Co-create and Co-develop With Children. The BODYSOUND Engagement Model

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Abstract
The article explores the use of participatory design processes, methods, and tools to develop interactive healthcare and wellbeing solutions involving children with motor disabilities and their caregiving system. This contribution provides a theoretical framework focused on the engagement roles that children participating in co-design processes can play, providing the description of BODYSOUND, a pilot project developed within the SISCODE H2020 European project. We will present the co-design process divided into two main phases: co-creation and co-development. For each of these phases, we carried out iterative design actions that will be presented according to the role with which children are engaged, the targets involved, and methods to collect data. All of these were subjected to the primary goal of each design action. The final part systematizes the results of the analysis and identifies different goals and methods for children's participation according to specific design phases.

Keywords
Co-design
Patient Innovation
Children engagement
Boundary objects
Makerspaces

Introduction

The article presents co-design practices developed by involving children in the specific domain of digital artifacts for healthcare and wellbeing sectors. Involving children with special needs in these processes is not without its challenges, and requires extreme flexibility and adaptability, but studies show that including them in technology development processes can become a way of including them in society (Kärnä et al., 2010). In our work, we consider co-design a collective noun that includes co-creation and co-development. The definition of co-creation as "collective creativity produced" (Sanders & Stappers, 2008, p. 3) is applicable to the phase of idea generation and refinement. Instead, co-development happens in a later phase of idea development, the prototyping phase. They are both defined by the active involvement of final users and stakeholders. In the following section, we will frame our research theoretically, focusing on the role of children involved in co-design processes. Afterwards, we will introduce the BODYSOUND pilot project considering the various design phases, the levels of the children's involvement, evaluation focus, and methodologies. Ultimately, we categorize and distinguish various objectives and approaches for the involvement of children, based on specific phases of the design process.

Theoretical Framework for Co-designing With Children With Disabilities

While a large body of research has been conducted on co-design with kids, relatively little of it has examined kids with cerebral palsy (CP) and their involvement in creating new designs (Borzenkova et al., 2023; Benton & Johnson, 2015; Börjesson et al., 2015). Jenkin et al. (2019) propose a decolonized approach to the involvement of children with disabilities, according to which they are not just described by their impairments, seen as disadvantages to be fixed, but also by a variety of human and social factors. Moreover, their involvement can increase self-esteem and confidence (Constantin et al., 2019; Bolster et al., 2021). However, the use of formal methods for involving children with disabilities in research might not be effective, especially when severe health conditions are present.

Markopoulos et al. (2008), using the approaches provided by Druin (2002) and Scaife and Rogers (1999), develop a model explaining the different levels of children's involvement, in which participation ranges from a minimum to a maximum level of involvement, from the stage in which the product is already developed and ready to be used through the ideation of the product itself at the very beginning of the design process. Children can be involved as end users of products with no engagement in their design; they can be testers of products and participants in their evaluation; they can be informants (Druin, 2002; Scaife & Rogers, 1999), and/or design partners (Druin, 2002) engaged throughout the whole design process, to which they contributed with their own ideas and opinions. The key difference between the roles of informant and design partner lies in their level of involvement. Informant children contribute at specific stages when researchers seek their input, such as observing their interactions with existing technologies or reviewing design sketches. In contrast, design partner children are equal stakeholders throughout the entire design process, collaborating fully in the creation of new technologies (Druin, 2002).

The BODYSOUND Pilot Project: Engagement Model

Polifactory, makerspace and fablab of the Politecnico di Milano carried out a pilot project as part of the EU project SISCODE (Co-design for Society in Innovation and Science) H2020 European project, aimed at stimulating the use of co-creation methodologies to experiment on public engagement and RRIs to integrate co-design and bottom-up co-creation initiatives (Deserti et al., 2022).

Polifactory's pilot project sought to investigate the various physical-motor needs of children diagnosed with infantile CP based on the principles of proprioception (Bordoloi & Sharma, 2012), with a specific focus on the translation of movement into sound stimuli. The Design research area of interest identified by the researchers has been that of wellbeing in relation to physical activity and the related improvement of motor capabilities. Indeed, studies show that, compared to their peers, children with CP engage in less physical activity (Yoon et al., 2022; Carlon et al., 2013); those who engage in physical exercise have higher levels of satisfaction and a higher quality of life, reducing the level of parenting stress. This highlights the need for professional care and research on interventions targeted at helping children with CP become more physically active (Maher et al., 2015), to involve them in more than just rehabilitation sessions, usually located in hospitals or healthcare centers. Lai et al. (2021) highlight that effective interventions include recreational activities, active video games, behavioral coaching, and motor skill training. For these reasons, the researchers worked to combine rehabilitation and Leisure-Time Physical Activities (LTPA) to escape the strict health and caring areas of action.

The process described below involved several making and rapid prototyping technologies. The focus on advanced technologies was dictated by the need to operate iteratively and quickly during development, following the co-creation and co-design phases and the related feedback. The researcher's approach responds to the "use low-tech interactions to design high-tech" principle of designing with children who have severe motor impairments suggested in Hornof (2009). These technologies, which are often open-source, are useful tools for the reproducibility of the process, and many of them are extremely versatile and have a very low learning curve. These characteristics make them accessible to children and the other stakeholders involved, who can use and test them without knowing how to use them in advance. Indeed, as will be presented in the following paragraphs, prototypes were used as technology probes (Hutchinson, 2003), to experience sound via other senses as well, such as touch or sight (Kucirkova & Kamola, 2022). Moreover, the process followed the deep engagement principle (Hourcade et al., 2012) defined as co-designing with individuals who spend much time with the main user, such as parents, caregivers, and practitioners (Borzenkova et al., 2023; Hornof, 2009).

The result is BODYSOUND, a product-service system based on a co-design process carried out with children, caregivers and therapists, and with the support of the FightTheStroke (FTS) foundation. Through a virtual avatar, the BODYSOUND system offers users visible movement directions that they can follow to create melodies, obtain points, and progress to new levels. The service was developed for pediatric psychomotority and motor rehabilitation professionals, to provide a "high level of personalization" tool for home rehabilitation sessions intended to help the kids maintain their training and monitor their development.

In the image below, the model of engagement for children and other stakeholders according to different participatory research phases is also exemplified based on the methods used to gather information, feedback, and insights from the participants.

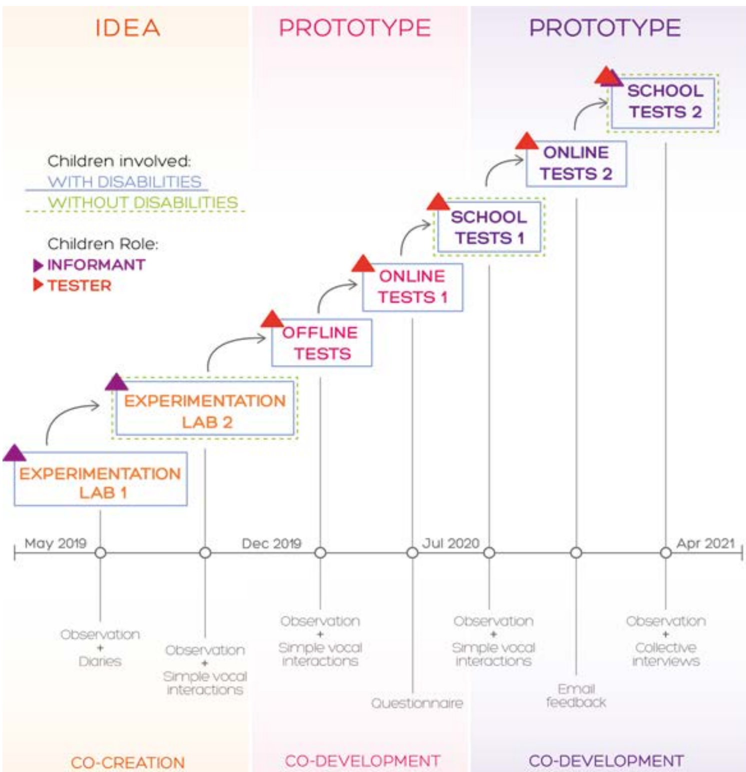

Fig. 1
Polifactory, BODYSOUND Children engagement model. Credits: Polifactory, Politecnico di Milano.

The step-by-step process model will be presented in the following pages.

Children as Informants: The Experimentation Labs

Conducted concurrently with the co-creation workshops with the children's families, the Experimentation Labs represented the initial endeavour, involving children as informants in the co-creation of the BODYSOUND solution.

Specifically, the research team carried out two Experimentation Labs:

- Experimentation Lab 1 (May-June 2019): 6 children (4-8 y.o.)
- Experimentation Lab 2 (October 2019): 20 children (4-8 y.o.)

Some raw technology was tested in both the Experimentation Labs, and the children's interaction and use of existing or prototyped products were observed. Specifically, the aim of these Labs was to observe how children interacted with different technologies and interfaces for playing music, ranging from touch to touchless .

Fig. 2
Polifactory, BODYSOUND, Experimentation Lab 1. Photo Credits: Polifactory, Politecnico di Milano.

The primary outcome of this first lab was "relational". Trust was built between families, children, and researchers. Feedback from the cultural probe diaries (Gaver et al., 1999) indicated that for families this moment was a valuable stimulus for activities that could be re-created at home. They identified accessible and engaging technologies and discovered solutions that could be adapted to meet some of their children's needs.

Experimentation Lab 2 was aimed at children experiencing the intangibility of sound through the tangibility of movement. Children with and without PC were involved and played three main roles during the activity: the deejays reproduced sound with an enlarged interface based on littleBits synth modules; the choreographers instructed the dancers on the movements to be performed; and the dancers performed the choreography.

This workshop was valuable in understanding the differences and similarities between the children, which is crucial in developing solutions that could be stimulating for all children.

Observation was the principal method of investigation and, in Experimentation Lab 1, the participants were also given a diary to report the pros and cons of the experience.

The results of our co-creation activities influenced researchers in assessing the idea of developing a digital game and establishing the essential features of the final solution, like portability in a non-care context and adaptability to a wide variety of needs and diseases.

From Informants to Testers: Offline and Online Engagement

The role of a child as a tester is focused on helping both with learnability, usability, and enjoyment, aiming to revise the prototype's releases. A gamification system was used to make the software interface platform more attractive and consistent in training, which was fundamental for our purpose of motor reactivation. Both offline and online tests were conducted iteratively (December 2019-November 2020) with 10 children (4-8 y.o.). Offline tests on the first prototype releases of the solution were carried out in a lab environment (at Polifactory). Online tests focused on the use of the solutions from home and on verifying elements that made the game pleasurable.

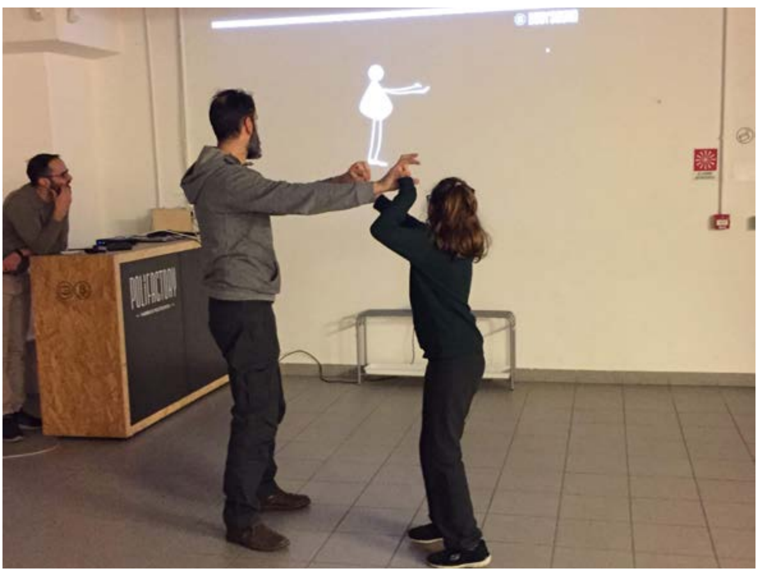

Fig. 3
Polifactory, BODYSOUND, First offline test session. Photo Credits: Polifactory, Politecnico di Milano.

Offline tests were organised in small groups of 2-3 children. Through these iterative sessions, the efficacy of the selected technology was tested, and the pleasing appearance of the game's interface, the visual representations, the efficiency of the sound feedback, and the chosen set of melodies were verified. Three researchers managed these sessions: one in a technical role, another focused on child engagement and the third dedicated to observing the behaviour and reactions of the children. The children were always accompanied by one parent and sometimes by their siblings too.

These sessions revealed that the children liked the chosen representation (avatar) very much. They enjoyed dancing to the songs because they could see their movements reflected in the avatar. The kids created "figures" with other players in the multiplayer game.

This offline testing phase was interrupted by the COVID-19 lockdown which influenced our decision to deploy BODYSOUND directly at home, under the supervision of parents.

The very first online test was developed using a tool to validate the graphics and sound feedback, and to keep in contact with the families and children. A board on the Padlet platform was shared with the families, and the children could easily provide their feedback with their parents' support.

BODYSOUND was transferred to personal computers to conduct the second online test, and an exercise recording tool was deployed. Motor rehabilitation specialists were asked to record their movements while listening to suggested melodies and to save the recordings, assigning a level of difficulty to each exercise. At the same time, the software was developed by integrating the ability to perform body tracking through a webcam, using Google open-source algorithms. A website containing a simple instruction manual and the BODYSOUND game customised for Halloween was designed and shared with 10 families. Participants encountered some difficulties since their computers were not very performing, and the setting did not allow the proper child recognition and tracking. This influenced our decision to go on with the development of BODYSOUND both for computers (in view of future technological improvements) and Kinect. For this test, evaluations were conducted via email, requiring us to depend on the parents' feedback without the benefit of direct observation or verbal interaction with the child testers.

Children as Testers: Verifying the Solution Scalability

After the prototype was developed new tests were carried out in a real-life context (school). The BODYSOUND prototype could thus be tested with a higher number of children who did not have any disability in most cases.

Two rounds of testing were conducted:

- School tests 1 (July 2020): 20 children (4-12 y.o.).
- School tests 2 (April 2021): 40 children (8-10 y.o.).

In School tests 1, the school environment was slightly different than usual because children were attending a summer camp. One room of the institute was set up for the tests.

A similar organisation was also put in place for School tests 2, during which the prototype final release was tested. In this second session, the testing activity was conducted during class hours, and was supervised by the children's regular teachers. This real-life setting influenced the children to pay more attention and behave as they do in class.

Common elements between the two testing sessions were the organisation in small groups, the presence of children without disabilities, the organisation of the research team, the evaluation through direct and indirect (video-recording) observations, the use of scoring as a way to engage the children even more. The BODYSOUND system was able to autonomously calibrate according to the child's body (e.g. height, arms opening) and offered just-above-level challenging movements. Scoring followed the same principle: given that the exercises were normalised according to each child's peculiarities, the final score depended on each player's ability.

Fig. 4
Polifactory, BODYSOUND, School test 1. Photo Credits: Polifactory, Politecnico di Milano.

Differences between the two testing phases were connected with the level of development of the prototype. In the first case, the visual and graphic elements were simpler, mainstream songs were featured, and the computer webcam was used; in the second, additional movement guides were added to facilitate the exercise, new songs were composed, and the Kinect was used. The typology of interaction also changed from one version to the other. In the first case, the song was divided into multiple track instruments, which were played if the child performed the movement correctly; in the second case, additional tracks were added to the song track base if the child performed the movement correctly.

These activities highlighted the limitations in tracking accuracy and the challenges of using the system in uncontrolled environments. As a result, the option to use either a single colour camera or a combination of a colour camera and a depth camera was integrated to enhance tracking reliability when needed. For the final testing phase, "movement guides" were integrated and refined to pre-trace and suggest the movements children were invited to perform with their limbs to receive sound feedback.

As previously explained, the research team consisted of three researchers each with different roles. In both circumstances, the children's tests were recorded; group interviews were conducted only in the second test because the children were older and could express their opinions more readily. It was interesting to observe that even though the kids were competing, they continuously encouraged and offered suggestions to their peers.

No previous instruction was provided to test the learnability of BODYSOUND; therefore, the first child using it had to understand how the game worked and what the rules were. After the first child's test, we asked all the children if they understood the rules of the game, and then proceeded with the other tests. All the children, including those presenting a disability, could play the game without difficulties. Once every child had finished their test, they were asked about several graphic aspects, sound and play elements of the game, the enjoyment and pleasurability of the visual graphics and music, and the BODYSOUND game overall. This final interaction with the children was very positive since in many cases they spontaneously played the role of informants and not only testers, giving us additional suggestions for the further development of BODYSOUND, and asking questions about features that they were interested in understanding.

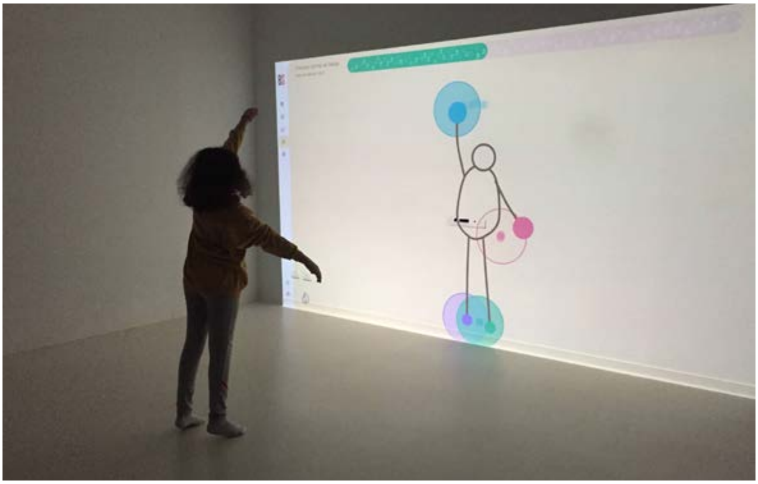

Fig. 5
Polifactory, BODYSOUND, Final school tests. Photo Credits: Polifactory, Politecnico di Milano.

Discussion

The BODYSOUND research experience indicates that a co-design process, particularly when involving children in the development of a digital solution, can be divided into distinct collaborative moments having different i) purposes and outputs, ii) targets and engagement roles, iii) methods of engagement and evaluation. In particular:

The co-creation phase is conducted to generate the idea, and this takes place during the first stage of the process. Only the main target is engaged at the beginning of the process and plays an informant role. However, to improve the first rough idea generated during this phase, the engagement can be extended to the next moment, which could include a secondary target and an informant role as well. Working with children in the co-creation phase requires a practical-tangible approach that concretizes elements which would otherwise be too abstract for them to understand. For this reason, the use of so-called boundary objects can facilitate the children's involvement. This means that even if the focus is the development of a digital interface, this very first phase should also include tangible artefacts to evaluate both the learnability and enjoyability of specific elements which might already be identified as peculiar to the final prototype (in our case, sound, music, and movement). The main method of evaluation and verification is through joint observation, which can eventually be accompanied by a voting/scoring method carried out by means of cultural probes. The co-creation phase of BODYSOUND helped to obtain demonstrators for the use of rapid prototyping technologies during activities focused on idea generation and not actual prototyping. This opens up possibilities for developing methods and tools to support designers in giving tangibility to idea generation through technology and creating opportunities for discussion about its use. It also allows children to be involved quickly in safe, controlled, and replicable tests and experiences, activating various engagement activities with different roles. It would be interesting for future research to consider children as co-creators of technological boundary objects as well, to become an active and generative part of a process. The use of machine learning and AI tools could further facilitate this transition.

As the name suggests, the co-development phase aims to develop the idea into a prototype. In this case, two different co-development macro-stages are recommended (there might also be more than two, depending on the level of readiness that the prototyped solution is expected to achieve). The first co-development stage should include the project's main target, which will be involved as a tester of specific features and elements of the prototype solution. In this case, the prototype's learnability, enjoyability, and functionalities are evaluated. The first co-development round should still be in person, while the second can be conducted remotely (in our case, this became necessary due to the pandemic). In this case too, the most relevant method for evaluating the children's experiences and prototype performances is observation (both direct and in video recordings). However, researchers can use quick and simple verbal interactions to acquire additional information on the prototype's effectiveness if the main target can answer basic questions (dependent on their age and mental conditions, for example). The second stage of co-development should be conducted in a real-life setting. The children involved attain mainly the secondary target; therefore, more children should be involved in playing both tester and informant roles. The third and fourth rounds include observations (direct and video-recorded) and collective interviews.

This phase of the children's development and involvement was undoubtedly complex. As the technology became invisible, imagining how children could actively intervene in its development was not easy. The research team, therefore, chose to involve children in developmental decision-making processes rather than in the development itself, as in the previous phase. This still allowed for good interaction with them. For future developments, even taking into account the very rapid advancement of technologies, it would be interesting to think of an open way to integrate the children's feedback into the software or co-develop it with them.

Conclusions

The article presented an overview of the different roles that children can play in co-design processes to develop technological solutions in the domain of healthcare and well-being. Based on the BODYSOUND case study, we identified an iterative process to involve children according to the different development phases.

Building on Druin's (2002) roles for children's involvement and Markopoulos et al.'s (2008) evaluation methods, BODYSOUND adopted an informant-tester-informant involvement model.

The iterative co-design process described here highlights the significant role that children can play both in idea generation and prototype development, demonstrating the value of incorporating their feedback and involvement to create effective and engaging digital solutions. Structuring the process into distinct collaborative moments, each defined by specific purposes, targets, and methods of engagement, can ensure meaningful and impactful contributions from children.

The use of tangible artefacts and boundary objects during the co-creation phase facilitates the children's understanding and engagement, making abstract concepts more concrete. Moreover, the integration of rapid prototyping technologies and the potential use of machine learning and AI tools further enhance the process, allowing for more dynamic and responsive development. Despite the complexity of involving children with CP in technological development, their participation in decision-making processes has proven valuable, paving the way for more inclusive and innovative design practices.

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