

What technology for autism needs to be invented? Idea generation from the autism community via the *ASCmeI.T.* app

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Abstract. In autism and technology research, technologies are often developed by researchers targeting specific social and communication difficulties experienced by individuals with autism. In some technology-based projects, children and adults with autism as well as parents, carers, teachers, and other professionals, are involved as users, informers, and (more rarely) as co-designers. However, much less is known about the views of the autism community about the needs they identify as areas that could be addressed through innovative technological solutions. This paper describes the *ASCmeI.T.* project which encourages members of the autism community to download a free app to answer the question: If there was one new technology to help people with autism, what would it be? This project provides a model of e-participation in which people from the autism community are involved from the start so that new developments in digital technologies can be better matched to support the needs of users.

Keywords: Autism; crowdsourcing ; e-participation; inclusion; social justice

1 Introduction

Increasingly there has been important recognition of the value of involving so-called ‘end-users’ in the development of technologies through participatory design processes [6]. Not only is such involvement important in terms of ensuring that technologies are more accessible and usable for everyone, including disabled users, but involvement can also be empowering for individuals by enabling their

digital and social inclusion [3]. Moreover, the participatory design of technologies has been suggested as an essential principle in ensuring that human-computer interaction as a field of study is more ethical and responsible with regard to innovation [1].

Our interest in this paper is how technologies could be developed better to meet the needs of people with autism and those who support them (including families, teachers, carers, other professionals and practitioners). Internationally, Autism Spectrum Disorder (ASD) is the fastest growing developmental disability [5], creating significant challenges for educational, health and social care services [4, 16], as well as for families and individuals (e.g. [7, 9, 10, 12]). The increasing prevalence of autism is recognised as a global health priority [20], with WHO member nations being urged to prioritise the needs of individuals with autism and their families and communities through increasing research in service provision in order to improve available support.

2 State-of-the-art

Technology has an important role to play in this context, with strong interest from the research community especially regarding how technologies can be applied to support the social and communication difficulties that are the core diagnostic features of ASD [14, 18, 19]. Participatory design of technology is an increasingly important part of this wider context, recognising the unique perspectives and experiences that people with autism, and those who support them, can contribute to the process (e.g. [8]). There are acknowledged challenges involved, not least the thorny issue about who actually makes the decisions about the features of a technology that may or may not get developed [15]. There are also important discussions and recommendations about how methodologies and activities can be planned and structured more effectively to support the communication and interaction needs of children and adults with autism (e.g. [2, 13]).

Nevertheless, despite there being more examples of projects that have involved people with autism in participatory design processes focusing on how to develop particular features or content, there is a lack of evidence that people with autism have been involved in the initiation of ideas about which technologies need to be developed in the first place. In other words, assumptions are made about the needs of people with autism and how technology may meet those needs, without first establishing whether those are the right priorities for people with autism and their families. The priorities targeted in research may of course be aligned with the priorities of people with autism, although there is evidence that suggests that substantial caution may be needed in making this assumption. Pellicano et al [17] found that individuals with autism and their families felt excluded from most research and wanted research to address issues that were of greater importance and relevance to them, namely: education for life skills and services to support a range of needs. By contrast, the bulk of research funding targeted biomedical topics focusing on etiology and treatment.

In technology-based research, it could be that the priorities of members of the autism community are already being addressed. Alternatively, it may be that there are overlooked areas that are important to the autism community but which are not yet being tackled by researchers. Either way, there is a need to find out more about the needs and wishes of people with autism and their families within this context. There is a strong social justice argument for ensuring the stronger representation of stakeholders' views in shaping the research agenda as well as participating more fully in research. The *ASCmeI.T.* project provides one way in which this social justice agenda could, at least partially, begin to be achieved.

3 The *ASCmeI.T.* project and methodology

3.1 Development of the app

The *ASCmeI.T.* project was inspired by Barnabear - a self-described 'Aspie and software engineer.' Barnabear was an invited speaker at our ESRC funded seminar series on 'Innovative technologies for autism: critical reflections on digital bubbles' (<http://digitalbubbles.org.uk/>). He highlighted the wide variation of needs of people with ASD, and challenged the audience to consider: 'What problem would you want solved and what [technology] would you invent?' This important question led us to develop a project idea based on sourcing suggestions for technology development directly from the autism community.

We subsequently secured funding from the Universities of Southampton, Bath and Sussex for the project, involving Barnabear as a consultant, to develop an app that allows members of the autism community to answer the question: If there was one new technology to help people with autism, what would it be? The format of the *ASCmeI.T.* app was based on a free crowd sourcing community app called 'ifOnly' to encourage people with disabilities to share the problems they encountered in everyday life. The 'ifOnly' app (developed by Austin at the University of Bath), allowed people to record, upload and share videos and audio that demonstrated everyday problems they faced at home.

Two versions of the *ASCmeI.T.* app (for Android and iOS) were developed at the University of Bath following iterative development within the research team. At the start of the development process, the app developers reviewed the 'ifOnly' app and developed some wireframes for the initial *ASCmeI.T.* idea. These were shared with the project team, and Barnabear provided feedback on the wording of the main question as well as clarity of the information and ease of navigation through the different screens. Users of the app can upload a short video (less than 1 minute) that describes their idea and/or email their idea to the project team. Figure 1 shows screenshots from the app, showing the main question and options for making, and submitting, ideas. The apps were made available for free download in July 2015 from the App store (for iOS) and from the Google Play store (for Android). A project website provided further information about the project, including the schools prize draw, and general terms and conditions (see <http://ascme-it.org.uk/>).

Research Ethics Committees at the Universities of Bath, Southampton and Sussex all reviewed and approved the project.

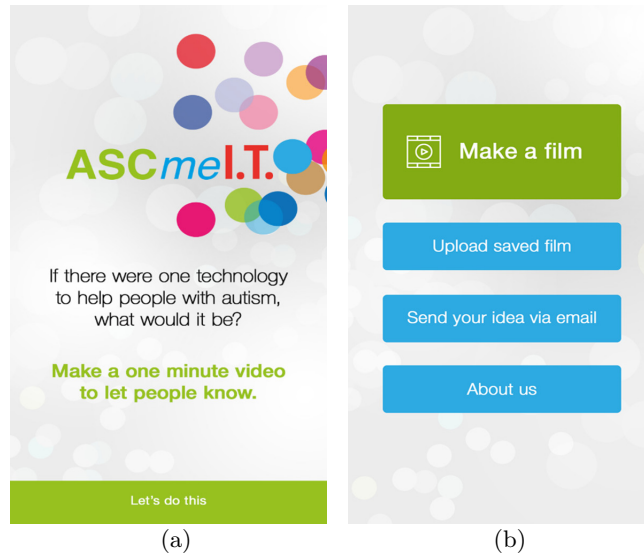


Fig. 1: (a) the opening screen of the app with the main question; (b) the screen showing options for submitting ideas

3.2 Encouraging submissions

We have promoted a first ‘wave’ of the project so far (Sept to Nov 2015), with a specific focus on encouraging schools (teachers, pupils and parents) to submit ideas via the app. We had 30 Raspberry Pi Starter Packs available as free prize draw entries to incentivise school submissions. We visited local schools, put out local press releases about the project (which were picked up by local radio and print media), and utilised our educational and autism specific networks to raise awareness. We have also promoted the project, and the free app, at various practitioner and academic conferences, nationally and internationally.

In response to the first wave of promotion we have had 198 (iOS) and 273 (Android) downloads of the app, with 28 usable ideas submitted via video upload or email, from the UK, US and India. We are currently collating and analysing these ideas and have given 12 Raspberry Pi packs away to school-based entries in the prize draw. We have recently launched a second wave of the project (March to June 2016) to encourage further submissions from schools and colleges, and the autism community more widely. This should allow us to continue to update our

picture of the needs being identified by members of the autism community so that we can begin to select and shortlist some of the ideas for further development.

3.3 Illustrations of ideas submitted so far

As an illustration of the ideas submitted in the first wave, 16 out of the 28 entries were from school pupils or adults on the autism spectrum. Other submissions, where participants supplied this information, came from friend / associates, parents, or teachers. Ten ideas related to academic subjects and skills, with five of these focusing specifically on Maths, for example:

“I struggle in the area of Maths and I was thinking of a Maths app. On the one side you could have tutorials on how to do different questions and on the other side you could have different kinds of categories that people struggle with, and so maybe you could start with the basics of adding and subtracting and there can be certain questions that would help them”—student with autism.

Eight submissions related to social communication and interaction, covering a range of issues including: bullying, anxiety, facial recognition, making new friends and being supported, asking the right questions, and expressing feelings:

“Having worked with lots of autistic children over the years, although they are all different, obviously one of the things that they do have in common pretty much is social communication problems. So an app that they could use to express how they are feeling would be really useful as a lot of the time, especially when they are frustrated, they haven’t got the words to tell you and a Boardmaker symbol doesn’t really quite cut it”—teaching assistant.

Other suggestions covered more general issues, such as having a personalised suite of games targeted at the things that an individual feels they need help with; helping individuals with scheduling of daily tasks; and suggestions for the functional organisation of a space. One especially thought-provoking suggestion came from a student with autism who said:

“My idea is . . . something that helps people that feel their autism is a curse that would boost their morale. It could contain weblinks to pages explaining autism and pages explaining what it might mean for them, how other people felt with it, and some statistics like 1 in 100 children is autistic. I think that could boost their morale and get them through their social life and their academic life”—student with autism.

Overall, we received an interesting first round of suggestions covering some of the things that we might have expected (e.g. those related to social difficulties) but also some things that may tend to be overlooked in autism technology research, particularly ideas related to academic subjects (cf. [11]).

4 Contribution to the field and next steps

The *ASCmeI.T.* project is unique in aiming to tap into the personal experiences and creativity of people with autism, and their families and teachers, to generate ideas about technological solutions that might help them and benefit others. This is the first opportunity in the UK, as far as we are aware, for people from the autism community to get involved from the start so that new developments in digital technologies for autism can be more closely matched with the identified needs of users. We have a strong foundation upon which we can continue to encourage the submission of ideas during 2016, including working with autism organisations in the UK to promote the app nationally, and with Masters students at our institutions to develop more detailed specifications and/or prototypes for some of the ideas. The aim of the project is to work with some of the ideas submitted to develop them further and bring them closer to reality. The eventual aim is to make individual and social impact with technology ideas generated by the autism community, for the autism community.

We also plan to research whether the issues that people have described in their submissions have digital technology solutions that already exist; looking at the first round of submissions our hunch is that this may well be the case for many of the suggestions. Therefore, it could be that one of the main challenges for users is being able to find existing solutions to the difficulties they identify, rather than those solutions not existing in the first place. Whatever we find out will be of value for the field: we will know more about the issues that people with autism, and those who support them, identify as areas of particular need; we will scope out the feasibility for further development of some of the ideas submitted; we will be able to signpost the autism community to current potential solutions (where these exist); and we aim to work with industry partners to bring some of the ideas to fruition with the goal of making a real difference to the lives of at least some people with autism.

More widely, the methodology of the *ASCmeI.T.* project establishes an approach that could be utilised with many other user groups. In this sense, the project provides a model of e-participation that has significant potential. As technologies continue to change at a dramatic pace, and the assistive technology industry undergoes significant change, this model of e-participation offers an accessible, and potentially powerful, way forward in seeking to ensure that concepts for new technology have evolved directly from user preferences and needs. In this way, the market may be more prepared to access and use the final product, with concomitant benefits for designers and companies who wish to seek a better return on their investments.

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