Designing for Special Education Schools

Involving Children with Intellectual Disabilities in the Design Process

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ABSTRACT

In this paper, an approach to designing technology for children with intellectual disabilities is presented. The paper introduces a recently initiated interdisciplinary research project, and discuss related work that can be utilized as a foundation for the approach being developed. Based on experiences from the project, the paper suggests a design program to be established in order to adapt existing models and frameworks for designing new technology for children with intellectual disabilities. The program is founded on two main key findings, namely the importance of involving both children and adults with intellectual disabilities in order to better understand the needs, and to involve a number of different technologies and stakeholders in the design process to design a range of different types of prototypes and systems.

General Terms

Human Factors, Design

Keywords

Interaction Design, Design Programs, Children, Intellectual Disabilities, Special Education Schools

1. INTRODUCTION

In 2009, children in the grades 6 and 9 in the Swedish Elementary School took part in a national health survey answering questions regarding psychosomatic symptoms, depression, bullying, attention difficulties, poor well-being and consequences of these symptoms in their everyday lives [6]. The findings from this survey were somewhat worrying, and showed a lower level of mental well-being among children and adolescents in Sweden than anticipated.

Perhaps even more worryingly, children suffering from intellectual disabilities (ID) in Sweden's Special Education Classes were completely left out of the survey; these Special Education Classes consists of nearly 11.000 pupils [19]. This is worrying considering the fact that surveys such as these forms the basis for planning future health-promoting interventions and research shows that children with disabilities more often show symptoms of poor psycho-logical health. As many as 30-50 % of children with ID fulfil criteria for one or several psychiatric diagnoses [16, 20]. The symptoms between children with and without ID does not differ substantially, but sometimes the symptoms in children with ID are seen as part of the disability or missed altogether, as children with ID have difficulties in the areas of communication, locomotation or social relations. Furthermore, the method used for these investigations, namely questionnaires, is not well suited for children with ID. Scott et al. tried to include children and adolescents with ID in national health surveys; the result showed that only 25% of the pupils managed to complete a standard health questionnaire to the extent required for being included in the result of a national survey[17]. The only issue was not the low response rates, but also reliability. For instance, 80% of the children answered that they had the "best possible" life to a question about general life satisfaction; a result that does not correspond with results from other studies where more qualitative methods were used[16]. Moreover, in national survey questionnaires, the response alternatives are often likert-scales. For students with ID, both the written form and the likert-scales used may involve challenges. By offering the children oral support and simplifying the questions, the response rate increased significantly. However, such methods are very time-consuming and might not be suitable for large-scale surveys.

Scott et al. suggested that digital versions of the questionnaires should be developed and evaluated[17]. In order to do that, the questions cannot simply be moved from "paper form" to "digital form"; it also requires the designer to consider how children with ID can be involved in the design process. This is important as research have shown that there is a tendency of assistive technology to be disliked and unappreciated by the people with ID meant to be using the technology, often due to not being consulted regarding how these technologies are designed and used [11]. Though studies have shown that these types of approaches can be problematic due to issues such as communicative, cognitive and behavioral difficulties; these issues seem to be possible to overcome by ensuring a well-planned and structured selection and management of the design process. Furthermore, an intimate knowledge and understanding of the user group become vital when customizing the design process towards a untraditional user group [7]. In an interdisciplinary research project between Interaction Design and Psychology from Chalmers University of Technology and Gothenburg University, methods for evaluating the psychological well being in children with ID will be developed and evaluated. One component of the project is to develop a digital questionnaire and evaluate different methods for involving the children in the design process. This paper describes the basic approach used in the project. The goal is to have 210 children in the sixth and ninth grade of Spe-

cial Education Schools from Gothenburg answer the questionnaire during the project.

2. THEORY

This section introduces the related approach of Cooperative inquiry along with other models that grew from that model and the Children in the Centre Framework [4, 5, 9, 12]. A number of other work has also been reviewed, but these two frameworks were deemed the most suitable to base the design process around, as they were among the few who actually presented a model or framework to base future work upon.

2.1 Cooperative inquiry and Levels of Involvement

In 1999, Druin developed an approach for creating technology for children, called Cooperative Inquiry that is grounded in theories such as cooperative design, participatory design and contextual inquiry[4]. The approach is based upon the belief that in order to understand what is needed when developing new technologies, partnering and building a relationship with the users is required. With this approach Druin attempts to capture the complexity and possibly "messy" real-life situations that occurs in an environment, such as a classroom. Furthermore, Druin means that a vast amount of information can be obtain quickly from that activities and artefacts that are part of a user's context. Understanding activities and artefacts of a user's context is crucial in researching and developing new technology. Druin points to three key aspects of Cooperative inquiry: *Contextual Inquiry*, *Participatory Design* and *Technology Immersion*.

In Contextual inquiry, researchers attempts to capture field data in the user's environment, for example in their classroom. It is important to note that Druin suggests looking at the children as *Research partners* rather than research objects; meaning that she thinks that children should be part of the actually researching, such as taking notes about the environment that is being observed. During the contextual inquiry, one (at least) researcher should act as an interactor, meaning: that person is responsible for occasionally asking the children questions in order to try to get them to reason about what they are currently doing. To free space for the interactor to actually interact with the children, note-takers - both children and researchers - takes notes of the observations made in the inquiry. Contextual inquiry allows researchers to explore ideas through observation. After it is completed the data captured is analysed and from that areas of interests can be found and pursued in more depth with different forms of prototyping; leading into the second part of cooperative inquiry: Participatory design.

Participatory design allows the researchers to through participatory design prototyping focus on certain areas of interest that unfold during the contextual inquiry. Druin points to the discovery that children wanted to be storytellers with technology as an example of what can be discovered during the contextual inquiry and later prototyped with the children by using different low-tech material. Druin means that children might find it difficult to communicate their ideas and thoughts about technology to adults and through low-tech prototyping the children are given a different way to express their thoughts and ideas.

Finally, Druin presents Technology Immersion as another method used in Cooperative inquiry. In technology immersion, children are free to themselves decide on what to do with technology in a technology rich environment. Druin emphasize the importance of adults not guiding the children in these environments, but rather allow them to themselves explore and decide what they want to do with the technology. Furthermore, technology immersion focuses on offering the children a time-intensive experience, ensuring that they have sufficient time to become comfortable with the technology. In their case the children were given 10 hours a day for five consecutive days to explore the different kinds of technology and evaluate what they liked and disliked about the technology.

Furthermore, Druin have defined four different roles that children can be assigned when involved in a design process: *user*, *tester*, *informant* and *design partner* [5]. To summarize, when a child's role takes part in the design process as a user, it contributes through using technology while researchers observe, videotape or test their skills in different ways. The main purpose being to allow researchers to understand the impact the technology has on the children and how future technology can be designed with the children in mind. The role as a tester means that the children use prototypes of technology that is not yet "released to the world". Researchers observe the children and ask them for their direct comments regarding their experience with the technology. As an informant, the children play a part at different stages of the design process when deemed useful by the researchers. The children might be observed using technology or asked for input on design sketches or low-tech prototypes. The two previous examples are done pre-development and taking into consideration when designing and developing the technology and when ready any digital prototype is once again evaluated through observation with the children. And lastly, as a design partner, the children are meant to be "equal shareholders" in the design of the new technology and involved throughout the entire process. The role of a design partner might even involve observing and taking notes, coming up with design proposals etc.

Guha, Druin and Fails developed - based on the previous work done by Druin - an inclusionary model for designing for and with children with special needs[9]. The model consists of three layers: Druin's Level of Involvement, Nature and Severity of the Disability and Availability and Intensity of Support. At the first level, the model always sets out to involve the children as design partners. However, at the second level, the children's involvement as design partners might be impossible due to the nature of their disability. Here at the third layer, support should be provided to allow the children to participate as design partners; overcoming any difficulties caused by their disability.

2.2 Children In the Centre framework (CIC)

Kärnä et al. developed a framework for developing technology for children with special needs called Children In the Centre - or CIC - framework[12]. The framework consists of the following five components: 1) Children's interests, strengths and needs; 2) Partnership between children, families, tutors and researchers; 3) Child-centred technologies; 4) Flexible everyday environments; 5) Participation and inclusion to the society. Based on this framework, Kärnä et al. ran several workshops with the children and their parents; these workshops was called "technology clubs" and tried to take advantage of a various range of senses, including visual auditory and kinaesthetic-tactile.

The CIC framework places the child's interests, strengths and needs at the core of the framework; this is essentially done to challenge the traditional ways of seeing these children as objects of interventions or users of technology, which traditionally places the problems-

rather than the children's interests and strengths- in the centre. Moreover, Kärnä et al. emphasize the important of including the parents as they know their children best and their relationship and knowledge of their children and their interests is vital for these children to successfully take part in a participation process. Kärnä et al. state that designing for this group of children and organizing these types of workshops are challenging, but that these challenges can be dealt with by: 1) having the same personnel working with the same children and their families and preparing children to work with different people alone and in pairs, 2) making small changes constantly to the tools used, 3) using pictorial aids such as personally structured maps of the activities, and 4) developing tools with a clear structure.

3. DISCUSSION

The work presented in the previous section emphasizes involving children, with or without ID, in the design process at an early stage in the design process. Druin even suggests that their aim is to always include children - even with special needs - as design partners, making them "equal shareholders" in the new technology. Druin discusses low-tech prototypes as an efficient and good way of allowing the children to express their ideas and make themselves understood to the designers and/or researchers. This is probably a suitable method for typically developed children, but this technique could be problematic when involving children with ID and expecting them to generate ideas and create concepts. Studies have shown that children with ID often have difficulties in reading, writing which results from poorly developed problem-solving strategies. Furthermore, deficiencies in functions such as reasoning and planning are also common in children with ID and this could probably affect inclusion in activities as this[21].

Furthermore, Guha et al. mentions children with visual and hearing impairments and in one the cases case children with autism [9]. The two first disabilities are not intellectual disabilities, which means that what is applicable to those disabilities are not necessarily applicable to the children considered in this project. The children in the Swedish Special Education Classes do often suffer from a mild mental retardation and hence cannot take part in the standard elementary school, which according to the ICD-10 implies an Intelligence quotient of approximately 50 to 69[18, 14]. Furthermore, Down's Syndrome is not listed among disabilities in their model. This probably mean that the children with special needs considered in Guha et al. differs from the children considered in this project. Related to the discussion, Millen et al. state that: "presenting a child with autism with a large blank sheet of paper and asking them to generate ideas is not an option". They point to the typical characteristics of children with autism such as poor imaginative skills, limited language and Theory of Mind impairment as characteristics which might inflict the possibility of including these children as design partners or ideation partners in a design process[13].

In regard to the second level of the inclusionary model, Kärnä et.al argues that the activities performed with the children should be focused on the children's strengths and interests rather than how to overcome the problems caused by the disability[12]. However, in the inclusionary model the second level states the disability of the child is arguable seen as an obstacle that needs to be overcome in the third level. Obviously, the disability and how it can limit involvement in certain type of activities cannot be ignored, but looking at the limitations of the child as obstacles might not necessarily be the most appropriate perspective to approach the target group, but rather looking at their strengths and interests and from there try

to involve them in fruitful ways in the design process. Hourcade et al discusses the tendency of children with autism to lose interest, walk out of the activity or request for changing activity when they struggled with a task[10]. Issues such as these could potentially be avoided by trying to build the activities around tasks that the children enjoy and feel comfortable in performing, rather than activities that the children find problematic but need to overcome.

In related research, with the exception of Alper et al., the idea of involving both children and adults with ID does not seem to occur [1]. One could argue that it presents different challenges when designing for children or adults with ID, but surely it could be beneficial to include both? For instance, perhaps some adults could be involved in different design activities than the children and possible work as a form of reference group were findings from the activities with the children can be evaluated. Furthermore, as stated by Frauenberger et al. designing for any group of people who's profile does not match that of the designer will be challenging and much time needs to be spend to even begin to understand the condition of a person with ID[8]. Alper et al. does discuss the inclusion of designers or researchers who themselves have disabilities in order to increase the solidarity towards the disability[1]. The inclusion of adults with similar conditions as the children as design partners or informants could be one variant of their suggestion of a more diverse community of scholars. Moreover, from the age of 21 and older it is not uncommon for people with ID to further develop their social, vocational and self-maintenance skills; this could mean that adults with ID could potentially be involved in more demanding design activities than the children [2].

As the domain of designing for children with intellectual disabilities seem to be a context that is rather short on strong and well-established practices, establishing a design program aimed at evaluate and develop practices could be suitable. Redström deems a design program as a suitable approach to a context where not many best-practices exists and were there is a need for the search for foundations is a core issue [15, 3]. Thus one could argue that what Redström calls "alternative proto-practices" might be useful in this case when striving towards new practices within this domain[15]. These practices could be developed by founding them on established practices in related fields, such as Druin's Cooperative inquiry, and be further evolved throughout a period of time.

4. CONCLUSION

In this paper, establishing a design program has been suggested in order to adapt existing models and frameworks for designing new technology for children with intellectual disabilities. One key part of this design program is to involve both adults and children with ID in the hope of the adults contributing to a greater understanding of the target group. Furthermore the program will involve other stakeholders such as parents, teachers, personal assistants, designers and researchers with the aim of getting a more diverse group of people involved in the research project, rather than only including the children and researchers. The main goal of the program is to evaluate different approaches and methods for designing for and with children with ID. The aim is to generate new methods of involving these children and other stakeholders in the design process. Initially, the first design case is a digital questionnaire regarding psychological well-being, however, in order to utilize the collaboration between design and psychology institutions, other designs will hopefully grow during the design program and further explore the domain of design for children with ID.

5. FUTURE WORK

At the time of writing this paper, the project discussed in the paper is still in its early stages. The most important step to take now is to establish relationships with both children with ID, adults with ID as well as experts within the field, such as teachers, parents and caretakers or personal assistants. Contact has been established with a Daily Activity Centre in Borås, which can be described as a place for adults with intellectual or cognitive disabilities where they can participate in activities and gain a form of employment; as well as with a Special Education School in Gothenburg and initial visits and observations have taken place at both places. An initial workshop has been held with the children at the school were different graphical representation (cartoons, photographs, abstract images) for three of the items to be used in the questionnaire was discussed and evaluated with the children. Moreover, different response options (see Figure 1) was also discussed with the children. The initial experiences have been promising, and point to the importance of adopting and developing methods for involving children with id in the design process.

Figure 1: Workshop in a Special Education Class.

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