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Sarah Parsons, Nicola Yuill, Mark Brosnan, Judith Good,

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“A child with autism only has one childhood”: main themes and questions for research from the “Digital Bubbles” seminar series

Sarah Parsons, Nicola Yuill, Mark Brosnan and Judith Good

Abstract

Purpose – *The purpose of this paper is to present an overview of the main messages and key questions for further research arising from the seven-seminar series entitled, “Innovative technologies for autism: critical reflections on digital bubbles”, funded by the Economic and Social Research Council in the UK.*

Design/methodology/approach – *A synthesis of the main ideas is presented, drawing on the presentations, discussions, participant feedback, and short papers from across the seminar series, which took place between November 2014-2016.*

Findings – *There were many positive examples where technologies were positioned and used as facilitative “bridges” between ideas, communities, understanding, and experiences. Researchers and community stakeholders also emphasised the importance of taking different perspectives and working in stronger partnerships with each other. Four overarching research questions were developed from these themes to provide a roadmap for future research, relating to: responsible innovation, technology-enabled social interaction, learning and pedagogy, and engagement.*

Originality/value – *The findings and methodologies produced by the Digital Bubbles seminar series, available on the project website (<http://digitalbubbles.org.uk/>) and in a series of short papers, provide a rich repository of state-of-the-art thinking in the field of autism and technology that is being utilised nationally and internationally in teaching and learning. This paper suggests some valuable future research directions and highlights the importance of establishing and maintaining multi-disciplinary research teams, with autistic people and their families at their core.*

Keywords *State-of-the-art, Autism, Multi-disciplinary, Innovative technologies, Future research, Co-construction*

Paper type *Viewpoint*

Introduction

Interest in the development, application, and evaluation of a range of technologies for supporting children and adults on the autism spectrum, and their families and friends, remains very strong. In this journal alone, some of the most downloaded papers report research situated in this field (e.g. Mintz, 2013; Tunney and Ryan, 2012). Media reports abound, highlighting both dire warnings and miraculous interventions when using technologies for people with autism (e.g. see examples in Parsons *et al.*, 2015; Parsons, 2015a), and research interest in this area has shown very strong growth in recent years (Ploog *et al.*, 2013). It was this expanding interest in the field, along with our own experiences of many years of relevant research, which provided the catalyst for proposing a series of seminars that would critically evaluate and discuss research and practice in autism and technology. We were interested in probing (or “popping” in the nomenclature of the series) the “bubbles” that tend to exist in the field. That is, we had observed tendencies for ideas, critiques, and teams to work in

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The seminar series “Innovative technologies for autism: critical reflections on digital bubbles” is a collaboration between the Universities of Southampton, Sussex and Bath, funded by the ESRC (No. ES/M002624/1). All summaries of feedback obtained during the seminar series are available on the website <http://digitalbubbles.org.uk>. The authors would like to thank everyone who took part in the seminar series as well as the many friends and colleagues who provided invaluable support behind the scenes.

isolation from each other without cross-fertilising research agendas and practice. We wanted to examine these bubbles and try to bring them together in meaningful ways through discussion, participation, and engagement. This endeavour was funded by the Economic and Social Research Council (ESRC) in the UK for the seminar series: “Innovative technologies for autism: critical reflections on digital bubbles”, which took place over two years between 2014-2016, with the series website being our main communication and dissemination tool (<http://digitalbubbles.org.uk/>).

The “Digital Bubbles” seminar series was designed around six core themes with an opportunity for synthesis and further reflection at the seventh, final seminar. We have previously reported on the main discussions that took place, and the questions that arose, from the six themed seminars as summarised in Table I.

The final seminar was named “The Cauldron of Many Bubbles” to reflect its role in bringing together the main ideas from the previous six seminars, highlighting key themes, and identifying priorities and questions for future research. The seminar took place at Cumberland Lodge, Berkshire, UK in November 2016. This short paper provides an overview of these aspects from the final seminar and summarises the main outcomes of the series, both practical and intellectual. We first address the knowledge gained, followed by the practical aspects that supported the development of a multi-disciplinary network through the series of seminars.

Key themes and questions for the field from the seminar series

There was an absolutely central question that underpinned many discussions, and which was posed directly by one of the delegates at the very first seminar:

Whenever you’re trying to develop technologies, think about whether it will really improve someone’s life – or do you just think it will?

Table I Summary of the six themed seminars in the series “Innovative technologies for autism: critical reflections on digital bubbles”

<i>Seminar</i>	<i>Date and location</i>	<i>Main focus or question(s) addressed</i>	<i>Related publication</i>
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 <i>et al.</i> (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 <i>et al.</i> (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 <i>et al.</i> (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, Parsons, Yuill and Brosnan (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 <i>et al.</i> (2017)
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 <i>et al.</i> (2017)

The importance of ensuring that technologies adequately address this question was also summed up very powerfully by the following statement of one of the speakers (a parent and researcher) at the sixth seminar:

A child with autism only has one childhood.

This was a crucial reminder that children with autism are children first and not experimental participants. We have to be clearer about what we are trying to aim for in research and practice in order to ensure that needs and expectations are appropriately met and that valuable time is not wasted on enterprises that may not be useful, engaging or fun. The same applies to adults participating in, or collaborating with, research of course.

In synthesising the core of the discussions across the series, there was a repeated and helpful metaphor, both explicit and implicit, that characterised many ideas, i.e. digital technologies as “bridges”, for example:

- to interactions between people, and between contexts;
- across gaps in understanding, for enabling people to understand and experience different perspectives;
- between real and virtual, in terms of making online connections and friendships as well as moving more smoothly between real and virtual contexts;
- between cultures, in relation to the positive representation and expression of autistic culture online and how this is raising awareness;
- between research and practice, through applying tools that support and document practitioner involvement in research;
- between communities, by establishing networks of interest and expertise that can be local, national, and international in nature;
- between disciplines, by encouraging a focus on what projects need to do rather than who we are as researchers; and
- between processes and outcomes, through questioning what an “appropriate outcome” looks like for individuals, and valuing participation in the process of engagement as much as any measured outcomes at the end of projects.

These bridges seemed to place an emphasis on the different roles that technologies can play as practical tools for enabling connections, understanding, sharing, and greater awareness in the field, and extended the initial idea of technologies as bridges proposed by Barnabear (2014), a self-described “Aspie and Software Engineer”, at the first seminar.

Beyond the nature of digital technologies as facilitative tools were core principles for research and researchers that emerged from the presentations and discussions at the previous six seminars. First, there was a strong message about the need to “look up and outwards” with regard to technology use and development for people with autism (particularly inspired by Yvonne Rogers’ talk at the fifth seminar, see Parsons *et al.*, 2017). This principle related both to researchers who are encouraged to consider wider perspectives from outside their own disciplinary bubbles, and also to how technologies can support engagement and creativity in a variety of ways. For example, some discussions across the series highlighted the need to “pop” the bubble regarding concerns about unhealthy or socially isolating uses of technologies and instead to reflect and report on how technologies can connect individuals in important ways. Examples provided by seminar participants included sharing family discussions about Minecraft, or by making friends with others who share a special interest.

Second, there was recognition that, as a field, we often need to “stand back” from neurotypical assumptions and expectations about the roles of technologies and how they could or should be used for supporting people with autism and their families. Technologies that focus on ameliorating social and communication difficulties tend to dominate the field (e.g. Ploog *et al.*, 2013; Wass and Porayska-Pomsta, 2014) reflecting a “medical model” approach that places an emphasis on fixing the impairment rather than on enabling the strengths, interests, and creativity

of individuals (Shakespeare, 2006). Instead, there is an opportunity to focus more on understanding the roles that technologies play in the everyday lives of people with autism and their families, and to value the meaning that they find in those uses and interactions.

Part of the “standing back”, therefore, also involves greater consideration and action regarding “taking the lead”. This means that researchers need to develop more inclusive and participatory approaches to projects and understand who should be involved, in what ways, and at what stages of research. There is always a balance to be struck here: some people with autism and their families may not want to be fully involved or to take the lead in projects, but may wish to contribute views and expertise in a range of ways (see Brosnan *et al.*, 2016). The key is ensuring that participation is planned for and enabled from the start of the project in ways that align with the core activities and research questions of the project, as well as with the needs and wishes of relevant stakeholders.

Finally, and overarching these three core principles, is the need for the field to develop more multi-dimensional and holistic ways of researching and understanding how and where technologies can be used, developed, and evaluated. This includes incorporating the perspectives of parents, friends, and siblings as well as the multiple other stakeholders whose views and expertise also shape and influence technology engagement. This also requires moving beyond narrowly defined outcome measures in research in order to capture the richness and complexity of the contexts, practices, and pedagogies of technology use.

In reflecting on these core principles, we developed four key questions (and sub-questions) that encapsulated what we had learned as well as signposted us towards a research agenda, informed by and formed with the many stakeholders who attended the series:

RQ1. What does responsible innovation mean in the autism and technology field?

RQ1a. How do we know that what we do really makes a difference or is valued?

RQ1b. For whom might it really make a difference or be valued? This could be from the perspectives of individuals with autism, parents and families, practitioners, as well as from the perspectives of professionals who may wish to use technologies to support individuals and families in a range of ways.

RQ1c. What is it that we are really trying to achieve with our work, and why?

RQ2. What does it mean to be social in a technology-enabled world?

RQ2a. Where or what is the “social deficit”? Where is the social isolation? In other words, it is important to question critically the idea that people with autism may be particularly socially disadvantaged by engaging with technologies.

RQ2b. From whose perspective are we making these judgements? 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.

RQ2c. How do we challenge normative assumptions, or start from a different place in our thinking? Addressing this question presupposes that much stronger collaborative working is fundamental for moving the field forward.

RQ3. What could be the focus for learning and pedagogy?

RQ3a. How can we encourage “looking up and outwards”? In other words, 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?

RQ3b. How can we enable fun, play, creativity, lightness, and subtlety? Much research in this area focuses on addressing social communication difficulties, but what are we missing by maintaining this narrow focus? Broadening our ideas of positive engagement and indicators of success would enable a more holistic understanding of the person or child.

RQ3c. What role could technologies play in addressing the “double empathy problem” (Milton, 2012)? This is the problem that people without autism have difficulties understanding the

world from the perspectives of people with autism, and vice versa. The affordances of technologies can be used to support sharing digital spaces and taking different perspectives (e.g. Parsons, 2015b).

RQ4. How can we think more holistically about engagement?

RQ4a. Do we need “bridges” at all? In other words, is it possible to think in more inclusive ways about how people, working or interacting together, may use technologies for shared purposes?

RQ4b. How can we more effectively enable support and mediation through technologies? This question requires us to consider technologies as mediating tools that can support engagement, interest, and communication in different ways, rather than simply as a means for rehearsal or practice of behaviours that may be difficult. A good example of this is from a Mum at the first seminar who described how her son’s love of Minecraft had opened up dialogue between family members as they shared in his enjoyment.

RQ4c. How can we integrate experiences, processes and outcomes and adequately address complexity and multiple perspectives within research and practice? This requires us to move beyond narrowly defined or standardised outcome measures of behaviour or communication to try to capture the richness and diversity of experiences, preferences, and interactions that take place between multiple stakeholders.

We intend to use these questions to help guide our own future research endeavours and, of course, share them here with the aim of generating further ideas, discussion, and debate. It is important to reflect that many of these questions are not necessarily autism-specific but could have more general applicability as a way of framing the value and usefulness of technology in a variety of contexts. The important point, though, is that these questions have emerged from sustained and shared discussions with stakeholders from across the autism and technology field. In other words, we have already started from a different place in our thinking. We next report briefly on the practicalities of engagement through the series to highlight the foundation that was established and upon which we can move forward with this research agenda.

Successful outcomes from the seminar series: engagement and co-construction

Through the seminars, we have developed a strong, multi-disciplinary community of academic researchers and stakeholders (people with autism, families and carers, professionals and practitioners) to review and critically evaluate ways that technology might support or impair the wellbeing of people on the autism spectrum. This community also includes international academics, national and local autism organisations, representatives from the technology industry, and autism research funders. Over the seven seminars, 240 delegates attended and we supported 50 travel bursaries to enable postgraduate research students (PGRs) and early career researchers (ECRs) and community stakeholders to participate. A particular success of the series was the sustained involvement of stakeholders, PGRs and ECRs throughout, enabling them to contribute to and participate in these important discussions. We also developed an international perspective with colleagues attending from Spain, Turkey and the USA. Academics and practitioners from an ERASMUS+ project entitled SMART-ASD (see SMART-ASD.EU) attended one of the seminars as part of their development days.

We have also developed an interdisciplinary co-constructed body of knowledge and an innovative method of e-participation for the autism and technology field (see below), both of which inform our agenda for future research. First, the participation of stakeholders was supported directly at the seminars through many opportunities for discussion and feedback, and continued through the website after each seminar. A simple, but effective, strategy at the seminars was to encourage delegates to note down questions and observations on Post-it notes during the day and place these on the wall for other delegates to see. Delegates were asked at the end of the seminar to spend five minutes writing down final reflections, including any key messages they took from the day and/or any burning questions they were left with. These Post-it notes were collated and shared through the website. They became 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. This feedback from speakers and delegates was incorporated into the previous six papers reporting on the discussions of the series (see Table I) and so became an essential mechanism for co-constructing key ideas and messages.

Second, we have developed and promoted a free innovative mobile app, ASCmel.T., inspired by the first seminar and jointly funded by each of the research team’s respective institutions from Enterprise Budgets and Research Council (ESRC and EPSRC) Impact Acceleration Funds. ASCmel.T. was co-developed with members of the autistic community who had attended the first seminar. The app is free to download (ascme-it.org.uk) and enables anyone to submit ideas about “which technology for autism needs to be invented?”, either using their mobile phones, or through the ASCmel.T., website. The autistic community can therefore input into the very first stages of the technology design process for the first time, and the app is a good example of an e-participation method that could be applied much more widely (Good, Yuill, Parsons, Brosnan and Austin, 2016; Parsons *et al.*, 2016).

The seminar series website (<http://digitalbubbles.org.uk>) is now a rich repository of key messages and short videos from national and international speakers about their research in the autism and technology field. This state-of-the-art resource is being used within teaching for students studying autism-related topics at all three academic institutions represented by the Digital Bubbles team (Universities of Southampton, Sussex, Bath). In addition, the website is a key resource within the SMART-ASD MOOC (Europe-wide in multiple languages) that has been developed at the University of Bath for parents and practitioners of children with autism (www.bath.ac.uk/research/news/2017/02/27/autism-mooc/), thereby having international reach.

Next steps

It is important to us as a team that we make an active commitment to work with the key principles and questions that have emerged for the autism and technology research field over the course of this two-year seminar series project. To that end, we have initiated a Call for Papers for a special issue in *Research in Autism Spectrum Disorders*, entitled: “Look up! Digital technologies for autistic people to support interaction and embodiment in the real world”. This special issue will be published in 2018. We have also surveyed the attendees at the final seminar to establish their priorities for action (e.g. joint writing, joint projects) as well as their priorities for research, and we will use this information as a starting point for conducting a survey with our wider group of seminar participants to further inform the future research agenda. We will report on these findings in due course. There have been numerous connections, activities, and projects undertaken as a direct result of people meeting each other at the seminars, and we hope that these ripples will continue to spread through and beyond this network. We will also be pursuing some of the ideas generated through the ASCmel.T., app via workshops and small-scale projects with the aim of bringing those ideas closer to reality. We would like to encourage any interested readers to get in touch and to watch this space (<http://digitalbubbles.org.uk>) for further developments.

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Authors' affiliations

Sarah Parsons is a Professor of Autism and Inclusion at the Southampton Education School, University of Southampton, Southampton, UK.

Nicola Yuill is a Senior Lecturer at the School of Psychology, University of Sussex, Sussex, UK.

Mark Brosnan is a Professor of Psychology at the Department of Psychology, University of Bath, Bath, UK.

Judith Good is a Reader in Informatics at the Department of Informatics, University of Sussex, Sussex, UK.

Corresponding author

Sarah Parsons can be contacted at: s.j.parsons@soton.ac.uk

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