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Who chooses what I need? Child voice and user-involvement in the development of learning technologies for children with autism

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Abstract

Children and young people with disabilities have rights to be included and heard, but remain under-represented in research due to perceived difficulties in gaining their views meaningfully. We present brief case studies from three different projects which have focused on developing virtual reality educational technologies for children with autism[1] to illustrate how this has been achievable in practice.

The ethical imperative of including and valuing 'child voice' in research

Since the publication of the United Nations Convention on the Rights of the Child (UNCRC, 1989) there has been a strengthening of awareness and practice about seeking children's views in authentic and meaningful ways (Lundy, 2007). Article 12 of the convention, ratified by the UK Government in 1991, emphasized the right of children to express their views in all matters affecting them 'in accordance with the age and maturity of the child'. Subsequently, there has been a much broader societal recognition (through research, policy and statutory responsibilities) of the importance of valuing children as social actors in their own right with a concomitant burgeoning of research about children's views on important topics (e.g. health, care and schooling; Burchardt, 2005; Cavet & Sloper, 2004; Lewis et al., 2007) and how to effectively seek these views (e.g. Emmel et al., 2007).

Particular challenges have been discussed regarding how to create methods and contexts where children with disabilities or special educational needs can also contribute their views (Lewis et al., 2005). Communication difficulties are most often cited as the main barrier to hearing views of disabled children (Lewis & Porter, 2006). The UNCRC recognised this type of exclusion as a serious problem and

> *'…stressed the particular need to guarantee the participation of children with disabilities on the basis that these children may suffer a 'double denial' of their right because of an 'even deeper inability to accept the child's competence'* (Lundy, 2007:935).

[1] We use the term 'children with autism' as a shorthand for children with autism spectrum conditions including, autism, autism spectrum disorder and Asperger Syndrome.

Thus, there is an ethical imperative for researchers to develop effective and inclusive approaches to enable disabled children's participation in projects, discussions and consultations about 'matters affecting them'.

In the field of technology development, the involvement of end-users in design and testing has been a longstanding approach, aiming to ensure that end-products are useful, usable and acceptable for the target market (Gulliksen et al., 2003; Coleman et al., 2012). Over time, there has been a strengthening of user-involvement in technology design projects signalled by changing terminology: from user-centred, to participatory, through to inclusive design. This shift represents a move from a position where end-users were merely the recipients and testers of products near the end of product development, to a more participatory approach in which users are respected and involved as more equal partners in the design process (Scaife & Rogers, 1999).

More recently, inclusive design approaches have emphasized the importance of considering the needs of a diverse range of potential end-users, including people with disabilities, in the design and development of technology products (e.g. Abascal & Nicolle, 2005). This shift is more than semantic because the authentic involvement of people with disabilities from the start of projects means that products are more likely to be facilitative, inclusive and effective in supporting social inclusion and communication (Abascal & Nicolle, 2005).

Virtual reality for supporting social skills for children with autism

Our own work, for over a decade, has focused on the development of virtual reality (VR) technologies to support the learning of higher-functioning children with autism. There are strong conceptual and practical reasons why VR might be especially helpful for children with these difficulties (Parsons & Mitchell, 2002), leading to a continuing interest in (Rajendran, in press) and optimism for research in this field (Parsons & Cobb, 2011). However, given that one of the defining characteristics of autism is a difficulty with social communication, this represents particular challenges for meaningfully involving users in technology design and development. For example, children with autism may find communicating their views and opinions difficult, they may have limited imagination skills and they may have difficulties in understanding another person's viewpoint (Millen et al., 2011).One of the main guiding principles of our work has been the importance of placing children's views at the centre of what we do. The short case studies we present next show how we have tried to embed our principles in practice. We make no claim to 'best practice' in this area, but offer these as examples on which we, and other researchers, can continue to reflect and improve.

Case Study 1: Single-user VR for children with autism

Overview: The *Asperger's Syndrome (AS) Interactive* project (2000-2003, funded by the Shirley Foundation) examined the suitability of VR technology and virtual environments (VEs) to support learning of social communication skills for teenagers with autism (Cobb et al., 2002). The project aimed to support social understanding of 'real-world' scenarios through replicating them in VEs, thereby allowing practice and role-play in a safe and supportive environment (Parsons et al., 2000). Two scenarios were developed, based on recommendations from teachers, representing social situations that teenagers with autism tend to find challenging: queuing and finding somewhere to sit in a café and a bus.

Methods for participation: The *AS-Interactive* project applied a toolbox of methods through which design of the VEs was informed by input from different representatives at different stages of development (Neale, Cobb & Kerr, 2003) using a variety of prototyping techniques and feedback mechanisms to elicit user opinion. Professional user representatives (e.g. teachers, domain experts, training advisors and facilitators) participated in workshops to review existing examples of the technology and discussion groups to identify how best to apply features of the technology to support student learning. User representatives, facilitators and program developers then reviewed elaborated concept storyboards to inform virtual environment layout, content and interaction activities.

3D low-tech models (Figure 1) were used by the research team to think about how well the planned scenario could replicate role-play methods they had observed in schools; for example, the task in the virtual café requires the student to enter the café, join the queue at the food counter and order their meal and then search the room to find a suitable place to sit down. Use of the 3D model allowed the research team to discuss options for task sequence order, room layout and positioning of characters within the virtual environment. This was useful to ensure efficacy of the VE with regard to the real-world scenario represented and to determine the need for automatic viewpoints within the VE to focus attention on specific objects or resolve usability issues.

Paper-based 'screen-shot' mock-ups (Figure 2) were then generated to facilitate decision-making of the appearance of the virtual environment and how the on-screen interface should be used to prompt user interaction and provide feedback (Figure 3). There was some concern from the teachers that students with autism would have difficulty in dealing with abstract representations and that the low-tech prototypes would not be suitable for them. However, a group of users comprising members of a social group for adults and adolescents with Asperger's Syndrome participated in concept review activities in which they tested a prototype version of the virtual café and then commented on design features using printouts of screen shots (Neale, 2001). Using this method, the users informed decisions about the aesthetic appearance of the virtual room (e.g. colours, decoration,) and design of icons used in the information toolbar (e.g. the ‘ear’ icon to listen to the instruction again).

Observation of user interaction with the VE identified a number of ‘critical incidents’; these were usability problems revealed through aspects of task performance (Neale, 2001) associated with controlling movement around the VE, interacting with virtual objects and understanding the feedback given by the computer. In addition to these, observation studies - conducted in the classroom - of teacher-facilitated use of the AS Café, revealed problems showing that users did not know how to use the interaction metaphors and did not know when they had completed a task. This led to the development of a training environment to lead the user through use of the interaction metaphors (e.g. how to sit down, how to stand up, how to communicate with a virtual avatar), and including positive feedback messages within the VE to reward successful task execution and to prompt the user to move on. Consequently, children with autism were involved in formative review and usability evaluation of VE prototypes. These studies subsequently informed decisions concerning interface design and functionality of the VEs as well as task structure and implementation of class activities.

Fig. 1. 3D model of the virtual café.

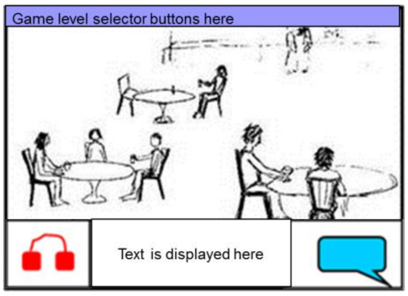

Fig. 2. Sketch of the virtual environment and interface

Fig. 3. First development of the virtual environment.

Lessons learned: It is important that relevant stakeholders are engaged throughout the design process so that we can fully understand user needs and requirements. However, it is not practical or necessary to involve everyone in all activities; involvement of different stakeholders at different stages of the design process, and the use of a variety of techniques to inform design decisions, were both successful and productive. We found paper-based methods to be most useful in early discussions with teachers and professionals associated with the target user group. These methods help to define functional aspects and can be used to generate the learning objectives for tasks to be performed in the VEs. However, one of the limitations of 2D prototypes is that they do not easily represent how the user can interact within 3D virtual space. 3D low-tech prototyping methods are useful to allow specification of the 3D layout of the VE and how the user should be able to interact with virtual objects.

Low-fidelity mock-ups of the virtual environment, with incomplete content and functionality, were useful for formative evaluation (by teachers) of VE development and also to facilitate refinement of all aspects of design specification. Testing of iterative high fidelity prototypes, conducted by teachers and pupils with autism within the setting in which we ultimately hoped to use the technology (i.e. the classroom) revealed important insights into understanding and where changes needed to be made. This was important to ensure that technology design was informed by user needs and abilities so that the final product was fit for use in school-based learning and led to identification of a need to include some 'teacher control' options in the software to enable them to guide the students through the activity (and prevent students going too fast).

Case Study 2: Collaborative Virtual Environments (CVEs) for children with autism

Overview: The *COSPATIAL* project (2009-2012) was funded by the European Commission under the framework seven ICT programme (Grant Agreement no.231266). The project developed and evaluated collaborative technologies for engaging children with autism in social communication. Three CVE applications were developed which emphasized different social skills: (1) a perspective-taking puzzle game; (2) a structured, facilitated social conversation game; and (3) a mixed reality application (video avatars in a virtual room) with the aim of providing an interim step towards being able to transfer these social skills into real world practice.

Methods for participation: The project involved a range of stakeholders in participatory design groups to inform different aspects of the CVE development. Teachers and autism specialists identified suitable scenario concepts and the required learning objectives of tasks presented. Workshop sessions were conducted in schools involving typically developing (TD) children and children on the autism spectrum who informed the game content and methods of interaction within the CVE. Whilst TD children could cope with open-ended activities that allowed them to generate new imaginary game tasks, these methods were adapted for the children with autism as a highly structured sequence of tasks with specific, focused questions based around a 'design a game' activity (Millen, Cobb & Patel, 2010). This included six progressive activities completed within a clear timetable conducted over a one hour period in total. Each activity focused on a specific aspect of design for a computer game for making friends. Students were first asked to think about what computer games they like/dislike leading to a discussion about what makes a good game. They were then asked to talk about what friends are, what makes a good friend and why we would want to play computer games with friends. The templates used for some of these structured activities are shown in Figure 4 illustrating: i) a visual timetable so that the students could see what activities they would be doing; ii) chart to list what they like/dislike in familiar computer games; iii) mind map to facilitate thinking about friendship; and iv) mind map to identify features in a new ‘friendship game’ (images reproduced with permission of the authors; Millen, Cobb & Patel, 2010).

Fig.4. Structured activity sheets for the designing a friendship computer game task (images reproduced with permission of the authors; Millen, Cobb & Patel, 2010).

At a later stage of the project, we incorporated these structured activities into a collaborative virtual environment that enabled ASC students to work through the task through the medium of the computer together with another user in a different location. Two users shared the same VE to discuss ideas using the templates presented on display boards within the CVE and generating their own game design concepts using interactive drawing boards (Millen, Cobb, Patel & Glover, 2012). Figure 5 shows game design concepts generated by ASC children illustrating: i) game design drawn on paper; ii) station 4 in the CVE where students created their game ideas; iii) station 5 in the CVE showing a gallery of student game designs.

Fig. 5. Concept designs for a ‘friendship computer game’ drawn by ASC students on paper and within the CVE (images reproduced with permission of the authors; Millen, Cobb & Patel, 2010; Millen, Cobb, Patel & Glover, 2012).

Lessons learned: A similar approach to that used in the *AS-Interactive* project was applied to the design of the CVE in the *COSPATIAL* project; different stakeholders used a variety of methods to contribute to idea generation, concept and prototype review throughout an iterative technology development process. However, whilst the toolbox in *AS-Interactive* was really helpful, we found that embedding structured design tasks into the CVE and using the technology itself as a medium for communication with students with autism enabled them to contribute more directly to ideation and concept design stages. Thus, not only were the CVEs the *targeted outputs* of the design processes with users with autism, they were also a valuable *methodological platform* for supporting user engagement in design discussions and decisions about technology development. We learned that using VR technology as the medium of communication can facilitate engagement and involvement of young people with autism; with structured and visual tasks to make the ideas 'real', this was a really powerful method for engagement that can inform development of new interactive computer games for social communication. This is an emerging area of interest which it would be fruitful to explore further.

Case Study 3: Immersive VR for children with autism

Overview: The *Your World* project (2006-8, funded by NESTA) focused on the inclusive design and development of an immersive VR (IVR) technology for children with autism. Specifically, the IVR was a 'Blue Room' in which users can stand at full height, consisting of four screens digitally 'stitched' together to create a 'highly immersive and fluid virtual experience' (Wallace et al., 2010; p.201). This was a large and expensive technology that would not be available for schools in the near future, and so the purpose of the project was to explore possibilities and test for initial acceptability and usability. We included two main stakeholder groups: (1) 5 pupils on the autism spectrum and 3 TD pupils (aged 12-15 years) who all attended the same school and (2) an adult group including a man with Asperger Syndrome, relatives of individuals with autism and experts in the fields of education, ICT and autism.

Methods for participation: We designed 'experiential focus groups' for the children taking part which consisted of a 2-hour session where they were introduced to the project, and could then experience the IVR directly. The group was then engaged in providing structured feedback about their reactions to the Blue Room and ideas for its educational potential and development, focusing on: (1) first impressions (2) fantasy scenarios (3) real world situations, and (4) improvements / changes for the physical space and layout.

Being aware that less structured discussion can be particularly difficult for young people with autism, we numbered each of the four questions and had these printed on a piece of paper at the start of the sessions so that children knew exactly what they would be asked. We first asked the children to write their ideas down on post-it notes or pieces of paper and share these with the group. The rules for participation were stated clearly: that each member was to have a turn and we would listen to each of them with speaking ourselves; they could also choose to skip their turn if they did not want to contribute. If members did not want to speak their idea, they could put their post-it on a flip chart and the facilitator would read it out. This method was very successful in enabling all members of the group to participate equally and everyone made helpful contributions.

Lessons learned: the structure of this one-off session was very effective in soliciting feedback from all of the young people involved. They were excited about and enthused by the IVR, and provided insightful and thoughtful comments. They took the task seriously, making clear distinctions between their 'fantasy' (e.g. Formula 1; walking on the moon) and 'real-life' suggestions (e.g. bullying, phobias, 'stranger danger'). Most notably, the young people with autism knew the areas in which they had social difficulties and specifically made design recommendations in those areas, particularly focusing on understanding the behaviours and intentions of others. Their comments differed substantially from the adult group who were concerned that the Blue Room would be experienced as uncomfortable for people with autism and that humanoid avatars may be too threatening. By contrast, children with autism specifically asked for 'people' in the scenes because they wanted to improve their social understanding. Whilst we know that adults raise important concerns for good reasons, the main lesson we learned was that children can be creative and enthusiastic designers of, and advocates for, technology partly because they are less likely to focus on the potential risks and challenges.

Conclusions

It would have been easier to work only with teachers and / or families as 'proxy' decision-makers for their children; however, our technology development was targeted specifically at supporting children's social skills and understanding and so it was imperative that we asked, and included, children directly. Crucially, we were working with (at the time) very new technologies, for which there was very little guidance or information regarding how they could or should be developed for education. Therefore, we assumed that children would know just as much, if not more, than us, their teachers and families about how these technologies could support their learning. Through incorporating carefully structured activities within a 'toolbox' of participatory design methods, we were able to engage users with autism in meaningful ways to directly inform the development of educational technologies and their evaluation in the classroom. The children's contributions were insightful, thoughtful and creative, helping us to target social understanding and skills in ways that we would not have initially thought possible.

These experiences have demonstrated that children with autism can be effectively supported to participate in research projects, sometimes over extended periods of time. There are ethical and moral imperatives for including children's voices in our research, and it is apparent when we do so the process and outcomes of their involvement can be rewarding and beneficial for all concerned.

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