How can participatory design inform the design and development of innovative technologies for autistic communities?

Mark Brosnan, Sarah Parsons, Judith Good and Nicola Yuill

Mark Brosnan is based at the Department of Psychology, University of Bath, Bath, UK.
Sarah Parsons is based at the Southampton Education School, University of Southampton, Southampton, UK.
Judith Good is based at the School of Engineering and Informatics, University of Sussex, Brighton, UK.
Nicola Yuill is based at the School of Psychology, University of Sussex, Brighton, UK.

Abstract

Purpose – *The purpose of this paper is to reflect upon on the opportunities and challenges of engaging with a wide variety of stakeholders during the design, development and evaluation of innovative technologies for people with autism. Autism is defined in part by difficulties in social communication and interaction, and is therefore particularly pertinent when considering the opportunities and challenges of participatory design (PD).*

Design/methodology/approach – *A series of presentations from key researchers and practitioners are reviewed, highlighting contemporary issues about how technologies have been designed to improve educational support using a range of methods and processes for stakeholder involvement.*

Findings – *Involvement per se does not constitute engagement as a design partner. The interdisciplinary nature of PD, combined with the viewpoints of communities beyond academia, need to be integrated in a manner that allows for different perspectives and voices, and for the "trace" of the contribution to be evidenced. The level of evidence required for demonstrating effective support needs to be considered in terms of both the outcomes of projects and the processes for involving stakeholders in PD.*

Originality/value – *This paper offers an up-to-date insight from lead researchers into key debates about the benefits and challenges of PD with autistic people and the broader autism community. Its value lies in raising questions about, and discussing evidence that challenges, some of the assumptions that underpin both PD processes and the needs of the autistic community.*

Keywords *Autism, Technology, Co-production, Methods, Evidence base, Participatory design*

Paper type *Viewpoint*

Received 4 December 2015
Revised 4 December 2015
Accepted 7 December 2015

The seminar series "Innovative technologies for autism: critical reflections on digital bubbles" is funded by the ESRC [ES/M002624/1] and is a collaboration between the Universities of Southampton, Sussex and Bath. The authors are very grateful to the rapporteurs who play an important and active role in summarising key information from the seminars and supporting the website and blog: Nigel Newbutt, University of the West of England; Clarence Singleton, Jo Black, Catherine Wise, Aurora Constantin, University of Bath; and Chris Girvan, University of Sussex.

Introduction

Participatory design (PD) has its origins in a Scandinavian democratic movement from the 1960s, which aimed to involve workers in the process of designing their work spaces. This principle has been extended to the design of technology by involving the people who will use the technology in the process of designing, developing and evaluating the technology. PD protocols have been developed to facilitate individuals with autism spectrum disorder (ASD) contributing to the design of assistive technologies (e.g. Cobb *et al.*, 2002; Benton *et al.*, 2011, 2012; Parsons *et al.*, 2014). Supporting the contribution of individuals with ASD to the design process is particularly pertinent as they can have an affinity for using digital technologies whilst experiencing difficulties with social communication and interaction (combined with restricted and repetitive behaviours, American Psychiatric Association, 2013). Through appropriate structuring of PD sessions (e.g. Benton *et al.* 2011, 2012; Frauenberger *et al.*, 2013; Parsons *et al.*, 2011), the benefits of delivering educational and therapeutic content through digital technologies can be maximised (e.g. Grawemeyer *et al.*, 2012, 2015).

The "digital bubbles" seminar series: the methodological bubble

Digital bubbles is a seminar series funded by the ESRC 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 (see www.digitalbubbles.org.uk). Commentaries drawing upon the first two seminars have critically reflected upon innovative technologies for supporting social communication and engagement, respectively (Parsons *et al.*, 2015; Yuill *et al.*, 2015). This paper builds on these commentaries by focusing on methodology. Specifically, different disciplines have their own methodological "bubbles", and the aim of the seminar was to integrate the interdisciplinary perspectives of methodology within an inclusive framework which extends to the broader autism community.

Richard Mills, Research Director of Autism Research (a UK-based charity), outlined the challenges and opportunities of a partnership model between the autistic community and researchers. Involvement within the research process is not always sufficient for developing authentic and meaningful partnerships, and can give rise to feelings of being a "guinea pig". Engaging with the autistic community in a manner that is mutually beneficial is clearly desirable. Any research directed at interventions for autism, including PD methodologies, that lacks social acceptability and fidelity within the real world is of limited benefit or relevance to end-users which, in turn, diminishes any sense of a rewarding partnership. Integrating research within real-world practices is essential for developing evidenced-based therapeutic and educational interventions. This aspiration also aligns with the "impact agenda" of the UK Government in valuing and encouraging research that can demonstrate an impact on people's lives and experiences beyond the confines of academia (e.g. HEFCE, 2011).

Developing the theme of technology being beneficial and relevant to autistic people, Sue Fletcher-Watson from the University of Edinburgh, described the design process of the iPad™ app "Face It[1]". Involving autistic people in the design of the app informed a better understanding of the motivations for engaging with the app, the role of repetition in task completion, the level of complexity of the tasks as well as the provision of rewards for completing tasks successfully. Evidencing Richard Mills' point of research extending beyond the laboratory to real-life situations, the research attempted to address whether engaging with the app impacted upon parent-child interactions generally. Unusually for technology and autism research, a randomised control trial methodology was employed to examine the effectiveness of using the app for supporting parent-child communication in non-technology-based contexts. However, there was no evidence for any transfer of benefits from the technology to the real-world environment of parent-child interaction (Fletcher-Watson *et al.*, 2015; see Fletcher-Watson, 2014, for review). This raised key issues for future research, specifically how the evidence for the effectiveness of apps is obtained and disseminated (e.g. are randomised control trials appropriate for understanding real-world effectiveness of use?) and how outcome variables are selected (e.g. what real-world interactions can be affected by, or studied with, an app?).

Sue posed the question "How do Autistic children learn from technology?", suggesting that without a model of how typically developing children learn from technology, answering this question is challenging. For example, she suggested that we do not know how universal existing models of learning and skill development are across learning contexts, and whether they account for how autistic children want to learn generally – let alone learn with technology. In terms of assessing learning through using technology, the crucial variable might be how well you use the system, rather than how much you use the system; however, the former is much harder to define and assess than the latter. An important question for digital interventions for children with autism is "how early is early intervention?" 15-month-old typically developing children can effectively interact with apps on an iPad™ when they would be expected to have a vocabulary of a few words, which highlights the potential for technology-based early intervention. Sue argued that such technology should provide "top up" support, that is, support that is in addition to, not a replacement for, existing provision.

The role of PD was further developed by Sarah Parsons, from the University of Southampton, who highlighted how engaging the perceived beneficiaries of research as design partners potentially facilitates digital empowerment and social inclusion, although the methods and processes for achieving this are not without significant challenges (Parsons and Cobb, 2014). Sarah drew upon two different research projects (Parsons *et al.*, 2011, 2015) to highlight that the context of the technological interaction, or situated learning (Harrison *et al.*, 2011), needs to be a central

consideration for how technological applications are designed, and who is involved in the decision making. One of the major contextual factors that influences the use of technology is the other people within the environment and their attitudes and approaches towards technology use. Thus, involving parents and teachers within the design process allows for the potential of co-constructing the knowledge, and therefore the evidence-based practices, that contribute to successful technology design because wider contextual factors can be taken into account. These stakeholders, therefore, are part of the end-user community whose views need to be incorporated into the PD process.

Involving multiple stakeholder groups within PD can create its own challenges, for example, if the PD requirements of the children differ from those of the parents, or teachers (Parsons and Cobb, 2014). Genuine involvement and partnership with stakeholders also require a rethinking of how research is designed to examine usefulness and effectiveness of technology development and implementation (Parsons *et al.*, 2015). Effective collaboration and involvement (co-construction or design partnerships; Druin, 2002) are more process-focused (inductive) than outcome-focused (deductive) and so there is a potential misalignment between more participatory approaches to technology development and traditional expectations about how the effectiveness of technology-based intervention is researched using experimental paradigms. In other words, it could be that there is as much to be learned by children and others through the processes of PD in the development of technologies as there is in the eventual evaluation of any change in learning outcomes as a result of using the technology end-product. The value of involvement in the design process itself, e.g. contributing ideas, problem solving, practising collaborative working skills, is something that is often overlooked and under-researched in this field.

Kaska Porayska-Pomsta, from London Knowledge Lab, UCL, further developed the discussion on outcomes in technology research by contrasting them with processes that take place within projects to arrive at useable technological prototypes or products (e.g. Bernardini *et al.*, 2014; Porayska-Pomsta *et al.*, 2013; Parsons *et al.*, 2015). Outcomes and processes may be incompatible, especially when involving interdisciplinary teams, because what may be a successful outcome for a designer or computer scientist, for example, may be very different from an educator or psychologist. To illustrate, it could be that a design feature or a way of programming or logging data in the technical specification of a technology (aspects of the processes of development) are considered good or desirable outcomes by designers or programmers, respectively. However, it could be that such process-based aspects conflict with how a teacher or psychologist may wish to support children's learning as an outcome of using the technology. Parsons and Cobb (2014) provide an example of this, describing how teachers' preferences regarding the importance of structure for supporting children's learning within technology-based tasks was at odds with the programming requirements from the computer scientists, who preferred less structure and more freedom in how users explored the tasks.

Kaska also discussed the accountability of PD within technology projects, and the ways in which researchers evidence and acknowledge the contributions made by different stakeholders within PD processes. She argued that the concept of "trace" is central to providing a more robust and valid approach to documenting participation; in this context, "trace" means the capacity to be able to track the ideas from PD sessions through to the final product, as well as document which ideas or suggestions were not taken forward, and why. As outputs from end-user contributions within PD sessions are interpreted by designers and implemented by programmers, a "lack of trace" can emerge. In discussing different perspectives on outcomes and processes, the audience suggested there is an inter-twining link between the two. Processes and outcomes can be interpreted and implemented differently depending on the nature of the research questions; for example, whether the focus is on the process of learning or the outcomes of learning, and the relative importance of these, relates directly back to the issues of how they are assessed via particular measures or observations within the research.

Damian Milton, a doctoral researcher from the University of Birmingham, took the perspective of an "Autistic Sociologist" to argue that taking personal ownership of technology and how it is used was fundamental, and that technology is most effective when it can be used by autistic people on their own terms. His own research identified that the most endorsed opinion from autistic adults he had surveyed was for research to "celebrate learners and not try to normalise them". Whilst PD may offer a means to facilitate this, Damian highlighted that not everyone wants to be in a design

team, but they do want their voices heard, and this means enabling different levels of involvement for different people, e.g. contributing to design ideas and feeding back about relevance and usability but not being responsible for making or implementing design decisions. The question posed to the audience by Damian was: "What is it that you are trying to achieve through your work and why?" It is feasible that researchers, autistic people and the broader autism community are going to have different desirable outcomes in mind for the PD process. These potential differences need to be acknowledged and mechanisms for more authentically integrating different perspectives developed – to include the perspectives of those who do not want to be in a design team and prefer to contribute in different ways. Continuing to reflect upon this question is essential for moving the field towards a better understanding about what participation and collaboration mean for different stakeholders in the context of autism-focused technology research (see Milton, 2012a, b, 2014a, b; Milton and Bracher, 2013).

One potential way forward was discussed by Lisa Austin from the University of Bath. Developed with the Digital Bubbles team (the authors of this paper), Lisa Austin described a new app, called "ASC mel.T." (www.ascme-it,org.uk), that allows autistic people and the broader autism community to upload a one-minute video to answer the question "If there was one technology to help people with autism, what would it be?" ASCmeI.T. is available to download free of charge for Android and iPhone and, for the first time in the UK, enables the autistic community to input to the very first stage of the design process rather than being invited in by researchers once many of the decisions have already been made. The uploaded videos (or e-mails) are reviewed by researchers and developers, with a view to some ideas being taken forward for further design and development, in collaboration with the autistic community whenever possible. The app was adapted from Lisa Austin's earlier work (http://ifonlyitworked.com/) and inspired by a proposal from an autistic participant at the first digital bubbles seminar (Parsons *et al.*, 2015) who asked: "What problem would you want solved and what would you invent?" (Barnabear, 2014). The aim of the ASCmel.T. project is to gather information about the needs of autistic individuals, as identified by themselves, their families, teachers, and other professionals, and use these community-generated ideas as a basis for developing technologies that may have greater ownership by autistic people, as Damian Milton suggests.

Key messages

PD has the potential to enable digital empowerment and social inclusion of those involved and can be an effective forum for developing interdisciplinary research and engaging with wider communities. However, many challenges and questions remain regarding the meaning of partnership and collaboration for different stakeholders and how a range of views, skills and expertise can be effectively and authentically integrated and mutually respected. The implications of the importance and value of participatory processes in the design and development of innovative technologies also need to be further examined in relation to how outcomes of projects are evaluated. Such considerations need to move beyond the narrow remits of experimental paradigms to a more thorough and multi-dimensional understanding of what constitutes successful outcomes for everyone involved. As innovative technologies proliferate, how best to capture the evidence of potential beneficial processes and outcomes is an immediate challenge.

Note

1. As this app is commercially available, Sue Fletcher-Watson made an explicit declaration of interest. The app is also available in a free format.

References

American Psychiatric Association (2013), *Diagnostic and Statistical Manual of Mental Disorders*, 5th ed., American Psychiatric Publishing, Arlington, VA.

Barnabear (2014), "A guided tour of autism and technology by Barnabear, Aspie and software engineer. Presentation at the 'Innovative technologies for autism: critical reflections on digital bubbles' " seminar series, University of Southampton, Southampton, November, available at: http://digitalbubbles.org.uk/wp-content/uploads/2014/12/ digital_bubbles_barnabear-Sem-1.pdf (accessed 15 July 2015).

Benton, L., Johnson, H., Brosnan, M., Ashwin, E. and Grawemeyer, B. (2011), "IDEAS: an interface design experience for the autistic spectrum", *Proceedings of the 2011 Annual Conference Extended Abstracts on Human Factors in Computing Systems, ACM Press*, *Vancouver*, pp. 1759-64.

Benton, L., Johnson, H., Brosnan, M., Ashwin, E. and Grawemeyer, B. (2012), "Developing IDEAS: supporting children with autism within a participatory design team", *Proceedings of the 2012 Annual Conference on Human Factors in Computing Systems, ACM Press*, *Austin, TX*, pp. 2599-608.

Bernardini, S., Porayska-Pomsta, K. and Smith, T. (2014), "ECHOES: an intelligent serious game for fostering social communication in children with autism", *Information Sciences*, Vol. 264, pp. 41-60.

Cobb, S., Beardon, L., Eastgate, R., Glover, T., Kerr, S., Neale, H. and Wilson, J.R. (2002), "Applied virtual environments to support learning of social interaction skills in users with Asperger's Syndrome", *Digital Creativity*, Vol. 13 No. 1, pp. 11-22.

Druin, A. (2002), "The role of children in the design of new technology", *Behaviour and Information Technology*, Vol. 21 No. 1, pp. 1-25.

Fletcher-Watson, S. (2014), "A targeted review of computer-assisted learning for people with autism spectrum disorder: towards a consistent methodology", *Review Journal of Autism and Developmental Disorders*, Vol. 1 No. 2, pp. 87-100.

Fletcher-Watson, S., Petrou, A., Scott-Barrett, J., Dicks, P., Graham, C., O'Hare, A., Pain, H. and McConachie, H. (2015), "A trial of an iPad intervention targeting social communication skills in children with autism", *Autism*. doi: 1362361315605624.

Frauenberger, C., Good, J., Alcorn, A. and Pain, H. (2013), "Conversing through and about technologies: design critique as an opportunity to engage children with autism and broaden research(er) perspectives", *International Journal of Child-Computer Interaction*, Vol. 1 No. 2, pp. 38-49.

Grawemeyer, B., Johnson, H. and Brosnan, M. (2015), "Can young people with autism spectrum disorder benefit from an open learner model?", *Artificial Intelligence in Education*, Springer International Publishing, pp. 591-4.

Grawemeyer, B., Johnson, H., Brosnan, M., Ashwin, E. and Benton, L. (2012), "Developing an embodied pedagogical agent with and for young people with autism spectrum disorder", *Proceedings of the 11th International Conference on Intelligent Tutoring Systems*, *Chania and Crete*, pp. 262-67.

Harrison, S., Sengers, P. and Tatar, D. (2011), "Making epistemological trouble: third-paradigm HCI as successor science", *Interacting with Computers*, Vol. 23 No. 5, pp. 385-92.

HEFCE (2011), "Decisions on assessing research impact", available at: www.ref.ac.uk/pubs/2011-01/ (accessed 10 August 2015).

Milton, D. (2012a), *So What Exactly is Autism?*, Autism Education Trust, London, avaiable at: www.aettraininghubs.org.uk/wp-content/uploads/2012/08/1_So-what-exactly-is-autism.pdf (accessed 13 May 2016).

Milton, D. (2012b), "On the ontological status of autism: the 'double empathy problem' ", *Disability and Society*, Vol. 27 No. 6, pp. 883-7.

Milton, D. (2014a), "Autistic expertise: a critical reflection on the production of knowledge in autism studies", *Autism: The International Journal of Research and Practice (Special Edition "Autism and Society")*, (accessed 17 March 2014).

Milton, D. (2014b), "What is meant by participation and inclusion, and why it can be difficult to achieve", *NAS Ask Autism Conference: Participation and Inclusion from the Inside-out: Autism from an Autistic Perspective*, *London*, January.

Milton, D. and Bracher, M. (2013), "Autistics speak but are they heard? ", *Medical Sociology Online*, Vol. 7 No. 2, pp. 61-9.

Parsons, S. and Cobb, S. (2014), "Reflections on the role of the 'users': challenges in a multidisciplinary context of learner-centred design for children on the autism spectrum", *International Journal of Research and Method in Education*, Vol. 37 No. 4, pp. 421-41.

Parsons, S., Newbutt, N. and Wallace, S. (2014), "Using virtual reality technology to support the learning of children on the autism spectrum", in Boser, K.I., Goodwin, M.S. and Wayland, S. (Eds), *Technology Tools for Students with Autism*, Brookes Publishing, Baltimore, MD, pp. 63-84.

Parsons, S., Guldberg, K., Porayska-Pomsta, K. and Lee, R. (2015), "Digital stories as a method for evidence-based practice and knowledge co-creation in technology-enhanced learning for children with autism", *International Journal of Research & Method in Education*, Vol. 38 No. 3, pp. 247-71.

Parsons, S., Millen, L., Garib-Penna, S. and Cobb, S. (2011), "Participatory design in the development of innovative technologies for children and young people on the autism spectrum: the COSPATIAL project", *Journal of Assistive Technologies*, Vol. 5 No. 1, pp. 29-34.

Parsons, S., Yuill, N., Brosnan, M. and Good, J. (2015), "Innovative technologies for autism: critical reflections on digital bubbles", *Journal of Assistive Technologies*, Vol. 9 No. 2, pp. 116-21.

Porayska-Pomsta, K., Anderson, K., Bernardini, S., Guldberg, K., Smith, T., Kossivaki, L., Hodgins, S. and Lowe, I. (2013), "Building an intelligent, authorable serious game for autistic children and their carers", *Advances in Computer Entertainment*, Springer International Publishing, pp. 456-75.

Yuill, N., Parsons, S., Good, J. and Brosnan, M. (2015), "Knowing me, knowing you: perspectives on awareness in autism", *Journal of Assistive Technologies*, Vol. 9 No. 4, pp. 233-38.

Corresponding author

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