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Engaging IT Students in Co-Design with People with Intellectual Disability

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Abstract

Current and emerging participative design practices are providing opportunities for people with intellectual disability to have a say in how technology can best support them and their individual needs. Yet technological experts and designers are not always confident to be included in co-design sessions with people with intellectual disability and often favour less inclusive projects to focus on. In this paper, we present lessons learnt from a series of co-design exercises aimed at designing mobile or web applications to support people with intellectual disability, including a reframing of the concept of reciprocity. We believe these lessons can serve as recommendations for IT experts or IT students, to be encouraged and enabled to design with people with intellectual disability, thus supporting a greater inclusion.

Author Keywords

Intellectual Disability; Co-design; IT students; ethics.

ACM Classification Keywords

H.5.2. Information interfaces and presentation (e.g., HCI): User Interfaces; K.3.2 Computers and education: Computer and information science education.

Introduction

Inclusive design practices are positively evolving towards co-design approaches, leveraging a wider range of user abilities to engage users with intellectual disability (ID). The American Association on Intellectual and Developmental Disabilities defines ID as "a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. This disability originates before the age of 18" (aaidd.org). With this in mind, we see co-design approaches [9] as a three fold opportunity: a) valuing people with ID as creators and designers and giving them a sense of agency, b) opening up inclusive design opportunities to people who are not expert in disability (such as IT students), and c) increasing the usefulness and usability of the designed products. As pointed out in previous literature reporting on co-design case studies, rapid prototyping provides a means to accelerate the designing phase with concrete probes that are meaningful to people with ID and allows them to express their ideas in terms of concrete creative evolutions and criticisms of proposed iterative designs.

IT students and technical experts have a tendency to have reservations about their own ability to engage with people with ID. Some resources propose tips for engagement to respond to the "daunting" feeling that too often lead people to simply avoid direct personal engagement. While we are not proposing here to specifically study student's populations and their feeling about co-designing with people with ID, we present our reflections and observations as positive insights from our experiences with the hope to encourage more inclusion in co-design activities between IT students and people with ID.

After introducing related work, we present our case studies in the following section. We then present our reflections and observations.

Related work

Lewthwaite and Sloan [6] highlight the importance of raising awareness of accessibility issues for computing students, however focuses on pedagogical aspects only. Kurniawan et al. [5] suggest instead that practical experiences of students in group projects or volunteering activities is effective to increase student's awareness. University instructors who teach accessibility interviewed by Putman et Al. [7] also highlighted direct interaction with people with disabilities as a primary approach and a way to build "true empathy". Rughinis and Rughinis [8] embed the concept of building empathy through a design that allows students to experience concepts related to accessibility for blind people.

Most of this work is focusing on pedagogical approaches and often on physical disability and blindness, but there is little work investigating interactions between computing students and users with ID. Users with ID often find questions such as "why" and "how" confronting, therefore typical approaches to participatory design and interviewing may not necessarily be seen as appropriate. For students who may or may not even be familiar with these methods, this can lead to discomfort in actually engaging with potential users of their systems who have ID, and they may be tempted to solely rely on proxies.

Ethical guidelines for the conduct of research could also be read as excluding students or IT experts who are not trained in supporting people with ID, as they request indications of training for those conducting interviews. However, what is actually required is merely the presence of a trained supervisor. Support workers can act in this respect, and also support the process itself.

Case studies

We reflect in this paper on three selected case studies where individual students have co-designed with participants with ID. The students were all Master of IT (coursework) students in their final year and elected to undertake their projects. They had varying levels of expertise and experience in design, and no prior experience in designing with people with ID. All projects were approached as a design iteration with an initial aim, a literature review leading to an initial prototype, co-design sessions with potential users with ID incorporating semi-structured interview and observation.

The first case study is for the design of an accessible mobile application to support people with ID when using public transport in a large city. The design was led by a student specializing in user experience. Co-design sessions were conducted with 3 users with ID accompanied by a person supporting them. The whole process has been supervised and observed by a researcher with experience in co-designing with people with ID. An initial design and prototype has been developed by the student based on the literature to serve as a probe, and each user has participated in a 1 hour co-design session that has been video and audio recorded (approved by the QUT ethics committee under application 1400000673). This student had a background in architecture and design, and had previously run focus groups.

Other case studies we reflect on include two projects where 2 students have each conducted interviews and trials of their respective prototypes with people with ID. The first project was an updated version of the transport application and run by a student specializing in data science with experience in user centered design and mobile application development. The second project included two iterations of an accessible search engine and was run by a student specializing in computer science with no experience or knowledge of interaction design. These sessions were attended by the same researcher, and reflected upon in line with the previous recordings, however were not recorded themselves.

All the applications designed aimed to support people with ID when accessing various forms of information. As a result, they were targeting users who are familiar with mobile technology and who have some ability to read and/or write. The users who participated in the sessions were selected and invited by a disability service organization (DSO), who is a partner on all the four respective projects. The DSO supports people with ID, according to the AAIDD definition presented in introduction. The organization supports an ability-centric approach to designing support, and followed these principles in selecting participants, rather than being diagnosis-centred. Staff from the DSO have invited users who could potentially benefit from the proposed designs to participate in the trials. The participants have taken part individually in the sessions, with a carer present (support worker or teacher).

Prior to each session, it was made clear to the participants that all study data will be kept confidential and that they can discontinue their involvements at any point of the session, if they felt uncomfortable.

Lessons Learnt

From our first case study, we have presented in previous research [10] an analysis of how the use of prototypes is highly supportive of engagement of users and key to eliciting suggestions from the users. We have also previously reflected there on the involvement of the carers in the process, and their ability to rephrase what students ask in a contextualized and easy to understand language. In this paper, we reflect on aspects of student engagement, with a view to provide a positive perspective.

Emotional response and fast learning

The most salient observation consistent across our case studies was the emotional state of the IT students. At the beginning of their first interview, they were all equally nervous, and relying extensively on either the carer or the researcher for reassurance after every question asked. As the sessions progressed, and between sessions, they all became more comfortable, picked up on ways that the support worker were rephrasing to start employing similar strategies, and were speaking in louder and more confident voices.

Reciprocity

The students involved all spontaneously embraced the idea that since participants are adults, then they should speak to them as adults. In some instances, the proxy/carer had to guide them towards speaking louder and slower than usual.

Researchers and designers are often in a power position that can be very difficult to attenuate when running co-design sessions. One of the reasons is that the concept of benefit from the work to a researcher can be very abstract for people with a disability and therefore difficult to grasp. In our view, this could actually result in them feeling in a position of being needy and supported. While ethical principles around the idea of reciprocity [3] would tend to favour giving back in the form of helping, we believe that providing a genuine feeling of agency may at times be more powerful and empowering for users with ID.

We are further proposing that the context of a student is much easier for them to relate to, and can therefore be a stronger element to re-establish. Indeed, students have a genuine requirement for honest input from the user of their designs, as this will impact on their assessment. As such, they can position themselves in an equal position of power as opposed to yet another “caring” role. We have found this critical in introducing and running the sessions. The message is no longer “I value what you have to say because I care about you” but rather “I value what you say because I need your input for my project”, which is both respectful and inducing a sense of agency for the participant. Being nervous and sharing this is another fabulous way to level the power and reach more genuine conversations.

In line with this, it is critical for students to include reflexivity early in the process. Such a look at who we are: our status, our gender, our experience, our religion, everything about us, impacts on our understanding of the people we are working with [2].

Communication

When working with participants with ID, the main challenge often perceived is the sharing of common language of conversation between the important stakeholders (i.e. researchers and participants). The carer/teachers were able to rephrase sentences when the participants were facing difficulties in understanding the students' questions, which prompted them to modify the question pattern in a more concrete way. Simple rephrasing would change the response of the participants. Examples we observed included mentioning "train or bus" instead of "public transport", or naming family members instead of saying "someone from your family". The students picked up these approaches very rapidly by observing how the carers rephrase their questions, and how open ended questions are not leading to constructive answers.

Visual clues

In our videoed work we found that after one hour, one participant began yawning, and another participant started looking at their watch, which meant that they wanted to end the session. This timing is consistent with what we have observed in the other case studies, as well as aligns with typical recommendations from DSOs. The student was always able to naturally read these clues and offer to end the session. However, in one instance, the student misconceived signs of boredom and disengagement (ie. changes in breathing patterns) with signs of tiredness such as yawning, eyes closing or slower responses, which would typically signal the end of the interview.

There is always a tension between the need to understand context around the participant through interviewing, and the challenge to keep participants engaged and motivated throughout a session. Interview responses and observation should normally be verified through repetition, and in turn repetition rapidly led to boredom with the participants. Throughout the case studies, varying the co-design tools presented (verbal ideation, paper prototypes, digital artifacts) served to re-engage participants. Digital artifacts worked particularly well in all our projects. The recorded sessions provided concrete evidence of this through facial expression: they were thrilled with excitement specially when hearing text to speech output from our digital prototype.

Role of the carer

Some researchers argue on the level of risk for researchers to rely heavily and uncritically on input of proxies who speak on behalf of persons with impairments [4] while others describe the importance of engaging them in the design process [1]. From our experience, carer and teachers act not only as a medium of communication between stakeholders but also, because of their good understanding of the person with disability, they provide important feedback and perspective. We also found them always very conscious to make sure people with a disability have a voice and are placed at the centre of their experiences.

Carer and proxies also provided valuable insights into meaningful participant behaviour. Carers are able to notice unusual levels of engagement as important clues that might not be obvious to an observer. An example during our sessions was a user who started smiling a lot at the point of trialling the digital prototype, which was not a common behaviour for that participant.

Conclusion and Future Work

We have shown that computing students, with minimal guidance, within the context of a DSO, and regardless of their prior experience of design, are perfectly able to take part in mutually enriching experiences of designing technology with people with ID. Our reflections can serve as simple guidelines that we hope will encourage more students and DSOs to take part in such co-design activities, which can support the development of more accessible technologies but also better train technical students with an ingrained awareness of inclusiveness.

In many ways, such derived guidelines would not be more elaborated than any guidelines on running participatory design sessions, and may seem trivial for the acute designer. It positively supports that people with ID should not be excluded from educative experiences in IT on the basis of perceived ethical risks. In future work we will survey students in order to better understand their motivations and experiences with this type of deep engagement with people with ID.

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