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Guidelines for research into the effectiveness of Assistive Technologies (AT)

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An ESRC funded seminar series entitled *Researching the use of assistive technologies by children and young people: interdisciplinary perspectives* took place in 2010-2011. The seminars were organised by Dr Chris Abbott, King's College London and Professor Jannet Wright, De Montfort University, Leicester. The focus of the seminars was on research involving children and young people with disabilities within Education, Health and Social Care. The seminars brought together researchers and users of research: teachers, therapists and developers, including those undertaking Doctoral research. One of the aims of the seminar series was to provide information for practitioners, researchers and developers and to help to build research capacity in this area.

These guidelines are one of the outputs from the seminars. Those contributing to this document include Professor Jannet Wright, Dr Kieron Sheehy, the Open University, Dr Sarah Parsons, the University of Southampton and Dr Chris Abbott. The bibliography provided is intended to help people extend their knowledge in this area of research.

Context

The term assistive technologies (AT) is used in these guidelines to refer to the wide range of digital technologies, often hardware or software-based, which have been developed to support interaction, communication, understanding and learning for children and young people with disabilities. This is a narrower definition of AT than that used for example by the World Health Organisation (WHO) which defines AT as: '*An umbrella term for any device or system that allows individuals to perform tasks they would otherwise be unable to do or increases the ease and safety with which tasks can be performed.*' (Glossary of Terms for Community Health Care and Services for Older Persons, 2004; cited by http://www.fastuk.org/about/definitionofat.php).

The wider definition used by the WHO can include devices such as hoists, ramps, wheelchairs and hearing aids, but in this paper the specific focus is on digital technologies that include 'standard' Information and Communication Technologies (such as PCs and laptops and associated software); specialist / adaptive devices (such as Voice Output Communication Aids) and new, emerging and innovative technologies (such as Virtual Reality and augmented reality technologies).

These new and emerging technologies are receiving increasing research attention, especially over the past decade, and often for particular groups of children. Parsons and Cobb (2011) have produced a review of virtual reality technologies for children with autism. However, other forms of AT especially those considered 'standard' or 'mainstream' are generally under-explored through funded research. There is variability in their use as highlighted in the Bercow Report (2008) on support for children and young people with speech, language and communication needs (SLCN), and by previous research into national systems of assistive technology use (Wright *et al.* 2004; 2006).

It has also been suggested (Abbott 2007) that much of the literature has been related to the evaluation of technology itself rather than its use, and this has led to a proposed taxonomy which may shift the emphasis.

- Technology uses to train and rehearse
- Technology uses to assist learning
- Technology uses to enable learning

This taxonomy has been adopted as the framework for the literature review covering the period 2007 to 2010 which has also been published as a result of the seminar series (Abbott *et al.* 2011).

The aim of the *UN Convention on the Rights of Persons with Disabilities* (CPRD 2006) is to safeguard the rights of disabled people. It encompasses issues such as accessibility, education and health. Its purpose is to '… *promote, protect and ensure the full and equal enjoyment of all human rights by persons with disabilities'*. A hundred countries have signed up to the CRPD including the United Kingdom (DESA 2011)

The CRPD requires governments to meet the AT needs of disabled citizens (Borg *et al.* 2011) and is specific about the importance of AT in supporting their rights. It should be noted that these safeguards mention digital technologies specifically alongside wider types of AT devices. For example

> Article 4(g) *'To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost'.*

> Article 4(i) *'To promote the training of professionals and staff working with persons with disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights'.*

> Article 4(h) *'To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities'.*

Research into the effectiveness of assistive technologies is seen by the CPRD as essential in supporting the rights of disabled people and as an activity that is underpinned by inclusive values. These values also inform the research process itself. The Convention stresses the importance of individuals being enabled to make their own choices and the importance of assistive technology in removing barriers to participation and in supporting independence in decision making (Borg *et al.* 2011) This therefore directs researchers to consider the affordances of assistance technology in supporting the full and informed engagement of participants with the research process itself.

Guidelines

As has been shown by Abbott (2007), much of the research on assistive technologies has grouped around key technologies or themes rather than uses, particularly those technologies that are primarily aimed at providing the opportunity to practice a skill that has already been acquired. Very little longitudinal research has taken place with regard to the long-term use of assistive technologies, although this is slowly beginning to be addressed. In the more recent review linked to the ESRC seminar series (Abbott *et al.* 2011) a series of new developments in the literature were noted. These included a growing acknowledgement of the need to involve users in research, the demand for assistive technologies to be located in mainstream devices, the role of serious games, the potential of haptic interfaces, immersive multimedia and brain interfaces.

Multi-disciplinarity

The value of multi-disciplinary research

The seminar series *Researching the use of assistive technologies by children and young people: interdisciplinary perspectives* highlighted the diversity of the researchers and practitioners who were interested in this area. Those attending the seminars included researchers from education as well as educational practitioners, computer scientists, designers, engineers, psychologists, occupational therapists and speech and language therapists. The value of a multidisciplinary approach to research is that everyone brings their own perspectives to the problems encountered when working in a particular area. This type of research enables a 'sharing of a common vision, working towards common goals and sharing a common language, in support of children and families' (Barnes 2008; 239). The multiplicity of views and approaches is further emphasised when the AT user is part of a research group. Then the value of different views, approaches and methodologies can be of benefit to researchers, professionals and service users. Indeed, Parsons *et al* (2011) suggest that multi-disciplinary teams are usually *necessary* for accomplishing the goals of assistive technology research (see also Beardon *et al.* 2001), and that '…it can be possible to work positively within these differing views [of multidisciplinary teams] if user needs and views are accorded appropriately high status within the development of the project' (Parsons *et al.* 2011; p.30).

Multi-disciplinary research provides an opportunity to share literature, gain new knowledge and be intellectually stimulated by the challenges from those who have different viewpoints from one's own. The common goal of trying to answer a particular research question should enable a multi-disciplinary research team to work together effectively.

The challenges of multi disciplinary research

However, there are challenges to face when involved in multi-disciplinary research. Everyone will have a different starting point and will often come from diverse theoretical backgrounds which give rise to different conceptual frameworks and research questions. It can be a struggle to understand the concepts and terminology of another discipline; appreciate a particular theoretical stance or value the methodological approach of colleagues from other subject areas. Different members of research teams have different skills and perspectives on the topic being researched and some may feel more comfortable in undertaking particular roles compared to others. A good example of this is working directly with end users (in this case, children and young people) who may be viewed as vital by some members of the team but not within the remit of other members. This can create difficulties when trying to bridge the gap between technologies 'in principle' and those 'in practice'; in other words, the difference between technologies being developed and tested in the lab versus their use and application in real-world settings.

A multidisciplinary team often has to work across agencies and institutions and this brings its own problems, for example in relation to administrative and financial accounting procedures which have to be coordinated across a project. If the team are geographically spread they are likely to have different employers who might have for example, different requirements regarding outputs from the research related to Intellectual Property Rights. Geographical spread can also create challenges with regard to communication between team members, both in terms of language and also in holding effective and regular team meetings. Online teleconferencing and other technologies can help with this but face-to-face meetings remain an essential aspect of successful collaboration. The final hurdle for any multidisciplinary research can be finding an appropriate journal in which to publish the outcomes of multidisciplinary research and so it is important to have discussions within the team from the outset about how a project's dissemination strategy will be planned and managed. Ideally, there should be publications that reflect the wider collaborative nature of the project (often with multiple authors) as well as those that allow individuals or discipline-specific foci to be developed.

Consent

Gaining children and young people's consent to take part in research is an area of considerable discussion and scrutiny (Alderson and Morrow 2004; Christensen and Prout 2002; Lewis and Lindsay 2000). This is unsurprising given the importance of consent within the research process itself as well as the careful thought needed with regard to power differentials between the researchers and the researched and the importance of making information appropriately accessible for the age and ability of the participants.

For children and young people in the field of AT research there are additional considerations beyond being young and presenting information at an appropriate age level; often there are also cognitive, sensory and physical capabilities to take into account. AT

research with and for children and young people most often seeks to address difficulties with learning and communication. It is the engaging nature of the technologies, as well as the different modes of presentation and access that they offer that make them amenable for exploration for such children. Dye *et al.* (2003) suggest that comprehension, decision-making and communication capabilities are key factors that can impact on the capacity of people with learning disabilities to consent to take part in research. These factors are likely to be just as important if not more so when the participant is a child or young person. Dye *et al* (2003) also note that communication takes place in different ways for people with different needs including through the use of touch, sound, pictures and alternative and augmentative communication (AAC), which can include digital technologies.

It seemed surprising when canvassing views and experiences as part of this seminar series that despite the positive rhetoric surrounding the value of AT for providing physical and cognitive access to information this was rarely used for supporting the informed consent process. Many researchers with significant experience in developing and evaluating AT with and for children and young people admitted that they developed 'accessible' paper-based information sheets and forms for younger participants which were intended to be read individually or with support from parents and/or teachers. In this context, 'accessible' usually meant incorporating simplified and shortened text, larger font sizes and the use of photographs and other images.

These are all familiar and helpful means for making information potentially easier to read and digest but there is a need to develop methods for informed consent that utilise the advantages of AT for enabling access to information and for supporting decision-making. It could be, for example, that written text is accompanied by spoken text and that short video vignettes or scenarios could be used to illustrate what a 'focus group' or an 'interview' actually look like. Touch screen technologies – widely prevalent now with the advent of smart phones and tablet devices – could be used for supporting and recording decision-making both at the start, and during the research process. In other words, for children for whom written or spoken responses may be problematic, demonstrating choice through touch may offer an important avenue for autonomous decision-making.

An ethical issue which can be particularly important in research into AT is that of ensuring ongoing consent i.e. that participants remain willing to continue in the research once it has started. For example, very young children or those experiencing significant barriers to communications, will need to have their ongoing assent monitored in a context where this assent can be identified.

With online, augmented or virtual technologies over time participants can forget that they are taking part in a research project. It may be necessary to monitor the participants' awareness that they are in a research project, or make clear delineations between private, public and research spaces. For example, participants in research within virtual worlds can easily forget that their interactions are being recorded and analyzed. Given the immersive and engaging nature of these technologies some researchers have felt it necessary to place distinct indicators of when actions are being recorded. For example, the researcher's avatar might display a 'Logging chat' message to ensure participants awareness and to support ongoing assent (Sheehy *et al.* 2008).

User participation – the importance of voice

Over recent years, children and young people have been regarded as having rights in connection with decisions affecting their lives. The impetus for this came mainly from the United Nations Convention on the Rights of the Child (UNCRC 1989) Article 12 which says that:

> *'State parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child'*

This places the rights of the children and their views on an equal footing to adults; in fact, the perceived potential to undermine adult authority was a key reason why the USA did not ratify the convention (Lundy 2007). It has been adopted by the UK so there is now a legal obligation to give effect to it in full and this includes submitting to reviews of progress and developments by the UN Committee on the Rights of the Child (The Committee).

Disappointingly, however, in 2002 The Committee reported that *'in education, school children are not systematically consulted in matters that affect them'*. This led to a recommendation that the UK Government should take further steps to *'facilitate, promote and monitor systematic, meaningful and effective participation e.g. through school councils'*. Attempts to address this can be seen, for example, in the Duty to Promote Community Cohesion (Education and Inspections Act 2006) which emphasises the importance of

> *'ensuring that pupil voice is heard and able to effect change: by involvement of pupils in governance and organisation of the school through school councils, in a way that facilitates their participation and ability to make a difference in school, in their local community, and beyond; or enabling pupils to take responsibility and to evaluate how well the school is building community cohesion'* (DCSF 2007).

Other legislative imperatives or guidelines have also supported children's rights, for example:
- the Children Act (1989) by prioritising children's welfare over parental rights in court cases;
- Every Child Matters, in which one of the five main outcomes is for children to be '*empowered to make a positive contribution*';
- the Special Educational Needs Code of Practice (2001) which states that:
> *'children with SEN have a unique knowledge of their own needs and circumstances and their own views about what sort of help they would like to help them make the most of their education. They should, where possible, participate in all the decision-making processes that occur in education including the setting of learning targets and contributing to IEPs, discussions about choice of schools, contributing to the assessment of their needs and to the annual review and transition processes. They should feel confident that they will be listened to and that their views are valued. However, "there is a fine balance to between giving the child a voice and*

encouraging them to make informed decisions, and overburdening them with decision-making procedures where they have insufficient experience and knowledge to make appropriate judgments without additional support". ' [section 3:2; p.27]

- the Disability Equality Duty (DDA 2005) which includes the Specific Duty to develop a Disability Equality Scheme, the central requirement of which is to include disabled people, and children, from the start i.e. a more active engagement of disabled stakeholders at all stages rather than simply participating in a consultation exercise. This extends to schools and the inclusion of disabled pupils in the development of the scheme.

Hearing what children have to say about matters that affect them is not just a good model for education and other services but a legally binding obligation. Following the UNCRC and the embedding of the 'right to be heard' in many different legislative contexts and guidelines it is no longer in dispute that children should be 'involved' and their views 'heard'. However, there are some groups of children who are less likely to have their views heard and these tend to be children from marginalised or disadvantaged groups, especially those with disabilities or Special Educational Needs. The need for their participation has been emphasised by the UN and The Committee has stressed the particular need to guarantee participation of children with disabilities. They argue that these children potentially suffer a 'double denial' of their right (through being children and through being disabled) because of an 'even deeper inability to accept child's competence'.

The reasons for listening to the views of disabled children are the same as the reasons for listening to all children. But with disabled children, engaging in decision-making processes may require specific skills and reasoning for the young person perhaps not used to participating in this way and this requires facilitation and support. According to Dickins (2004) it is important to make extra efforts to include disabled children in decision-making because they:

- are subject to much higher levels of adult intervention and so their scope for making day-to-day choices is often limited;
- have many things done to, and for them – significantly more vulnerable to abuse;
- are more likely to be subject to medical treatments and interventions;
- are more likely to be involved in various kinds of assessment procedures and less likely to be involved in the process;
- are more likely to be excluded from consultations due to reliance on written and spoken language;
- are supported by parents and staff who may see their role as advocate rather than listeners or neutral mediators;
- are more likely to have contact with multiple carers who may lack the skills to understand child's communication system.

Indeed, communication difficulties are most often cited as the reason why disabled children, especially younger ones, are not consulted, at least in research contexts

> '*Children who could not read, who were cognitively impaired, or those with emergent or serious illnesses were excluded*' (Tait *et al.* 2007; p.359).

This is partly due to assumptions that are made about children's capability to form and express views but also, often, because researchers and practitioners lack the skills and knowledge to make information appropriately accessible and to support responses in different ways. It is clear that AT could have a significant role to play in these regards. There is a greater onus on researchers and practitioners to ensure that they are equipped with the right materials, skills and knowledge to be able to attempt this in meaningful and authentic ways. This also accords with Article 13 of the UNCRC which states that children's right to freedom of expression includes a right to impart information 'either orally, in writing or print, in the form of art, or through any media of the child's choice'.

However, there are relatively few studies regarding children's views about schooling and fewer still regarding young people's perspectives on AT. To paraphrase the comments of McIntyre *et al.* (2005) it cannot be claimed that AT are intended to benefit young people if their views about what is beneficial to them is not actively sought and attended to. Children with disabilities have been an unheard and marginalised group. Where these children have significant communication barriers the situation can be compounded. It this therefore important that researchers explore and seek genuine opportunities for children and young people's voice to be heard.

> '*Listen to what disabled children say about their lives, respect their wishes and support their choices*'. Shakespeare and Watson (1998) p. 26

In this context it is important to highlight that a communication device is only one part of the person's communication repertoire and researchers need to consider placing it within a broader communication context, for example speech approximations, signing, and the interpretation of those who are familiar with the child. A variety of methods are being developed to support this endeavour, and for children with the most severe communication difficulties (such as profound and multiple learning disabilities) this may involve structured conversations or technologies' mediated by those who know them well. This can raise issues of consent, ownership, power relations and control. This creates a complex situation within which researchers need to be sensitive to different communication routes and influences when seeking to promote the young person's voice and agency.

Parents

Parents have been a useful source of information for researchers about the ways in which AT are used or perceived to be used and what is the value of a particular aid or system (Newton *et al.* 2007; Golbart and Marshall 2004). When observing parents and children using a communication device together certain patterns of interaction can appear. Researchers need to avoid making assumptions based on their observations as Clarke and Kirton (2003) remind us that in some situations particular patterns of interaction may occur because one partner has a communication problem rather than the behavior being a '*function of pre-determined roles*'(p145).

Practitioners

Practitioners may be involved in two ways with research into the AT area. They may be members of a research team or they may themselves be subjects in a research project.

If practitioners are involved in carrying out research in this area then they need to ensure that they have the right materials, skills and knowledge to be able to elicit the views and experiences of children and young people who use AT. The advantage of a multi-disciplinary approach described earlier is that it enables those who work closely with the children and young people on a regular basis, such as teachers and speech and language therapist, to share their expertise with other colleagues in providing information about successful ways of interacting with pupils who have SLCN. These professionals will also be able to provide information about how to establish the children's levels of understanding and expression.

Practitioners may find themselves as subjects when research in the AT area is being carried out. Their own professional training, role and prior experience will be a reference point for them if they are involved in completing questionnaires, being interviewed or observed. Participation in research often provides practitioners with an opportunity to reflect on their own views and practice. It provides an opportunity to explore views that one may have about the work but which had never been articulated until asked about a particular aspect in an interview.

Conclusion

These guidelines are one of the outputs from the ESRC funded seminar series '*Researching the use of assistive technologies by children and young people: interdisciplinary perspectives*'. They outline many of the issues to consider when carrying out research in the assistive technologies area especially the facilitation of the involvement of children and young people. The guidelines provide information for those planning research in the area of assistive technology and for those who have no experience in this area, the bibliography provides an excellent starting point.

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