

Parents must assume expert role in interactive technology development for children with special needs

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ABSTRACT

Parents are one of the most powerful people in the lives of children with special needs, because they – mostly – have lived closely together. Including parents into technology development provides invaluable information for researchers about children per se and working with them. In this paper, I first present benefits about working with parents. Second, I introduce three areas of primary challenges of parental participation: motivation, organization, and interaction. Finally, regardless whom to include into technology development – parents, teachers, or both of them – the goal must be searching for the best for the child.

General Terms

Design, Human Factors

Keywords

Parents, technology development, children with special needs

1. INTRODUCTION

Children have typically many important people around them: friends, parents or care-givers¹, grandparents, and teachers. Teachers interact with children mostly in school environment, while parents stay with their children at home and in free time. Because children use technologies everywhere, parents' expertise of their own children is therefore worth of investigating and supporting in design, use, and evaluation of interactive technologies.

According to research in education and psychology, parental participation has a positive impact on children's lives, especially when parents have an active role and they work as partners with professionals. Participating parents have a positive impact on children's academic and social performance [3, 15], early intervention programs [6], extracurricular activities [5], and therapy [12]. Few studies exist about families' participation in participatory design of technologies [10]. So far, impact of parental participation has not been discussed in design, use, and evaluation of interactive technologies.

Based on our experience in technology development with children with special needs and their parents, parents provide crucial information for researchers but they also gain invaluable knowledge by themselves. Parents, for example, share their expertise and knowledge on their child which helps designing appropriate and interesting technologies. Many children have limited means to communicate, because of their age or

communication skills. Even though researchers know the language child uses – including sign language or augmentative and alternative communication methods like pictures – a parent interprets the child naturally as a whole, including verbal and non-verbal communication, gestures and body language. This tacit knowledge is gained by living closely together. When working with children and their parents, researchers should observe and ask for the ways how parents interact and communicate with their children. Understanding the children from the wide perspective helps to design technologies that fit the children's individual strengths, interests and needs.

In 2011, 85 percent of households in Finland had a personal computer at home [13] and more than every fourth had a video game console [11]. Most of the 10-12 year old Finnish children (75 %) play digital games at least once a week [1]. According to the same study, about 20 % of children play together with their parents and about 55 % would like to play with them.

The use of interactive technology *together* would be beneficial both for parents and for children. When parents see their child working with interactive technologies, it may provide novel, positive and even surprising perspectives on their own child [4]. Based on our experiences, interactive technology may also provide a child a possibility to teach a parent in its use. This role shift can affect family life dramatically by increasing child's active participation in everyday environment.

When interactive technologies for children are designed for school or therapy use, parents are occasionally heard as informants along with teachers, therapists, and other professionals. Parents' active integration into design, use and evaluation of technologies, however, supports transfer of children's new skills and technical tools into everyday life at home [4]. As it is known, parents have a crucial role in determining which – if any – technologies are utilized at home, to which intensity, when and how. In other words, when we pursue development of technologies that are used also at homes or free time, it is crucial to include parents to technology development. In what follows, I will describe technology clubs as a context for research with children and their parents.

1. PRACTICES FOR PARENTS' PARTICIPATION

Practical examples in this paper are based on experiences in technology clubs for children with special needs and their parents that we have implemented since 2009. In our clubs, children are four to thirteen years old, both girls and boys who are diagnosed as having physical (cerebral palsy) or learning difficulties (autism spectrum disorders, developmental delays, and/or difficulties in academic and life skills, such as concentration and communication) [4]. The technology clubs are organized by the

¹ Parents and care-givers are here referred to as parents and children with special needs are here referred to as children.

Everyday Technologies for Children with Special Needs project². The purpose of the project is to support children's active impact on their everyday lives and their equal participation in the society. We contribute this by investigating and developing children's and their families' participation in technology-based environments. Altogether seventeen families have participated in the technology clubs; most of the families have attended at least for two years, each semester including nine to ten clubs. Children were typically accompanied in technology clubs by their mother and/or father.

From research point of view, we conduct action research using the principles of participatory design [9]. We co-design family-centered activities together with families so that the activities are based on families' needs, lifestyles, and cultures. We also treat parents as experts and equal partners and we work collaboratively partnering with them.

From parent's point of view, the clubs consist of three stages: *planning*, *implementing*, and *reflecting* the activities and technologies that are designed and used in the clubs. During the *planning* stage, parents share their expectations about upcoming technology clubs. Parents describe their children and the ways how we all can support a child during the clubs. Parents also envision novel technologies that can be developed to strengthen the child's motivation and abilities.

During the clubs (*implementation*), parents use interactive technologies with their children in various workshops. The main focus of the clubs is on child's activities that the parent shares and encourages. During the club sessions, the parents' role oscillates between being a passive observer and being an active collaborator. This fluctuation is due to situational and human factors. However, we emphasize and support parents' expertise in conversations and by having them share responsibility in guiding the child and developing club activities and technology.

During third stage, parents *reflect* and evaluate both activities and technologies. Parents fill a feedback form after each club and highlight what worked, what did not work, and what needs to be changed. Feedback is collected regularly to a log, as accurately as possible. This guarantees that opinions are collected and processed correctly.

While evaluating, parents are aware that everything in the clubs can be questioned and changes are possible to implement. For example, during the first workshops, parents suggested that children prefer to have a map of the activities made from a laminated paper that can be carried along constantly. This low-tech solution replaced self-made software that children have utilized for selecting and evaluating the workshops. Parents also envisioned, for example, the physical locations, lighting, and timing of each workshop, the need for more social interaction between children, and the need for a place for a child to calm down between the workshops when needed.

After one or two semesters, each semester including nine to ten clubs, parents shared their experiences in individual or group interviews, parents' meetings, and/or questionnaires. When interviewing parents outside the clubs, we noticed that parents observe the club activities and technologies from wider point of view compared to that collected after each club. At the same time, parents generated ideas together during parents' meetings and group interviews. These ideas remained for the most part unimplemented [9], but they reflected parents' creative ideas on what kinds of technologies could be designed in general.

In sum, we claim that including parents in design, use, and evaluation of technologies for children is very useful and worth of trying. However, parents' participation may bring about challenges. Next, I describe the main challenges that need to be taken into account in early stages when working with families.

2. CHALLENGES OF INCLUDING PARENTS IN TECHNOLOGY DEVELOPMENT

When working in technology clubs, we have found three primary challenges that have to be taken into account: *motivation*, *organization*, and *interaction*.

The first challenge is to find *motivated* parents. In order to do that, researchers have to convince parents about benefits of participation. Parents are not always familiar with the possibilities of technologies to support the development of their children [7] or they feel that technologies do not fit the needs of the children appropriately [16].

Participating in design of interactive technology is often totally new for parents. It is common to merely use technologies and not to control them actively, not to mention creating them [17]. Moreover, as it is in our technology clubs, nobody knows beforehand what exactly we are striving for. This lets us to develop activities and technologies in a flexible way but, at the same time, we cannot guarantee any specific products or skills learned during the process. Therefore, researchers have to dedicate enough time for discussing with parents beforehand.

Researchers also have to be motivated to work with families. If we compare working with teachers or parents, teachers interpret, in general, children from their professional point of view that includes specific vocabulary and extensive knowledge about children's growth and skills. Compared to that, parents represent more heterogeneous group from education to backgrounds and lifestyles. Parents are also connected with their own child. Parents' perspectives are – in general - interpreted as narrow and as focusing on gaining advantage for their own children [8]. This makes their actions subjective, holistic, and often filled with emotions. However, parents stay in children's lives all the time while teachers and other professionals change.

Many researchers are also attracted to work in a school environment instead of free-time activities that are often organized after the office hours. Working at schools happens usually at day-time. Compared to that, working with families is usually organized as a free-time activity in the afternoons or evenings because of parents' work time. Besides, recruiting one teacher with ten children in class is arguable easier than ten families with one child in each.

In addition to lack of motivation, parents may have limited means in participating, because of *organization* of practice such as scheduling, organizing childcare and transportation, or differences in language and cultures [3]. When parents are participating equally in design, use, and evaluation of interactive technologies, family-centered activities needs to be optimized. At our clubs, parents have co-designed with researchers, among others, timing of the club. Families can also bring siblings of children to the club and siblings are also treated as participants. Different family cultures are also reinforced by perceiving parents as the main supporters of the child while researchers and other staff serve as secondary source.

² http://www.honkalampisaatio.fi/evtech_in_english

When motivational and organizational aspects are taken into account, it is time to consider the last, possibly the most essential challenge: *interaction* between families and researchers. When partnering with researchers, parents may feel that they are not heard by professionals or that collaboration is not equal [2, 14]. The reasons are many. It is well known that parents may feel alienated because of too much formality in collaboration [14]. Professionals may also use specific terminology that is unfamiliar for parents. Dominating professionals or structured, inflexible activities restrict communication as well. As cited in [2], "none of the known studies treats users and employees with equal importance. Users can utter wishes and take part in the development process, but they do not have any influence on the decisions that are finally made."

Our way to avoid unequal collaboration is to have close partnerships and gaining trust with parents during the whole process. This happens by reflecting and opening out with parents. We take parents' feedback seriously by writing it down which helps us to return to the ideas later on. Parents can observe how their ideas are implemented in the reality. This is made possible with quick design/development cycle [4]. We have noticed that the more parents can influence and see changes that are based on their ideas in technology development, the more they are engaged with it.

3. PARENTS AS EXPERTS IN TECHNOLOGY DEVELOPMENT

When planning to include parents – among other participants - in design, use, and evaluation of interactive technology for children, it is necessary to think about the ways how to achieve the best for the child. What is, then, the best for the child? Who can determine it, a parent, a teacher, a child, or someone else? Does the best happen both at school and in free time?

Regardless of the goals of research implemented at school or in free time, research about design, use, and evaluation of interactive technologies is needed to provide multifaceted knowledge. The main difference between working with teachers or parents seems to be in their relationship with the child. A teacher's role during ordinary teaching and many technology projects seems to be somewhat similar. A researcher works in a classroom in co-operation with a teacher. Children may perceive a researcher as an extra teacher in a classroom. On the contrary to that, if collaborative working with parents happens outside home, a child works together with his/her parent and has a chance to have parent's whole attention. When staying at home, the parent has to share his/her attention with siblings, a spouse, household work, and other elements of everyday life. If design of technology happens at families' homes, these factors have to be taken into account. Wherever happening, working together should support adults' and children's connection and binding to each other.

Quality design, use, and evaluation of interactive technologies require different aspects and environments to guarantee a wide view of the interactive technologies for children. We have perceived parental participation to be very useful method in design, use, and evaluation of interactive technologies. In whatever context, researchers should feel their responsibility towards empowering families to have a positive impact in their own lives. Technology development provides one way for parents to influence their and other people's lives. In the long run, active participation diminishes social exclusion and marginalization of families with children with special needs.

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