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Borzenkova, Ganna , Tang, Jingshu and Niedderer, Kristina  (2023) Co-designing with children with cerebral palsy: context and co-design principles. In: IASDR 2023: Life-Changing Design, 09 October 2023 - 13 October 2023, Milan, Italy.

DOI: <https://doi.org/10.21606/iasdr.2023.614>

Publisher: Design Research Society

Version: Published Version

Downloaded from: <https://e-space.mmu.ac.uk/632862/>

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Additional Information: This is an open access conference paper which was presented at IASDR 2023: Life-Changing Design

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Co-designing with children with cerebral palsy: context and co-design principles

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doi.org/10.21606/iasdr.2023.614

Co-design with children with cerebral palsy sets challenges for researchers and designers because of differences in their living experiences and because many current well-established co-design approaches and recommendations may not be appropriate and require adjustments. Based on an overview of existing literature, this paper identifies co-design principles and approaches for including children in the co-design process and explores how these need to be adjusted to ensure the active participation of children with disabilities, specifically those with cerebral palsy. The aim is to derive a set of key principles and related approaches for application in the Peer2Peer project, and to provide practical guidelines for researchers and designers working with children with cerebral palsy.

Keywords: *co-design; children; cerebral palsy; co-design principles*

1 Introduction

This paper develops a set of key principles of co-designing with children with cerebral palsy for the application in the Peer2Peer project. The Peer2Peer project (<http://peer-2-peer.co.uk/>) will use participatory action research to involve children with cerebral palsy aged 7 to 10 years old to co-design design-based interventions to promote their peer social engagement and enhance their socialemotional wellbeing.

Co-design is the act of creating something together as it is applied throughout the design process (Sanders and Stappers, 2008). It commits researchers and designers to interact with people who will use or be affected by their design products or services in order to prioritise their agency and quality of experience (Rajapakse et al., 2021). It is based on a partnership and collaboration where participants make a significant contribution of their own context and experience, while researchers bring design and facilitation skills for mutual learning and development. When people have different communication mechanisms and cognitive, physical or sensory abilities, it is especially important to fully involve them in the design process, as researchers and designers have little experience to see the world from their point of view. In recent years, the number of studies involving people with different



abilities in co-design has been growing, while still substantially fewer have specifically focused on people with cerebral palsy. A high number of studies provided insights on co-design with children, but very few focused on children with cerebral palsy and their engagement in developing new designs (Benton & Johnson, 2015; Börjesson et al., 2015). Moreover, Rogers and Marsden (2013) defined the problem that when identifying someone who seems different, there is a tendency for researchers to ask carers instead of the person themselves about their needs and wishes or to engage in compensatory design, by focusing on a lack of something (sight, verbal skills, memory, cognitive and physical abilities etc.).

Co-design offers the opportunity to give participants an active role, to understand better their needs and aspirations. Children with cerebral palsy should be seen as experts of their own lives and experience in the design process, and in order to take on this role, they must be given 'appropriate tools for expressing themselves' (Sanders and Stappers, 2008). Commonly used codesign approaches may not be appropriate for working with children with cerebral palsy and acknowledging their competence. Many methods are based on skills which children have challenges with, for instance, they are based on verbal or visual expressions, use visual or hands-on techniques, and may require higher order cognitive skills (Sanders and Stappers, 2008). Thus, common co-design methods may not be suitable without appropriate adjustment.

2 Approach

To understand better how to co-design with and for children with cerebral palsy, this paper aims to elicit the essence of co-design principles used to implement co-design methods with children in the design process. The paper starts with a brief discussion of how the level of children's involvement in co-design is linked to the current views on disability, and cerebral palsy in particular, followed by mapping the roles which children can play in the co-design process. The paper then reviews literature on existing principles of engaging children, including children with disabilities, to enable them to express themselves in a co-designing context. By analysing how researchers and designers use and adapt existing codesign principles to suit the needs and abilities of the children, the paper derives principles for a co-design approach specifically for children with cerebral palsy, where they become active agents and experts of their life and experiences. The aspiration of such an approach is to provide practical guidelines for researchers and designers working in co-design with children with cerebral palsy.

3 Co-design and the views on disability

The importance of involving children with cerebral palsy in the design process and the idea that such involvement requires a different, more appropriate co-design approach corresponds to the current views on disability. Traditionally, the medical model of disability views cerebral palsy as a functional impairment that should be treated. It is about what an individual cannot do and is situated within a person. While the medical view remains dominant in the United Kingdom, it encourages mainly children's passive participation and emphasizes dysfunction, rather than focussing on children's abilities (Rozahegyi, 2014). In terms of co-design, in recent years, there has been a number of studies engaging people with a broad range of abilities in co-design. However, the role of children with

disabilities in many of these remains passive or limited to single sessions (Börjesson et al., 2015; Benton and Johnson, 2015).

The social model sees disability as the result of the interaction between people living with cerebral palsy and an environment filled with physical, attitudinal, communication and social barriers (Goering, 2015). It suggests that disability is the result of response from society to a person with cerebral palsy and suggests removing any barriers that might prevent a person to participate fully in society. In terms of co-design, this means that researchers and designers should make the co-design process accessible for people with disabilities and develop appropriate approaches to remove any barriers that might limit their participation.

Cerebral palsy is an umbrella term used to define a group of permanent conditions, indicating that there is heterogeneity in these conditions such as visual, cognition, perceptual and/or behaviour, sensation problems and learning disabilities (Krageloh-Mann et al., 2009). Because cerebral palsy is a group of conditions, signs and symptoms vary from one individual to the other. It is a complex condition, impacting all-round development differently in different children. In terms of co-design, this implies that researchers should pay enhanced attention not only for applying co-design principles and co-design approaches adapted for children with cerebral palsy as a group, but individually adapted to each child-participant.

4 The role of children in co-design process

Read et al. (2002) defined three modes of children's involvement in the design process in the IBF Participatory Continuum Model, where co-design is a continuum along which identifiable but not discrete modes are located. These modes are Informant design, Balanced design and Facilitated design, delineated by the amount of a child's contribution to the design. In Informant design, children's contribution is largely limited to informing the researchers and designers. In Balanced design, there is an equal partnership between children and researchers. The leading role of children is emphasised in Facilitated design, where children are involved in idea generation and in realising these ideas, while the researchers play the role of facilitators.

Druin (2002) identified that children can be engaged in four different roles in the co-design process: user, tester, informant and design partner. These roles define at what stage of the design process children are involved, relation of researchers and designers to children and what aims they pursue by engaging children. While the roles are hierarchical, there are no clear boundaries between them and co-designing with children may include their combination at different stages in design development. As users, children are observed while they are using a design product to help researchers and designers to gain an understanding of what impact that design product has on them. In the role of tester, children test prototypes of a design product before it is released. Researchers and designers observe children and ask them for comments concerning their experiences. This role corresponds to Informant design mode from the IBF Participatory Continuum Model. As informants, children are involved in informing the design process before a design product is developed or to use an existing design, which aligns with Balanced design mode from Read et al. (2002). In the role of design partner, children engaged in collaborative process and are considered to be equal partners in the design of new products throughout the entire experience. They are involved in creating designs and could guide

and evaluate the design decisions, which corresponds to Facilitated design mode from Read et al. (2002).

Large et al. (2006) presents children’s engagement in the design process in relation to different methodologies. On a scale extending from the lowest level of children involvement to the highest, these methodologies are user-centred design, contextual design, learner-centred design, participatory design, informant design, and cooperative inquiry. Cooperative inquiry involves a multidisciplinary partnership with children. Children are treated as full design partners alongside the researchers and designers.

The three approaches discussed above can be schematically systematised based on the level of children’s involvement in co-design process (Figure 1). Children’s roles are not discrete and there are no separating lines between levels of involvement. Moreover, each mode may comprise elements from the previous modes.

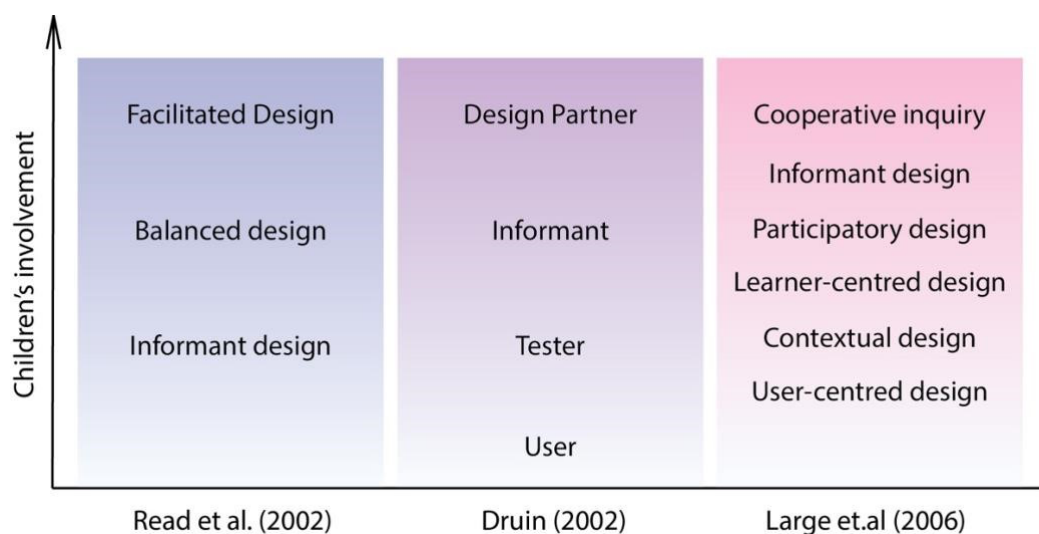


Figure 1. Children’s involvement in the design process.

Engaging children in the design process as partners is crucial for developing an understanding about their needs and wishes. It enables researchers and designers to broaden their perspective and introduces them into children’s world. One of children’s most important contributions may lie in their creativity, and Hagen et al. (2012) summarise the advantages of co-design with children:

- Increasing imagination and creativity in design: children's cognitive, social and emotional intelligence develops at a different level to that of adults. Through their curiosity and rich imagination, they are extremely creative and less constrained by reality.
- Broadening designers' design horizons: children are honest and playful, and designers can benefit and learn from including children as expert users in collaborative design sessions.
- Discover the physical limitations of products: by giving children their own voice in the design of children's products, they may come up with unimaginable ideas and contribute in design decisions (Hagen et al., 2012).

In addition, children have unconventional views on all, even the most complex matters, and are always ready to share their ideas. This is especially true for children aged 7-10 years, who belong to the fourth

stage of 'Erik Erikson's stage of psychosocial development', where children are rule-oriented, eager to work in teams and develop a sense of pride by successfully completing tasks (Orenstein and Lewis, 2021). Therefore, it is critical to support children in the design process because adults do not experience the world as children do and do not have the same insights into the world as a child.

5 Co-design principles with developmentally diverse children

Previous literature provides guidance and recommendations for engaging people with disabilities in the design of assistive technology, and for working with children with severe motor impairments, autism and Asperger's syndrome but little guidance on how to engage children with cerebral palsy in co-design process.

Hodson et al. (2019) proposed four critical elements of co-design in the Mellow project for youth: preengagement, acknowledging power imbalance, collaborative idea generation and end-user skill development. Pre-engagement means engagement with the participants before the design process starts to build trust and create awareness of the design process. The importance of building trust, partnership and shared understanding is also highlighted by Iversen and Smith (2012) and Gaudion (2015). Acknowledging the power imbalance means taking steps to reduce power imbalance between researchers and designers, children and others involved in co-design (Hodson et al., 2019). Collaborative idea generation is about replacing standard question and answer format by small group workshops where all participants of co-design process work collaboratively under the guidance of a facilitator. End-user skill development - further engagement after producing the final product to introduce end-users to new skills, so that they can apply these skills in other contexts.

Hourcade et al. (2012) proposed four principles to consider when designing technologies for people with disabilities: deep engagement, interdisciplinarity, individuality and practicality. Deep engagement here understood as involving in co-design people who spend much time with a participant, such as parents, siblings, carers, and practitioners.

Holone and Herstad (2013) involved children with severe disabilities with a combination of cognitive, sensory and physical impairments in their project. They found that patience and extra time are amongst the most essential principles when working with such children. Children often took the role of recipient, and it required a lot of time for them to get used to the role of decision-maker, and to adjust power relations. Assigning specific roles to children as user, informant, designer and tester in the process to make it clearer for children and researchers was recommended by Bossavit and Parsons (2016).

In order to overcome barriers and engage children with disabilities as design partners it is important to do it in appropriate context and pay attention to social and physical environments (Brereton et al., 2015). Co-designing and working together with the same goal might benefit from using organically occurring groups, such as friends or classmates. Hornof (2009) offered eight guidelines for collaborating in design activities with children with severe motor impairments, such as with disabilities resulting from severe cerebral palsy. These are: accept the awkwardness and nervousness, advocate for the children's self-expression, use low-tech interactions to design high-tech, interact with as many different caregivers as you can, specifically learn how to hear "I'm done", join the other teams working around the child, and decompose design activities into discrete subtasks.

A couple of studies argue that there is a need for flexibility in the co-design approach, which should be situated rather than predetermined (Raman and French, 2022; Aldridge, 2015; Porayska-Pomsta et al., 2012). Any activities designed need to be easy to edit in the process to accommodate the diversity of children's needs. Developing visual languages and incorporating visual elements make it possible for children to use different communication preferences when completing activities, as children may provide non-verbal and/or verbal information (Aldridge 2015). Using sketches, props, roleplaying, and easy prototypes may support ideation, as well as incremental tasks' introduction (Khaled and Vasalou, 2014). It is not recommended to start co-design sessions with a blank page (Hummerstone and Parsons, 2023). Some initial ideas and examples often simplify generation of new ideas or reviewing the existing ones with more details (Benton and Johnson, 2015). Children may have difficulty analysing design products or generating new ideas out of context and abstractly discussing features of designs that they prefer (Druin, 2002), therefore providing context for activities and tasks would be beneficial. Melonio and Gennari (2013) suggested using avatar and set roles for children because most children place themselves in the characters that provides attentional and motivational benefits. Using physical objects and creating tangible prototypes also increase motivation and enthusiasm in children.

Some studies highlighted an importance of mutual learning and empowerment as prerequisite for co-design with children (Raman and French, 2022; Zamenopoulos et al., 2019; Hussain, 2010). Psychological empowerment, promoting children's voice and facilitating self-expression contribute towards equalising relations and increasing self-esteem in children, as well as confidence and enjoyment.

6 Principles for co-designing with children with cerebral palsy

Based on the above discussion about the co-design approaches and principles used in various studies conducted with children, including children with disabilities, it is possible to summarise the childfriendly co-design principles for including children with cerebral palsy, which suit their needs and abilities. The principles are grouped together under the following themes: involving experts, environment, engagement and motivation, co-design sessions organisation, ethical considerations.

Involving experts:

- Acknowledging the power imbalance,
- Deep engagement with caregivers who know children in order to adapt methods.

The involvement of parents, carers, teachers and practitioners allows for a deeper understanding of the context. However, engaging experts requires consideration of how equal contributions and collaboration are supported, whether the experts' viewpoints differ from that of children and how these differences are addressed, and how valuable the experience is for all involved.

Environment:

- Social environment: conducting co-design sessions with organically occurring groups of friends or classmates; arranging pre-engagement in order to build trust, partnership and shared understanding with children,
- Emotional environment: patience and extra time for children to get used to their roles and to researchers,

- Physical environment: safe, familiar, comfortable and age-appropriate setting should be chosen for the co-design sessions.

Engagement and motivation:

Children with cerebral palsy may not be able to conduct a high level or reflective narrative to discuss activities and tasks that they participate in, however, their reactions and interactions in each moment fully contribute to co-design by expressing their choices. It is important to ensure engagement and motivation at each level of co-design and at each interactional turn by giving children chance to lead, following his/her natural interest and by relying on the following principles:

- Flexibility of any activities, so they can be easily adapted in the process to fit the diversity of children's needs,
- Using visual languages to allow children using different communication preferences,
- Identifying children's interests and hobbies to incorporate these in co-design activities and discussions,
- Using personal strengths of each child to build up their confidence in co-design activities,
- Using sketches, props, roleplaying, and tangible and easy prototypes to support ideation and ideas expression,
- Using avatar and/or set roles,
- Providing context for activities,
- Focusing on individuality of children.

Co-design sessions organisation:

- An optimal workshop length for children is often between 30 minutes and 2 hours, depending on the age and skills level,
- Arranging regular bathroom breaks and providing snacks,
- Decomposing design activities into discrete parts and incremental introducing of these parts.

Ethical considerations:

- Learning how a child indicates that he/she is done with an activity.
- Mutual learning and empowerment
- Advocating for the children's self-expression. Researchers should learn children's communication techniques before introducing any activities and find opportunities for the children's voices and opinions to be heard.
- Developing children's skills
- Ensuring that demands on children do not outweigh the benefits of their inclusion.

In addition to these principles, an emphasis should be put on personalisation due to heterogenous character of cerebral palsy and on modifying co-design methods to meet individual abilities (Hendriks et al., 2015). Much emphasis should be placed on understanding personal characteristics, needs and wishes of children and tailoring design engagement to make it suitable for a particular child and the context.

7 Conclusion

Despite this growing body of research, co-design with children with cerebral palsy still remains a rather fragmented practice. These children are usually not actively involved in all phases of co-design, and their involvement is often in the form of feedback (Hernandez et al. 2013). Also, there is a tendency to mainly focus on a result and developing actual products rather than on a reflection on the principles and methods used and their adjustment. However, supporting children with cerebral palsy in codesign process is crucial, as researchers and designers do not experience the world as children do, and they do not have the same understanding and insights into the world as children. From cooperating and levelling design process with children, researchers and designers can gain meaningful and valuable experience and knowledge of how to look at a design task from a child's perspective and in a creative way.

Co-designing with children with cerebral palsy requires careful planning and rethinking of many of its activities, including establishing communication, teams, developing flexible tools and methods, etc. Enabling meaningful participation and a sense of ownership of the process in these children requires individual support for each child. Researchers should ensure the right conditions for genuine participation, empowerment and expression of children's views to shape decisions in each stage of co-design. These include that children are willing to participate, they feel motivated, respected and their well-being is a priority.

Co-designing with children and its benefits is not a fixed product or outcome, rather it is a process that offers important context and valuable insights though its every phase, allowing to include children as active agents in the co-design to meet their needs and wishes.

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