Mail Online 2013)

Table 1. Summary of the seven seminars in the series 'Innovative Technologies for Autism: Critical Reflections on Digital Bubbles'.

Seminar	Date and location	Main focus or question(s) addressed	Related publication
Seminar 1: The Social Bubble	University of Southampton, November 2014	Whether technologies create a social bubble and, if so, do they increase social isolation, or provide helpful ways of engaging with other people in a remote way?	Parsons et al. (2015)
Seminar 2: The Developmental Bubble	University of Sussex, March 2015	How can developmental psychology inform approaches to understanding of autism (and approaches to intervention)?	Yuill et al. (2015)
Seminar 3: The Methodological Bubble	University of Bath, July 2015	What are the useful strategies as well as challenges that have been found in developing, researching, and evaluating technologies for autism?	Brosnan et al. (2016)
Seminar 4: The Technology Bubble	University of Southampton, November 2015	How do different kinds of technology support interaction and communication? What are the benefits and costs of the development and use of different types of innovative technologies (e.g. virtual reality; tangible devices; augmented reality)?	Good et al. (2016)
Seminar 5: The Disciplinary Bubble	University of Sussex, March 2016	What is it that we are trying to achieve with technology and how can we collaborate constructively across these disciplines to realise our goals?	Parsons et al. (2017b)
Seminar 6: The Diversity Bubble	University of Bath, July 2016	What can we learn from research being conducted with other groups of users and how might awareness of such diversity inform a wider agenda of social inclusion?	Brosnan et al. (2017)
Seminar 7: The Cauldron of Many Bubbles	Cumberland Lodge, November 2016	What are the key messages arising from across the previous seminars? What have we learned? What research should we be doing in the field of autism and technology, and how should we be doing it?	Parsons et al. (2017a)

> Smartphones making children borderline autistic, warns expert. (The Telegraph 2015)

Similar concerns about a 'social bubble' were raised 20 years ago when researchers started to investigate the potential of technologies for supporting the learning of children on the autism spectrum, suggesting that there was a danger of children becoming addicted (Howlin 1998) and being '… reluctant to re-enter the real world' (Latash 1998, 105). Thus, the accusation – then and now – is that technologies can create 'digital bubbles' which surround the user, such that the person is then less engaged with the real world with potentially detrimental effects. For autistic children who are diagnosed based on the existence of profound social and communication difficulties, the implied accusation is even stronger: that by using technologies for supporting learning we are somehow 'colluding' with children's disability (Parsons and Mitchell 2002).

However, given the claimed affinity with technologies noted earlier, as well as cognitive strengths in systemising (the drive to analyse or construct

physical systems) that make technology attractive and motivating for some autistic people (Baron-Cohen 2012), technology has made possible supports for some autistic people to engage socially in ways that might otherwise not be accessible (Benford and Standen 2009; Stendal, Balandin, and Molka-Danielsen 2011; Brosnan and Gavin 2015). As highlighted by Davidson (2008), the use of technology by some people on the autism spectrum has extended beyond the idea of technology as an assistive or augmentative device, even though the latter still dominates the research literature. Specifically, the neurodiversity movement has developed almost entirely online, and mostly comprises autistic self-advocates who propose, support, and defend the value and importance of autistic identities (Kapp et al. 2013). Thus, for some, the 'digital bubble' that is created through online interaction is essential and positive through enabling and empowering voice, advocacy, and participation in ways that would not have been possible without it (Blume 1997; Davidson 2008; Brosnan and Gavin 2015). Such positivity can also shade into hyperbole, however; for example, there are many claims that appear in the media, usually unsupported by research evidence, about the positive (sometimes miraculous) impacts of technology in the autism field, creating a sense of 'mythical practices that are not empirically based' (Knight, McKissick, and Saunders 2013, 2629):

> Minneapolis autism teachers 'blown away' by new classroom technology. (Twin Cities Daily Planet 2012)
> Autistic Teen uses Tech to break silence: 'I escaped my prison'. (NBC Los Angeles 2013)

Consequently, it is important to provide some balance and to critically reflect on and evaluate what the technology bubble really means from the perspectives of stakeholders.

The field of autism and technology irreducibly crosses disciplines, and this can lead to methodological bubbles, whereby research is multi-disciplinary and comprises, broadly speaking, the technology domain or the evaluation domain based within the context of interest (e.g. education, clinical practice, employment, therapy). Each discipline brings particular theories, practices, and assumptions to the research, which can be difficult to share and reconcile (for example, Zancanaro 2012). However, this means that there is a tendency for researchers to work within their own disciplinary and methodological 'bubbles'. In our experience, the field is limited generally by a lack of communication between the different academic disciplines involved (e.g. psychology, education, computer science, engineering) and between academics and the 'user community' (Pellicano, Dinsmore, and Charman 2013; Parsons et al. 2009). There is also a tendency for researchers to focus only on autism research in terms of developmental disability, or only a small part of the age range of children on the spectrum (for example, Edwards

et al. 2012). Hence, there is limited consideration of wider perspectives and needs, which could provide useful cross-fertilisation, application, and extension of ideas and knowledge.

Finally, there is a transformation taking shape within autism research more widely, which mirrors the progress made through the self-advocacy movement in the disability field over the past 30 years (Oliver 2013). Specifically, there are critiques from autistic self-advocates and researchers (for example, Milton 2014; Robertson 2009) regarding the dominance of the research agenda by people without autism and, therefore, legitimate questions raised about the validity and ethical defensibility of such research (Woods et al. 2018). In a large-scale survey of autistic people and their families, as well as academic researchers, Pellicano, Dinsmore, and Charman (2013) found that there was a mismatch between the kinds of research that autistic people felt was needed (focusing on high-quality services, education, and support) versus the focus of most research funding, which was targeted at brain and biology research. In response, Autistica, a UK research funder, has recently revised its entire funding strategy based on its own survey of priorities from the autism community, and state that: 'We believe that research should answer questions raised by autistic people and their families' (Autistica, n.d.).

This is a good example of how some areas of autism research are beginning to move to a research agenda, and a set of research practices that are more co-constructed and inclusive (Nind 2014). In such research, people who have traditionally been the subjects of research become partners in the research such that decision-making is more shared, and research agendas are more strongly aligned with the needs, interests, and wishes of otherwise marginalised groups (Chown et al. 2017). Such research requires adopting different epistemological positions relative to the more traditional knowledge transfer and exchange models of research (Guldberg 2017; Woods et al. 2018) because the ways in which knowledge is generated are different (Parsons and Cobb 2014; Rose, Carr, and Beresford 2018), complex, and often methodologically 'messy' (Seale, Nind, and Parsons 2014). Crucially, expertise through experience is valued as much as formalised knowledge shared and constructed via traditional research, and so individual perspectives, views, and experiences are essential ingredients in co-construction (Nind 2014). These considerations directly informed our 'digital bubbles' seminar series and the curation of stakeholder perspectives that provide the data analysed in this article.

What follows is an overview of the methodology of the seminars, including how data were generated for analysis. We utilise a socio-cultural lens for the analysis and discuss the findings within a Freireian (1970) conceptual framework. Freire (1970) challenged the dominance of power in education,

and the reification of practices that exert control and dominance over disadvantaged and marginalised people by those in power, to propose radically different ways of enabling and empowering individuals to transform the world through their own reflection and action. Specifically, he argued that leadership in education should be 'co-intentional' (1970, 51), in which there is a more shared understanding and investigation of reality between 'teachers' (those who hold more power) and 'pupils' (those who hold less power) that avoids authoritarianism and conformity. The educational focus adopted by Freire is relevant because we use it here to frame and inform the learning that we propose would be transformative within this field. Moreover, technologies offer a very flexible set of tools through which reflection and action can take place, thereby applying Freire's analysis to contemporary debates.

Research process

We organised seven seminars over 24 months at intervals of roughly three or four months between November 2014 and November 2016 in the United Kingdom, each focusing on a digital bubble within the autism and technology field. Each of the seminars has been summarised and published in short papers and the references for these, as well as the main topic of each seminar, are included in the overview presented in Table 1.

Seminars and participants

Participants were asked to sign up to attend the day and were made aware that places were limited. Including the organisers, we restricted attendance to a maximum of about 40 people for each seminar in order to facilitate plenty of discussion on the day. Each seminar included four to five invited speakers, who were academics, parents, autistic individuals, or practitioners (and of course, they could have one, some, or all of these identities). Some speakers, as well as some of the participants, were international (from Europe, the United States, and Turkey). Other participants were local community stakeholders (autistic people, families and carers, professionals, and practitioners), from national and local autism organisations, representatives from the technology industry, autism research funders, and academic researchers. Thus, at each seminar there was a mix of people who self-selected for participation and those who were invited by the organisers.

In total, 240 participants attended and we supported 50 travel bursaries to enable postgraduate, early career researchers, and community stakeholders to participate. A particular success of the series was the sustained involvement of autism stakeholders, and early career and postgraduate

researchers throughout, enabling them to contribute to and participate in these discussions.

Data collection

Each seminar was scheduled to support group discussion throughout the day; for example, a 30-minute talk followed by 15-minute discussion in small groups, and then plenary feedback. During each group discussion, and at any point during the day, participants (including ourselves as organisers) were encouraged to write on post-it notes any main points, pertinent comments, or burning questions or issues that arose. They/we would then put these up on the wall so that a set of comments was generated during the day and other participants could see what was being written (see Figure 1). This was a very simple, yet effective, method for generating comments and feedback as no-one had to contribute orally if they did not want to and no judgement or prioritisation was made of any comments during the seminar. Moreover, it was appropriate for our notes and comments to be included in the mix since this was conceptualised from the beginning of the series as an opportunity to co-construct our understanding and interpretations of the field. In short, all contributions were welcome.

These post-it notes were collated at the end of each seminar, and shared through summaries on the project website (www.digitalbubbles.org.uk), although these summaries were not systematically organised or analysed. The post-it notes were an important source of information since they provided evidence of scrutiny and reflection on the invited talks and ensured that everyone who attended a digital bubbles seminar had the opportunity to voice their views or queries, anonymously, if they wished.

Figure 1. Example of post-it notes used to collect comments and feedback during the seminars.

Analysis

Conceptual framework

Our approach to the analysis drew upon the socio-cultural activity theory (AT) framework of Engeström (1987; extending from Leontiev 1978), which is rooted in the traditions of Vygotskian social-constructivist understandings of learning and development. AT considers the people and practices involved in any system or form of activity as well as aspects of the environment and culture. Put simply, the theory proposes that human consciousness is located in everyday practices, which are located within social contexts. An activity is given meaning by the social context in which it is carried out, and the context comprises both people and artefacts/tools that make up activity systems (Russell 2004). The AT framework gives prominence to the role of tools as mediating artefacts that influence and shape thinking and practices. Tools can be physical (e.g. textbooks, pens, documents) or psychological (e.g. language), and the activities of their use are directed towards a particular object of the activity (e.g. writing a letter, getting to the shops, making yourself understood). In other words, there are motives that drive mediated activities, and these activities may result in different outcomes, which in turn shape thinking and practices. Thus, a particular activity comprises dynamic relationships between people (Subject, Community, Division of Labour), the factors that constrain or support the activity (Rules), the mediational tools (Tools), and the Object(s) and Outcome(s) of the activity. These relationships are depicted in Figure 2, from a conceptualisation by Engeström (1987).

Given our current focus, technology represents a very powerful range of mediating tools that shape social processes in important ways and so AT is a very useful framework to apply. The AT framework also provides a coherent approach to analysing data according to the wider socio-cultural lens that we were interested in through the seminars.

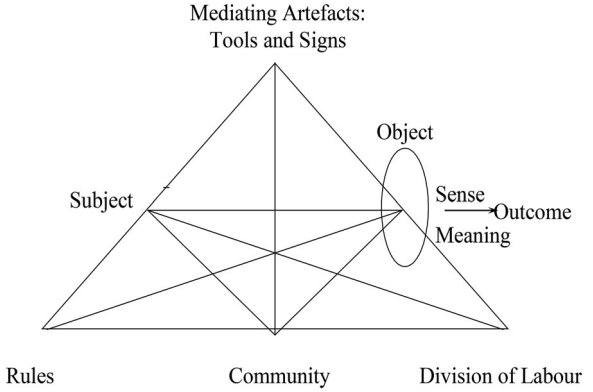

Figure 2. The core structure of a human activity system (Engeström 1987, 87).

Table 2. Summary of main findings and key questions and implications for research.

Activity theory category of analysis	Main findings	Illustrative quotes from stakeholders	Key questions for research	Implications for research practices	Implications for social and research policy
Subject: whose perspective(s) do we need to consider, and what might those perspectives reveal or mean?	Much research and thinking about autism comes from a 'neurotypical' perspective, but we need to strive for a better understanding of the benefits and limitations of technologies from the perspectives of the people who use them There is a need to challenge traditional, normative assumptions, and start from a different place in our thinking The assumption that autistic people may be especially vulnerable or socially disadvantaged by engaging with technologies is important to challenge. There are many benefits reported and, as for all users, there should be appropriate and balanced recognition of pros and cons	'Getting the first person perspective (from people with ASD) about what is appropriate to focus on is really important' "'Neurotypical syndrome' – assuming their way is the right way and that way is superior' 'Whose problem is it? If the person with ASD is happy to mainly communicate online is this a problem for them?' 'How far is society moving towards digital communication and are we all within our own social bubble?'	What does it mean for everyone to be social in a technology-enabled world? Where or what is the 'social deficit' when using technology? Where, and for whom, is the social isolation? How can technologies be used to help non-autistic people understand the views, perspectives, and experiences of autistic people? Or, what role could technologies play in addressing the 'double empathy problem' (Milton 2012)?	Starting point for framing research questions should come from the needs and contexts of autistic people, their families, and other stakeholders, rather than only from research Consequently, much stronger collaborative working between academics and the wider autism community is fundamental for moving the field forward (e.g. Parsons and Kovshoff 2019)	The United Kingdom's industrial strategy (Department for Business, Energy and Industrial Strategy 2017) is clear about the grand challenges that it seeks to address in the United Kingdom, including the application of innovative technologies to support healthy ageing, and using artificial intelligence to transform the global economy. Including autistic perspectives and expertise in meeting the challenges would be a major strength (e.g. through the new UK Parliament Knowledge Exchange Unit)
Community: who is involved?	The involvement of people across the diversity of the autism spectrum can bring many strengths and creativity to the technology design and development process	'Users need to understand what academics do, teachers + parents should understand about the design implementation' 'How can innovative technologies be used in	What are the wider cultural implications for research questions and findings with respect to geographical, linguistic, social, and personal diversity (including, age,	Avoid assumptions of mono-culturalism, and over-generalisation of claims Collaboration should not only recognise and include the diversity of the autism spectrum, but also seek	Existing limitations of narrow cultural assumptions in the autism evidence base need to be fully acknowledged Actions must be taken to broaden representation of diverse voices and

(*continued*)

Table 2. Continued.

Activity theory category of analysis	Main findings	Illustrative quotes from stakeholders	Key questions for research	Implications for research practices	Implications for social and research policy
	Challenges remain in how such diversity can be appropriately integrated and managed within technology-oriented participatory design processes Schools and teachers as gatekeepers and stakeholders require particularly careful consideration. Schools should not simply be construed as testing sites for technology developers	different cultures? Can all these methods be transferred in a different language environment?' 'What does [the] school get? It's not a zoo!'	ethnicity and gender)? What methods and practices can enable the participation and engagement of the most marginalised and excluded voices? In what ways are questions, methods, and evaluations shaped through the involvement of educators from the start of technology development processes?	comparative, multi-cultural, and international perspectives Educational contexts, especially schools and teachers, should be involved as partners in research rather than positioned as passive testers and recipients of it	experiences in research and consultations that are commissioned. For example, the 2019 consultation on the Autism Strategy in England only allowed for written responses to online or print survey questions Autistica.org.uk provides an example of how different views are being sought and the under-representation of some groups in autism research is being tackled
Division of Labour: how is or should the work be distributed?	The diversity of the spectrum should be recognised through acknowledging the differing perspectives that individuals will bring. Advocating for, and enabling, different perspectives (e.g. by parents, older, more verbally expressive people) is important, but is not the same as including first-person perspectives of autistic people Not everyone wants to take an active role in research. There are other ways of supporting and	'Participatory design needs to be creative to include less able children with autism in the process' 'Should/can HFA [high functioning autism] people advocate for LFA [low functioning autism] people?' 'How can we match those who see solvable problems with those who can engineer solutions?'	In what ways can multi-disciplinary groups, including stakeholders, work or interact together to develop and use technologies for shared purposes? How can we more effectively enable support, mediation, and participation through the use of technologies as tools for engagement and communication within participatory design?	Open, accurate, and reflective identification of roles, assumptions, and expertise is needed Methods need to respect a range of preferences, as not everyone may wish to comment or be involved in everything, or be involved in the same ways Clear communication and clarification of project objectives from the outset, and throughout, are essential	Research and project funders in all sectors can actively promote and encourage participatory approaches to project design, development, and completion Policies for funding should recognise the value of a range of inputs and methodologies for supporting wider participation

	encouraging engagement and support that do not pre-suppose or require co-creation				
Rules: what are the factors that support or constrain participatory design?	Everyone involved will have different views about the issues that need to be addressed All views matter and add value, but there should be appropriate recognition of the need to prioritise the needs and views of autistic people and families in deciding research agendas Those who may be gatekeepers within participatory design processes need to ensure inclusive, rather than exclusive, approaches The overall cost, as well as the personalisation, of new technologies might be prohibitive and exclusionary	'Programmers as gatekeepers' 'Personalised technology might be excluding' 'The technology clearly has a role to play – but is it prohibitive due to cost? How can we make it more available?'	What are the needs and priorities of autistic individuals and families in relation to technology use and development? How might these needs and priorities be met through the investigation and development of existing and/or readily available technologies? In what ways can longer-term research horizons (blue-sky thinking, new technologies) enable these needs and priorities to be met?	Value for money, and impact, relevance, and availability for individuals are vital considerations These considerations need to be balanced against the push towards innovation and blue-sky thinking Research innovation is important as well as meeting everyday needs, and so research teams should plan for ways in which more experimental (blue-sky) prototypical approaches can be made more available and accessible for everyday use	The priorities for project development and research set by funders should explicitly recognise the importance of agendas led by the autism community
Object of the activity: what technology is being made, might be made, and what are the assumptions about what is made (and how)?	Participatory design of technologies in the autism field is essential There are many ways in which technologies can be enabling, motivating, engaging and fun. Technologies can support choice, agency, identity, individual preferences, and communication in a range of ways The participation	'Technology can open doors to communication' 'Depending on the aim the process may be more important than the outcome' 'Real life is not necessarily distinct from digital life if it has similarly meaningful experiences!' 'Are traditional scientific methods such as	How can researchers and practitioners take a wider view of what is happening within and around the technology to support e-inclusion (Abbott 2007)? How can technologies be used to enable connections and interactions with others in a range of ways? How can we enable fun, play,	Participatory design (as a range of approaches) should be an essential starting point for research projects in this field. These approaches should document and value the engagement and development of the process of the design (and the benefits/challenges experienced therein) as	The importance and use of technologies in everyday life for many people move beyond narrow economic interpretations of intervention or assistance (see Burch 2018). Fun, play, leisure, and friendship are all vital aspects of technology use that need to be fully recognised A more

(*continued*)

Table 2. Continued.

Activity theory category of analysis	Main findings	Illustrative quotes from stakeholders	Key questions for research	Implications for research practices	Implications for social and research policy
	in the process of technology design and development may be as rewarding, if not more so, for individuals than the more specific outcomes research teams may hope to achieve There is a fundamental interconnectedness between uses and functions of technologies and the 'real world'. Maintaining artificial distinctions between 'digital' and 'real' is outdated and likely to be limiting for the field	randomised controlled trials of use here or not?'	creativity, lightness, and subtlety through the development, application, and exploration of technologies (new and existing)? In what ways could broadening our ideas of positive engagement and indicators of success enable a more holistic understanding of the person or child?	much as what is produced and what the outcomes may be Research needs to more fully recognise and explore the rich variety of ways in which people are using technologies in their lives, and broaden out from the narrow focus on social communication and interaction, and skills/ behaviours Research designs that assume a distinction between 'digital' and 'real' require critical evaluation	inclusive and expansive understanding of this could be recognised through special educational needs and disability legislation (for example, Department for Education/Department of Health 2015) that guides approaches to support and learning
Outcome: what does the autism and technology field as a whole hope to achieve?	It is important to reflect on whether and how we know that what we do really makes a difference to people's lives and experiences. Those experiences must be of value to those taking part This could be from the perspectives of individuals with autism, parents and families, and practitioners, as well as from the perspectives of professionals who may wish to use technologies	'How can we better link the pool of talent that autistic people are with the essential technical and engineering roles that they can so aptly fulfil?' '"An inclusive common social framework" as opposed to an "interventionist medical model"' 'Ethics and responsible innovation'	What does responsible innovation mean in the autism and technology field? How can we more appropriately define, identify, and characterise 'outcome' measures that matter to individuals, families, and other stakeholders? How can we ensure that the processes and purpose of participation are valued as much as possible eventual 'outcomes'? Through a focus on strengths,	Work with stakeholders to generate new frameworks for participation and evaluation Adopt and develop more inclusive approaches to research that move away from a dominance of decontextualised, one-off experiments towards a more consultative and context-aware range of methodologies	Commercialisation and innovation strategies for the development of new technologies need to be mindful of the need for responsible innovation and ensure that intended outcomes for technology use are in line with user needs and preferences. Commitments to these principles can be included in objectives for delivery plans (e.g. via Innovate UK [n.d.] strategy) to ensure commitment to action

	to support individuals and families in a range of ways Focusing on strengths, creativity, talents, and positive flourishing is very important for the field There is a need to think very carefully and ethically about what it is that we are really trying to achieve with our work, and why		creativity, and talents, what and how could we design differently?		
Tools: what technologies are being or should be used, developed, and tested?	Online spaces, including social media, can be powerful for enabling communication, friendships, agency, and choices Online communication and interactions have value in their own right, and can also be stimuli for face-to-face initiation and interactions Digital and face-to-face communication and interactions are important There is a need to consider the features and uses of existing technologies in order to understand the value and relevance for individuals	'What [technologies] are people with ASC [autism spectrum conditions] really using?' 'Social media – less information, asynchronous. Face-2-Face unpredictability, less control' 'Is modifying existing tech better than inventing new tools?' 'One of a box of tools that can be useful depending on individual need' 'Technology can never replace human contact and learning. This must be used carefully with ASD'	In what ways are existing technologies being used by autistic people, and for what purposes? What technologies would autistic people like to see developed, and for which purposes? In what ways can technology-based interactions and activities support face-to-face communication, and vice versa?	Co-design of projects using participatory methods is vital for informing research agendas. These agendas should consider what and how technologies are currently being used, as well as what is needed or desirable for development Evaluation must be amenable to the range of interactions and uses that occur within, through, and around the technologies in order to really understand needs, preferences, benefits, and challenges	Policies for shaping the direction of research and innovation need to be sufficiently context and user aware to prioritise where new developments are needed and avoid unintended consequences of technology withdrawal or lack of support (where useful technologies are already valued by users)

Practical steps

Following the end of each seminar, all post-it notes were collated and transcribed as a list of individual comments in a single Word document. Each of these documents was first printed as a hard copy and then uploaded as a source document to NVivo qualitative data analysis software (QSR International Pty Ltd. Version 10, 2012). The analysis proceeded according to a series of steps, designed to be both a reliability and validity check as well as a collective curation of views and interpretations between ourselves as seminar organisers and co-authors. The latter was important to try to mitigate any dominant voices that may have arisen through the creation of the post-it notes (including our own) and/or through the early stages of analysis. The steps of the analysis are summarised in Appendix 1. We next present the results according to the main AT categories, followed by a discussion of the overarching interpretive themes from the data, drawing upon Freire (1970).

Results

The activity system of interest here was the autism and technology field of research and practice. The findings are summarised under each of the main AT categories in the following and relate to this field. Some comments were from autistic people and some not, but we do not and could not separate these (unless the perspective is clear, as with the first comment). Table 2 provides a summary of the main findings alongside key questions and implications for research and practice.

Subject: whose perspective(s) do we need to consider, and what might those perspectives reveal or mean?

This theme explored the relationship between the perspectives, needs, and experiences of autistic people and those of non-autistic people (i.e. those who are 'typically developing' or 'neurotypical'). The assumed differences are keenly experienced by autistic individuals:

> 'Neurotypical syndrome' – assuming their way is the right way and that way is superior.

However, many participants questioned the nature of this difference and others considered the extent of such purported differences:

> What is social isolation for people with autism? Is this different from social isolation from neurotypical people?
> How far is society moving towards digital communication and are we all within our own social bubble?

Further, the tendency for there to be a unidirectional focus on who uses what technology, and for what purposes, was questioned:

> Rather than using technology to enhance individuals with ASCs' [autism spectrum conditions] understanding of us, can we use technology to enhance our understanding of them?

When designing technology, it is crucial to consider the full range of potential stakeholders. This is not simply to ensure that the technology designed is appropriate; rather, there are much deeper implications in terms of who sets the agenda for research and technology design in the area, and who determines what goals we are trying to achieve as a community:

> Who knows what is 'best' or most 'appropriate'?
> Getting the first person perspective (from people with ASD [autism spectrum disorder]) about what is appropriate to focus on is really important.

Ensuring that the autistic voice is represented in design decisions was noted as crucial due to potential sensory issues, as well as differences in focus and/or motivation. For example, participants raised issues relating to colour; sounds; preferences for focusing on different aspects of an image, scene, or object; different ways and tempos of learning; and how anxiety may influence responses. Thus, the heterogeneity of autism in conjunction with the aspiration to meet individual needs was recognised as a major challenge:

> If everyone is different, can we make general statements?

The participatory nature of this challenge was further highlighted in relation to the appropriateness of such a methodology for certain users, either because of their age or limited interests:

> What is it that children bring to the design problem that is so good that adults don't?

Community: who is involved?

Participants commented that involving members across the autistic community (verbal and minimally verbal; children and adults) as well as the broader autistic communities (parents, practitioners) within interdisciplinary research and technology development practices brings many strengths – for example:

> creativity of people with autism – ask them to solve problems.

Challenges were also mentioned, including managing constraints (such as time and resources) across differing priorities from different stakeholders, which entails careful management of expectation and compromise. For example:

> Users need to understand what academics do, teachers + parents should understand about the design implementation.

The complexities of integrating interdisciplinary perspectives can be challenging for some stakeholders, whose views may need to be represented by advocates, without resorting to token involvement: '"Small steps" vs "tokenism"?' Ensuring cultural diversity (ethnicity, class, gender) within the autistic and broader autism communities is also central to inclusion:

> How can innovative technologies be used in different cultures? Can all these methods be transferred in a different language environment?

Schools represent an environment within which inclusive design approaches to digital technology are frequently attempted. Within this context, teaching professionals are clearly major stakeholders as well as gatekeepers. Clarity concerning the benefits that developing digital technology may bring for learning is crucial for ensuring staff engagement:

> How do we support teachers in learning about how different technologies may be beneficial in supporting collaboration (& learning)?
> What does [the] school get? It's not a zoo!

The digital technologies developed should encourage and enhance interaction with the broader community, such as family, friends, and professionals, and should reduce, not enhance, social isolation:

> Social isolation can be improved by the use of technology AND someone to share with.

Division of labour: how is or should the work be distributed?

The central theme was how best to ensure autistic voices are accurately represented within the design and development of digital technologies, such that these voices are dominant in determining what is appropriate to focus on. One intervention, intensive interaction (for example, Nind and Hewett 2012), was mentioned as a good example:

> Intensive interaction is about following the lead of the child/person (i.e. the impetus is the other way around).

Autistic adults relatively rarely engage in the design and development of digital technologies, and this was noted explicitly:

> We have talked a lot about children (+ adolescents) and not much on adults. What issues from today are relevant in adult population?

Similarly, minimally verbal members of the autistic community rarely take a direct role within participatory design: 'PD [participatory design] needs to be creative to include less able children with autism in the process'. This

raises questions about whether verbal members of the autistic community are or should be potential advocates for minimally verbal members – 'Should/can HFA [high functioning autism] people advocate for LFA [low functioning autism] people?' – or whether parents are in a better position to be an advocate for their minimally verbal children. Identifying and communicating what is possible is crucial, as well as drawing upon relevant expertise:

> How can we match those who see solvable problems with those who can engineer solutions?

One solution is to support key stakeholders or users of technology and research (e.g. parents, teachers, and autistic people) to be active contributors, whilst also being sensitive that this may not be an aspiration, or desirable role, for some.

Rules: what are the factors that support or constrain participatory design?

A participatory design process enables ideas, suggestions, and perspectives to be integrated, developed, and dropped. Typically, someone who has initiated the process (such as a researcher who has been awarded funds though a funder) will lead on the coordination of the process. The issues to be addressed within projects are also often determined by researchers, rather than the wider autistic community, leading to genuine questions about appropriate representation and contribution. This includes acknowledgement that parents, practitioners, clinicians, and researchers all have different relationships with members of the autistic community and may have different perspectives on what issues need to be addressed. These, in turn, may differ from the views of autistic people themselves:

> Whose agenda? Who knows best? Whose voice?
>
> Programmers as gatekeepers.

Tensions were also highlighted between the value of individual and personalised solutions and whether these could support inclusion:

> Personalised technology might be excluding.
> Everyone is an individual. Does 1:1 technology isolate individuals?

Thinking about how technology can be facilitative and enabling for autistic people, there is limited value in designing and developing technologies that are unaffordable. Cost is a major consideration to ensure that the autistic community and related professions can access the technologies which they have helped to design and develop:

> The technology clearly has a role to play – but is it prohibitive due to cost? How can we make it more available?

In addition, training to use technologies can also be a crucial determinant of successful uptake of the technology:

> Need of training for families and professionals to use tech to full potential not toys.

Object of the activity: what technology is being made, or might be made, and what are the assumptions about what is made (and how)?

Reflecting many of the comments already noted, participants were clear that one of the main objects of activity within the autism and technology field should be participatory design itself. The importance of technology for expression and engagement was also a very common thread. Comments mentioned motivation and many related terms such as social communication, interaction, encouragement, wishes, opportunities, freedom, and choices (including the choice not to engage). The power of technology to support communication in a variety of ways featured strongly here:

> Technology can open doors to communication.

Individuality was again highlighted as a key aspect that needs to addressed by the field, with personal, individual, and differentiation being mentioned in almost every comment coded within this category. Comments also highlighted different aspects of participation and process; for example, placing value on the experience of being involved in the development and design of ideas and activities, rather than only on the outcomes for learning that may or may not be supported by the technological tool:

> Depending on the aim the process may be more important than the outcome.

One of the largest categories regarding the object of the autism and technology field raised questions about the validity of fundamental assumptions that are typically drawn, notably the real/virtual distinction and its relevance or redundancy:

> Real life is not necessarily distinct from digital life if it has similarly meaningful experiences!
> How do we measure transfer of skills from the lab to the world?
> Does communication transfer across all environments? Should we take our bubble with us?

Comments also related to whether there is a 'right' way to interact, with technology and with each other, and whether a 'technology' versus 'everything else' distinction can or should be made. Some questioned whether technology can compensate for, facilitate, or replace 'real' interactions: 'Much more important as a tool for facilitating human – human interaction'. This category also included the difficulty of evaluating interventions

and designs, and how we know whether and why an intervention might have helped: 'are traditional scientific methods such as randomised controlled trials of use here or not?'

Outcome: what does the autism and technology field as a whole hope to achieve?

The need to respect and reflect autistic skills and strengths emerged as an important issue. There is often a focus on the significant challenges inherent in the field; for example, how to address the high unemployment rates and underemployment of autistic people (for example, Baldwin, Costley, and Warren 2014). Without denying these challenges, a focus on strengths considers how to prioritise the invaluable contributions that autistic people can make to the development of new technologies:

> How can we better link the pool of talent that autistic people are with the essential technical and engineering roles that they can so aptly fulfil?

When looking at ways in which technology use can become more widespread, it is important to start at the design stage, considering how ideas move from concepts to reality. Once developed, there should be a continued focus on how these new technologies are adopted and appropriated by their intended users, so as to try and avoid a situation of 'technology left "on the shelf"'. However, concern was expressed in relation to the extent to which current funding mechanisms are able to support all stages of this process:

> Practicalities: research funding may not cover the whole lifecycle of a project through to 'wild' deployment. May not support follow up documentation support for users.

Concurrent with maximising technology reach is the idea of how the field can move forward in positive, innovative, and even disruptive ways. Technology design can function as an iterative process, allowing researchers to learn more about and better understand the nature of autism and, in some cases, to challenge accepted methods for evaluating the effectiveness and outcomes of research and intervention. At the same time, technology development can facilitate changes in pedagogy and intervention, acting to support the empowerment and self-determination of its users. It is important, however, that these initiatives do not, themselves, exist in their own bubble:

> How do we disseminate these positive notions of the functions of technologies to the wider public society, to distil the notions/conceptions of 'technology = bad'?

Technology design does not exist in a vacuum, it is part of a broader context which includes human contact and learning. Inherent in every design decision are a number of ethical, social, and cultural assumptions which

need to be explicitly considered. Participants suggested that 'ethics and responsible innovation' should be the guiding concepts with respect to technology development in this area, focusing on things 'that really matter'. One participant noted that this involves adopting '"an inclusive common social framework" as opposed to an "interventionist medical model"', which respects the schools/centres/individuals involved, and values the participation of the autism community.

Tools: what technologies are being, or should be used, developed, and tested?

Many comments related to online communication and interaction via social media. Specifically, that autistic people can have more control over interactions via online media, including its pace, and the impact of sensory experiences, compared to face to face. In turn, having control over these aspects can lead to a reduction in anxiety:

> Social norms on social networks are more stable than face-to-face interactions. Everything is on record and you can copy that norm e.g. you can go back to instances of similar conversation, see the response and consequences, work out the preferred or better responses and then decide what to do. You can't do that in real life. There is no time to record, no help in face-to-face settings.

Rather than seeing social networking sites as isolating individuals, many felt that they had huge potential in allowing people to practice and learn about social skills which they might later be able to apply in face to face interactions:

> … getting to know people through the Web first works well. You'll know who is likely to behave in a predictable way so it's 'safe' to work with in real life. That's when you can leave the bubble.

Social networking sites were also seen as levelling the playing field, in some sense: 'Everybody's autistic online!' However, others cautioned against broad-brush comparisons: 'An online world is neither better nor worse than a "real" world'. Participants talked about the role of technology in facilitating simultaneous face-to-face communication, while still advising caution:

> Really interesting to see how technology can promote social *initiation* (both robot and Virtual Reality). I think it's worth researching that aspect deeper. (original emphasis)

Participants were also keen to identify the importance of function, the purpose, of context of use:

> In order to move forward as this field, we really need to move away from the 'technology versus non-technology' debate. It's about the affordances of particular objects, situations, activities, and whether they motivate engagement and

communication (and enjoyment!). It might be a high-tech environment, but it could equally be a bubble wand.

Indeed, some participants acknowledged that many of the benefits of social networking sites could apply to technology in general; for example, providing more control over the pace of an interaction and/or activity, as well as over sensory inputs. The question of which technology tools to use and develop is key, not least because of the rate at which technology is advancing. This suggests a careful consideration of the current landscape in terms of technology usage, as well as a focus on both user needs and wants:

What are people with ASC really using?
What do autistic people actually want/prefer?

A number of different types of technology were mentioned:

Social media – less information, asynchronous. Face-2-Face – unpredictability, less control.

Different needs or lack of literacy but can use symbol systems.
Importance of hardware as part of context (and embodiment).

Given these factors, it is important to consider whether the focus should be on new technology tools at all: 'Is modifying existing tech better than inventing new tools?' One possible solution focuses on giving users the ability to create their own environments: 'authoring of environments is key!'

Discussion

The seminars, and the stakeholder comments generated therein, provide important, co-constructed perspectives on the autism and technology field of research and practice. The socio-cultural analysis utilised reflects and communicates a much wider, as well as more nuanced, understanding of the drivers, activities, and motivations in the field than typically reported elsewhere in the literature. Crucially, participants indicated that the processes and experiences of engagement and participation were valued as much as (if not more than) any possible, more formalised, indications of 'outcomes'. It was also evident that participatory design as a core focus for action was taken as a given; that is, autistic people should be more involved in decision-making and design of technology in the autism and technology field. However, stakeholders were also clear that challenges remain in how representative such involvement can or should be and, therefore, who should be involved in such decision-making and development. The lack of representation of autistic people who do not communicate via speech, and the importance of recognising the variety of ways in which communication takes place, were regularly raised issues. Relatedly, responsible innovation was highlighted both in terms of which technology tools should be the focus of

research and how the places and participants of research are involved and respected. Especially pertinent here were comments relating to schools not being 'zoos' and the rejection of an 'interventionist medical model' approach to research, including the idea of whether randomised controlled trials are appropriate for determining what 'really matters' to autistic people and families.

Our participants questioned fundamental assumptions that underpin approaches to research in the field, not least what was commonly perceived as the perpetuation of an inappropriate and unhelpful dichotomy between technology on the one hand and the real world on the other. In line with other commentators (for example, Eklund 2015), the validity of this distinction was strongly critiqued. Notwithstanding the power and value of such a critique *ipso facto*, there are also important ramifications for the nature of research questions posed in the field and the methods and research designs used to address them. Specifically, if there is questionable validity regarding the dichotomy between real and digital, then a research paradigm premised on training skills in the digital with the aim of generalising or transferring to the real becomes problematic if the sole basis for judging value lies only on eventual 'performance' in the real world. Such assumptions may limit the otherwise numerous available opportunities for learning and development that occur through, within, and around technology use; as emphasised in Abbott's (2007) conceptualisation of 'e-inclusion', for example.

Our data from 240 participants suggest there are three main overarching themes that characterise the discussions which took place (as recorded via the post-it notes) and the findings that emerged from the socio-cultural analysis. These main themes challenge researchers to think (at least in some cases) differently about the nature and direction of research and practice regarding: social inclusion, perspectives, and participation and agency. We suggest that these three themes could underpin an 'inclusive common social framework' for advancing the field, as envisaged by one of our participants. These themes chime very loudly with Freire's (1970) seminal work *Pedagogy of the Oppressed* in which he challenged the dominance of power in education to propose a more shared, co-intentional, approach to enabling learning and transformation. Applying Freire's lens to the autism and technology field, autistic people have been, and in many ways continue to be, the oppressed in Freireian terms, not least because (usually non-autistic) researchers have traditionally held all the power and autistic people have not always been involved in ways that move beyond the role of passive participant. This is beginning to change in some areas (for example, Beck 2018; Chown et al. 2017; Fletcher-Watson et al. 2018) but such approaches represent the exception rather than the norm.

Social inclusion

Social inclusion as a core concept for the autism and technology field is informed by Freire's (1970) emphasis that the world is not a given reality to which adjustments are made but, rather, something which human beings act upon and transform (ontologically, of course, this argument also has an extensive mirror in research philosophy). Specifically, Freire argued that an individual's reflection on action (praxis) is central for human development, flourishing, and the generation of knowledge:

> For apart from inquiry, apart from the praxis, individuals cannot be truly human. Knowledge emerges only through invention and re-invention, through the restless, impatient, continuing, hopeful inquiry human beings pursue in the world, with the world, and with each other. (1970, 53)

Similarly, AT explicitly posits that human behaviour in the world is mediated via physical and psychological tools that are of human invention. Technologies are particular kinds of tools that mediate human behaviours and, as such, cannot be considered separate or distinct from human actions upon the world. From our own data, autism stakeholders emphasised that technology is a part of everyday ('real') life, not separate from it, and often does function as a means for shared interaction and/or initiation of communication in valuable ways. Technology-mediated spaces, especially online, were considered places that recognise and respect autistic strengths and preferences, and technological tools were agreed to be important for the many varied and different means of expression, engagement, and empowerment across a diverse range of needs.

Important questions were raised about who is defined as having the 'problem'; whether this should be characterised as a 'problem' in any case and, therefore, where and for whom does the 'problem' lie? Such questions are also represented in Milton's (2012) characterisation of the 'double-empathy problem', which discusses that the 'problem' (and, therefore, answers provided by research) is generally identified as being located within the autistic individual; that is, as the person having difficulties in understanding and communicating within neurotypical assumptions and contexts (Beck 2018). However, as one of our stakeholders said: 'Rather than using technology to enhance individuals with ASCs' understanding of us, can we use technology to enhance our understanding of them?'

Perspectives

This point links strongly to the second main theme of 'perspectives', which relates to where the dominant agendas and voices in the autism and technology field lie and who contributes, or not, to those. Freire conceptualised the dominance of perspective as 'cultural invasion', namely:

> One cannot expect positive results from an educational or political action program which fails to respect the particular view of the world held by the people. Such a program constitutes cultural invasion, good intentions notwithstanding. (1970, 76)

Seminar stakeholders highlighted how important it is to critically examine the cultural assumptions embedded in the field; for example, questioning 'is there only one right way to communicate?' and whether there should be 'Theories of mind' rather than a dominant 'Theory of Mind' (see also Beck 2018). Mark Bushby, an autistic self-advocate who presented at the second seminar (see Yuill et al. 2015), cautioned about the danger of 'neurotypical syndrome', which is 'assuming their way is the right way and that way is superior' (http://digitalbubbles.org.uk/?page_id=904). This position also aligns with Davidson's (2008) analysis of online representation and inclusion of autistic people as noted earlier, and challenges the idea that utilising technology to support and enable communication and interaction is inevitably a 'collusion' with the social difficulties that individuals experience (see Parsons and Mitchell 2002). As one of the stakeholders from the first seminar queried: 'Collusion vs. alternative channel [for communication]?'

Agency and participation

As a corollary to recognising a socially inclusive approach that equally values a range of different perspectives and voices comes the importance of respecting the agency and participation of individuals; our third and final overarching theme. Again, Freire recognised that for a field to revolutionise there needs to be co-construction of knowledge between those who have traditionally held power and those who have not:

> Teachers and students (leadership and people), *co-intent on reality*, are both Subjects, not only in the task of unveiling that reality, and thereby coming to know it critically, but in the task of re-creating that knowledge. As they attain this knowledge of reality *through common reflection and action*, they discover themselves as its permanent re-creators. (1970, 51; emphases added)

This stance is reflected in the views from the stakeholders that autistic individuals should have the agency to choose what is right for them, and to make decisions about this. There was also recognition of the need to embrace and support the strengths, creativity, and skills of individuals in relation to the ways in which autistic people may (or may not) want to participate in technology design, development, use, and evaluation. Collaboration was also mentioned frequently by stakeholders, and it was acknowledged that skills and understanding are needed from all sides to enable successful collaboration, including between researchers and practitioners, and between those who are autistic and non-autistic (see also Bolton 2018). The joint construction of knowledge is critical here since co-

construction recognises and respects that all stakeholders bring different expertise to research problems that should be valued. As Seale, Nind, and Parsons suggest:

> Sometimes, creating initial boundaries in (researcher-led) research, and clarifying roles, can be helpful rather than compromising in relation to engagement and participation. (2014, 349)

Conclusions

This point returns us to the critical aspect of power and how power is negotiated (or not) within autism and technology research and practice. This is by no means a unique challenge in the broader field of inclusive research (Islam 2014; Oliver 2013; Nind 2014; Rose, Carr, and Beresford 2018) and emerging accounts and critiques of participation in autism research (Bolton 2018; Chown et al. 2017; Fletcher-Watson et al. 2018; Woods et al. 2018). However, as Parsons and Cobb (2014) highlight, co-construction within the technology and autism field may create special challenges because it is not always clear what the best answers or processes are and, therefore, who has the necessary expertise: technology tools develop and change swiftly, as do the expectations from the contexts of their use.

In addition, forming the conditions for the kind of critical consciousness that Freire (1970) supports can be very challenging for those who may struggle with more abstract uses of language (Islam 2014), as well as disciplinary jargon. Thus, technologies as mediating tools can be both the method as well as the substantive focus for promoting more equitable participation and engagement since more accessible forms of communication are possible, for example, through augmentative and alternative communication systems and devices (Robertson 2009), including iPads (Cumming et al. 2014). This is also the case for enabling families and practitioners, as well as autistic children and adults, to participate in this construction of knowledge about the value and importance of technologies in everyday life and to provide counter-narratives and examples of positive technology use that challenge the 'conceptions of technology = bad' (as one of our participants said). Where research agendas are co-constructed, the space for different voices and ideas to contribute knowledge and share ideas and learning widens (Parsons and Kovshoff 2019).

We argue that the key to moving the field forward is, therefore, the adoption of an appropriately critical stance that starts in a different place from where it tends to be now (Parsons et al. 2017a), such that social inclusion, perspectives, and agency and participation become the conceptual and methodological means for shaping research questions, designs, objectives, and the eventual utilisation of outcomes. These ideas are in line with:

Fletcher-Watson et al. (2018), reporting on their seminar series focusing on the meaningful participation of autistic people in research more generally; Beck's (2018) rethinking of what empathy means in autism research; and Robertson's (2009) analysis of quality of life and neurodiversity. Our roadmap for research in the autism and technology field (Table 2) provides the basis for thinking differently about research and, therefore, doing research differently. Both are needed. We argue that it is through the processes and outcomes of such practice-relevant and participatory research where impacts on practices and policy are more likely to materialise and begin to make differences to the lives of individuals and families.

Finally, we emphasise Freire's (1970, 31) stance that it is insufficient to simply recognise and reflect on the challenges inherent in a field of activity, but rather one has to act differently in order to make meaningful changes – in other words, make a commitment to action and dialogue: 'Solidarity requires that one enter into the situation of those with whom one is solidary; it is a radical posture'. We very much hope that this article provides food for thought about why a radical stance is needed and how the field could work together more effectively in order to create more transformative and enabling contexts for autistic people and their families.

Note

1. In line with the preferences of the UK autism community, the terms 'on the autism spectrum' or 'autistic person' will be used rather than 'person with autism' to represent identity-first language; for further discussion, see Kenny et al. (2016). Direct quotes from other authors retain their original terminology.

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Appendix 1. Practical steps for analysing the data

1. A broad initial AT categorisation of each comment was undertaken by the first author, reading and re-reading the hard-copy transcripts, in reverse seminar order, and making annotations on the script. This was a top-down process that began with the seven main orienting categories of the AT framework (Subject, Object, Community, Rules, Division of Labour, Tools, Outcome), ascribing each comment to one or more of these categories.
2. Within NVivo these initial categories were then applied to the comments, and each category was then sub-divided to reflect specific features or aspects. For example, the main category 'Rules' was sub-divided into: flexibility, funding, time, training, what does 'individual' really mean, and who has the knowledge? This was the more emergent, bottom-up part of the analysis because the sub-divisions were based solely on the data rather than any pre-conceived ideas or groupings.
3. The first author then provided each co-author with a roughly equal sub-set of the coded outputs:
    a. author X received all coded comments for all sub-divisions of 'Community', 'Division of Labour', and 'Rules' ($n = 149$ coded statements);
    b. author Y received 'Tools', 'Subject', and 'Outcome' ($n = 143$ coded statements);

c. author Z received 'Object', which was the single biggest category with 11 sub-categories ($n = 156$ coded statements).

Each co-author was asked to summarise the main themes arising from each main category of codes and also propose any overarching themes that spanned more than one category (if relevant or possible).

4. Each set of summaries from the co-authors was then swapped with one other team member for further checking and sense-making. Authors were given feedback and asked to check that the summaries made sense in relation to the raw data (post-it note comments) that were provided to each person. Further details were added by all three co-authors at this stage, especially specific quotes used to illustrate particular points. A small number of quotes were also moved to other categories as part of ensuring there was a clear and coherent narrative.
5. Finally, the first author collated and read through all summaries, making notes about the overarching themes that were helpful for characterising the data. This was an interpretive step where knowledge of the literature, the field, and the seminars themselves was inevitably present. Each of these overarching themes was then discussed and agreed between the team members before being presented in this article.