
Only for and with Children with Autism, or Mixed groups? - Reflections on IDC Special Needs Research

Peter Börjesson

University of Gothenburg
Gothenburg, Sweden
peter.borjesson@gu.se

Olof Torgersson

University of Gothenburg
Gothenburg, Sweden
olof.torgersson@gu.se

Eva Eriksson

Aarhus University
Aarhus, Denmark
Chalmers University of Technology
Gothenburg, Sweden
evae@cc.au.dk

Brief Personal Bio:

The authors belong to **IDAC** – Gothenburg working group on Interaction Design and children, <http://www.idac.se/>

The specific project mentioned in the text is **Touch AT!** - Designing interactive assistive touch based technologies for children with intellectual disabilities (ID) <http://touch-at.se/> funded by the Marcus and Amalia Wallenberg Foundation grant 2013.0063

Peter Börjesson is a PhD student in Interaction design at University of Gothenburg.

Eva Eriksson is a senior lecturer in Interaction design at Aarhus University and Chalmers University of Technology.

Olof Torgersson is an associate professor in Interaction design at University of Gothenburg.

Abstract

In this paper, and in relation to IDC research with autistic children, we will address the three questions 1. Are we trying the right thing? 2. Is it working? 3. Does it matter? We will do this based on experiences from our own research with mixed groups of children, meaning children with and without some developmental diversity, including also children within the autism spectrum. We propose 1. To extend the focus of IDC research on children with autism to mixed groups of children, 2. To carefully consider the difference in taking a medical or a socio-constructionist approach, and finally 3. To consider when the IDC researcher responsibility end.

Introduction

Explicitly defining the target group within the special needs field is not without problems. Sometimes researchers explicitly focus on a specific condition, such as Cerebral Palsy or Asperger syndrome, sometimes they specify the children as having Special Needs, (or in the UK Special Educational Needs), and sometimes the target group is specified as having intellectual or cognitive disabilities. Furthermore, many terms have rather negative connotations, e.g. mental retardation.

In one of our papers we choose to introduce the overarching term 'developmental diversity' [5], where we combine the terms 'developmental disability', with 'Neurodiversity'. The concept of 'Neurodiversity' grew out of a movement of people with autism wishing to remove the label of being disabled. Instead, they wanted to underline that diverse neurological conditions appear as normal variations in the population. Since then the movement has grown to include more disabilities. While the term is used to indicate the diversity of people, it generally does not include people with Cerebral Palsy and may or may not include people having Down Syndrome. With this term we want to emphasize the fact that we are talking rather broadly about diverse groups of children, which may have e.g. Attention-deficit/hyperactivity disorder (ADHD), Autism Spectrum Conditions (ASC), Down Syndrome, Cerebral Palsy, Intellectual Disabilities, or combinations thereof. However, we are aware that this term may also have some problems, being either too all-including, or becoming stigmatizing over time as well.

Are we trying to do the right thing

As part of our work, we have done a systematic review of the literature on interaction design with developmentally diverse children based on a sample of 88 papers out of 663 papers found in academic journals and conferences, and focuses on how developmentally diverse children are included in the design process [5].

The results show that indeed, there is a growing tendency to include developmentally diverse children in the design process. Children with autism and especially high functioning autism (HFA) are the ones that are most commonly involved in the design process. This phenomenon cannot be explained by the prevalence of

autism in society [5]. There may be several other reasons, e.g. verbal communication with high functioning autistic children is easier than with some of the other groups of children, meaning that methods for typically developing children relying on verbal communication can relatively easily be applied or adapted. Another possible explanation may be found in the interest for technology that is shared between many children with autism. Developmentally diverse children involved in design are generally between 6 and 12 year old. Most research is performed in the children's natural setting, e.g. the school or the rehabilitation/therapy center.

Besides a relatively strong focus on children with high-functioning autism, many technologies are only designed for and with children with a particular diagnosis. This is problematic when technologies are to be introduced in the real world, such as a school, which is the most common context for working with developmentally diverse children according to this overview. In many schools, especially in Northern Europe, children with a range of different diagnoses are often grouped together, and in some cases, they also attend the same class as typically developing children. This means that not only the technologies themselves, but also the methods for involving children in the design of these technologies, should be adapted to accommodate diversity within groups. Many of the methods and techniques used with these children are also used with typically developing children. However, the approach is often slightly different, giving more weight to the coherence of activities, a clear structure in the sessions, verbal as well as textual explanations, and the active participation of caregivers, teachers and therapists. When necessary, additional tools, like

Talking Mats and pictorial feedback, are used to facilitate the communication. These tools are often the same tools as the ones used by children and their caregivers or therapists during daily interactions. Most of the approaches and guidelines could also be beneficial for typically developing children. We suggest that in some cases, instead of focusing on the disabilities of the children, it might be more fruitful to talk about the environment in which the children reside. Based on this literature review we can give the following directions for future research:

- An increased focus on how to develop and adapt design methods in order to fit the level and needs of other groups of children than those with high functioning autism.
- Devise and investigate approaches and methods for mixed groups of children, both children with different disabilities as well as developmentally diverse and typically developing children.

Is it working?

One observation from the review was also that in many papers it was hard to determine the actual target group for the research and how this target group was similar or dissimilar to other target groups.

First of all, there are generally two different approaches towards describing the target group: a medical approach, and a socio-constructionist approach. Papers taking a medical approach usually describe their target group in terms of a medical diagnosis, such as children with Cerebral Palsy or Down's syndrome. Papers taking a socio-constructionist approach see the disability not merely as a natural deficiency but as a culturally constructed deficiency. Therefore the target group is described as e.g. children with learning difficulties or

disabilities or intellectually disabled children. This, usually implicit, difference in approach makes it hard to compare the advice on e.g. techniques and methods to be used in a project. For example, does a certain method developed specifically for working with children with Down's syndrome also fit when working with children with learning disabilities, or does this technique really only target children with Down's syndrome?

Furthermore, according to the socio-constructionist view disabilities are situated, meaning that a disability is mainly perceived as a hinder to participate in a specific context, such as a school. Children in special education are thus perceived to have a certain hinder in attending regular education. This means that although some terms such as special (needs) education and intellectual or developmental disabilities are often used together, they are not completely interchangeable. For instance, a paper may say to focus on children with ASC (Autism Spectrum Conditions), however this does not necessarily mean that these children also attend special education.

We thus urge IDC researchers to be careful when describing their target group. First of all, a conscious decision needs to be made about whether one is taking a medical or a socio-constructionist approach. Thereafter it needs to be decided whether one is specifically interested in a certain deficiency, and/or whether the focus is on children residing in a certain context, such as special education.

Does it matter?

With this question, we will reflect on the IDC researcher's responsibility in relation to delivering an

end product. The discussion is based on our experiences with an ongoing project aimed at investigating how assistive technology can support increased communication between children with intellectual disabilities in the Special Education school and their parents and teachers. In the project, we have developed several applications that are currently used in schools, or there is a request for using them in schools: TellMe and WellSEQ. TellMe consists of two applications, the TellMe Diary and the TellMe Contact Book. The applications are used to support communication between children, parents and teachers in special education. The second application, WellSEQ, is an interactive touch-based questionnaire aiming to support self-reporting of the psychological health among children with intellectual disabilities (ID) aged 12-16. Both applications show promising results in evaluations, and have been fully developed. They are being used daily in several schools, and can (in principle) be released to the public. This raises the ethical question on when, and how, do we end IDC research?

In common for both the workshop series at CHI on ethics [2, 3, 4] and the In-Ethics framework [1], is a focus on ethics in the process and methods. However, one aspect that we recently have run into and daily face has unfortunately not been discussed as extensively, namely the researcher's responsibility after the project is over. This raises the question: When does IDC research end?

References

- [1] Christopher Frauenberger, Marjo Rauhala, and Geraldine Fitzpatrick. 2016. In-Action Ethics. *Interacting with Computers* (June 2016). DOI: <http://dx.doi.org/10.1093/iwc/iww024>
- [2] Waycott, J., Munteanu, C., Davis, H., Thieme, A., Branham, S., Moncur, W., McNaney, R., and Vines, J. In Press. Ethical Encounters in HCI: Implications for Research in Sensitive Settings. In: *Proceedings of the 2017 ACM SIGCHI Conference on Human Factors in Computing Systems Extended Abstracts*, 6 – 1 May 2017, Denver, USA
- [3] Jenny Waycott, Cosmin Munteanu, Hilary Davis, Anja Thieme, Wendy Moncur, Roisin McNaney, John Vines, and Stacy Branham. 2016. Ethical Encounters in Human-Computer Interaction. In *Proceedings of CHI EA '16*. ACM, New York, NY, USA, 3387-3394. DOI: <https://doi.org/10.1145/2851581.2856498>
- [4] Jenny Waycott, Hilary Davis, Anja Thieme, Stacy Branham, John Vines, and Cosmin Munteanu. 2015. Ethical Encounters in HCI: Research in Sensitive Settings. In *Proceedings of CHI EA '15*. ACM, New York, NY, USA, 2369-2372. DOI: <https://doi.org/10.1145/2702613.2702655>
- [5] Börjesson, P., Barendregt, W., Eriksson, E. and Torgersson, O. Designing technology for and with developmentally diverse children: a systematic literature review. In *Proc. 14th International Conference on Interaction Design and Children*, ACM Press (2015), 79-88.