Drivers and barriers for use of assistive technology among children with autism and/or intellectual disabilities: Parents perspective

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Abstract
The aim of this study was to detect drivers and barriers for use of assistive technology (AT) among children with autism spectrum disorder and/or intellectual disabilities. An online workshop with researchers and two parents produced the material. The main drivers for using AT are knowledge about its existence, its inherent possibilities, access and funding. Barriers are related to lack of information, accessibility, knowledge in schools, funding, poor user interface, and poor retail and maintenance service. The workshop co-created an online form which subsequently will be sent to other parents to address these issues further. The study highlights perspectives and aspects that are important to parents and encourages researchers and AT-designers to systematically include end-users in design and implementation.
Keywords
Participatory design, inclusive design, assistive technology, autism spectrum disorder (ASD) and/or intellectual disabilities (ID), social inclusion

Introduction

Social inclusion can be facilitated through access to education and employment [1]. However, while the prevalence of people with autism spectrum disorder (ASD) and/or intellectual disabilities (ID) is growing [2], these groups are among the most disadvantaged and socially excluded in society [3]. Research suggests that the use of assistive technology (AT) can contribute to increased self-management and participation in education and work [4,5]. Despite the promising results of AT in research projects, the adoption of such technology in everyday living, education or work settings is slow [6]. So far, there is a lack of scientific knowledge about drivers and barriers for uptake and use of AT amongst persons with ASD and/or ID [6]. The body of knowledge on the use of AT by children with ASD/ID is even more scarce.

This paper presents results from a workshop with two parents of three children with ASD and/or ID, about their experiences and opinions regarding acquiring, learning and using AT for themselves and their children. One of the parents identified as living well with ASD.

Background

Persons living with ASD and ID face a range of challenges in everyday living. Some of these challenges include difficulties with communication, social interaction, concentration, time management and self-regulation. While the range of available AT for persons with ASD/ID is soaring, its implementation is slow, which suggests that there might be several challenges that hinder technology adoption or its continued usage [6]. While AT has potential to add value to everyday living for persons living with ASD/ID, it is essential to address both drivers and barriers to uptake. Known barriers are related to mismatch between design of the user-interface and the wider social and material contexts. To our knowledge, end-users with ASD/ID and other stakeholders are not systematically involved in research or technology design and implementation processes. Henceforth, drivers for uptake might be overseen or ignored.

Method

The authors hosted an online interactive workshop for parents to children with ASD and/or ID in early December 2021, under Covid-19 restrictions. Parents were invited to participate through peer support organizations for persons

living with ASD/ID. Covid constraints, time-constraints in the Advent, and unpredictable everyday lives with a child with a disability, caused large drop out. The workshop had a total of two parents to three children. The small group format gave all participants (researchers and parents) an eminent opportunity for in-depth discussion [7].

The workshop had three main parts. The first part consisted of a joint discussion and conversation about what type of AT they had experience with, how they and or their children used it, which advantages and disadvantages they had discovered, as well as what needs and wishes they had for AT and digital tools. For the second part we presented an online form where participants could enter their experiences related to AT, as a summary of the previous discussion. The participants were invited to discuss and comment upon this form. Finally, we wanted to get feedback on their experiences and wishes for user participation in the development of AT.

The workshop was hosted on MS Teams and recorded using its built-in function. The recording was downloaded for secure storage. The participants consented to videorecording by confirming acceptance of the informed consent letter via email, and verbally in the beginning of the workshop. The transcribed workshop data were analysed using thematic analysis.

Preliminary results and discussion

The participants expressed that it was meaningful to participate in the workshop. They were able to convey their experiences to the researchers and each other. Some of the main themes from their experience with adoption and use of AT are:

- How to get advice on which technology might be usable and suitable.
- The process of acquiring AT including economic aspects, as well as trial and error to find aids that work for their children.
- That school personnel sometimes lack understanding of the need for AT and their function.
- Guidance, training, and support in relation to AT products for all relevant stakeholders.
- Time management is a feature in many ATs for persons with ASD/ID. Organizing and coordinating the task of adding and managing entries connected to time management, between caretakers and the kindergarten or the school can therefore be an issue.
- How to help the child become more independent by gradually transferring responsibility for handling the AT to the child.

The second part of the workshop was a co-creation session on the further development of an online form with questions for use in similar workshops. The participants made comments and suggestions for improvement to the online workshop arrangement so that it could be even better and more suitable for parents with ASD. The participant with ASD underscored that most people with ASD like to be well informed and prepared, and the advantage of being able to think through questions in advance, in peace and quiet.

Therefore, they suggested that questions to be discussed should be distributed beforehand, possibly as an online form. The participants suggested reformulations and amendments to questions in the online form that were presented to them. For example, we received the following advice: "the questions could have been more focused on things such as how did you find out about the tool, did you get advice from someone about the tool and issues related to this". They also suggested a question about whether parents have encountered positive or negative attitudes when seeking help and advice about AT. This discussion shed light on topics that the participants were concerned about and where they believed there is a need for more knowledge. Both the need for easier access to information about AT and the need for involving stakeholders, including end-users, in the design of such systems, is in line with the views of AT professionals [8].

Conclusion

The workshop generated several insights on drivers and barriers related to uptake and use of AT for use in daily life and at school for their children with ASD/ID. Main drivers are systematic inclusion of end-users in design and sharing of knowledge about promising AT. Main barriers are lack of information about potentially useful technology, lack of training, high demand on cooperation and coordination of entering content to the technology, lack of interest, knowledge and support from schools and lack of funding. The parents were clear about the need to include them, young persons and others living with ASD/ID in design and implementation of AT. Additional research is needed to ascertain the degree to which others share similar experiences and to assess the applicability to different products and contexts.

Acknowledgements

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