IN THE MIDST OF AN UNKNOWN WORLD: UNDERSTANDING CHILDREN WITH AUTISM THROUGH PARTICIPATORY DESIGN RESEARCH

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ABSTRACT

Involvement of children with autism in product design is very limited even though they have the potential to contribute to the design process through active participation. They are often excluded from the design process because of their impaired social and intellectual functioning and the lack of appropriate participatory tools and methods. Although reviewing the autism literature is informative regarding the general characteristics of the disorder and the observations we make may give a general idea about the behaviors and conditions of children with autism, these findings are always limited, since it is impossible to learn their thoughts and real feelings behind those actions and thoughts through these methods. However, participatory design ensures understanding them through immersing oneself in their worlds as well as empowering and emancipating them by giving the opportunity to have an impact on the design product. This brings about the need of developing appropriate tools and methods for prompting interaction and communication with children with autism. This paper, as a part of an ongoing study, presents an overview of participatory design with children with autism and a case study conducted with children with autism, their parents, and teachers in order to investigate the designers' ways of learning about the worlds of children with autism through participatory design research. The design task was reconsidering the conventional design of the trampoline, which provides relaxation and regulation of the body through repetitive movements, to develop design solutions for an improved, safer, and enjoyable bouncing activity for children with autism.

Keywords: Participatory design, design research, children with autism

1 INTRODUCTION

Participatory design ensures the involvement of children with autism, who are often excluded from the design process, through giving them a central role in the design process as well as giving a voice to their caregivers, who are living with and affected by the disorder as well, for designing more appropriate products for these children's use. Autism is an inborn neurodevelopmental disorder that has no medical cure and reveals itself in the first three years of childhood and characterized by impaired social interaction and communication skills and restrictive repetitive behaviors, interests and activities as well as co-occurring disorders and health conditions, such as sensory impairments, severe anxiety and depression, eating and sleeping disorders, hyperactivity, and motor disabilities (Howlin, 2004; Bogdashina, 2006; WHO, 2010; APA, 2013). The symptoms of the disorder may vary in intensity. Children with autism have a different sense of the world and a different relation with their social and material surroundings due to their impairments in social and cognitive functioning, stereotyped behaviors and interests, and difficulties in conceptual thinking and generalizing ideas and/or experiences affected by various factors. Therefore, designers need to understand the underlying causes of their physical and emotional reactions towards their environments, objects, and people (Howlin, 2004; Farrell, 2006; Bogdashina, 2006; van Rijn and Stappers, 2008; WHO,

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2010; APA, 2013), and participatory design provides designers the opportunity to learn more about them through living, experiencing, feeling, sharing, and making with them while encouraging their participation to achieve the highest possible inclusion of these children in the process of developing appropriate designs with the aim of increasing their wellbeing.

Within this perspective, this paper provides an overview of participatory design with children with autism and presents a participatory product design case study conducted with eight children with autism, seven parents, seven teachers, and eight industrial design students in order to investigate the ways of learning about these children's worlds through participatory design.

2 PARTICIPATORY DESIGN WITH CHILDREN WITH AUTISM

Participatory design requires the direct involvement of people, who are affected by the outcome of a process and the process itself, especially those who are ignored and excluded, in the design of products, environments, communities, and organizations etc. to enhance social progress within a community for, with, and by them through democratic, emancipatory, and transparent practices using various methods and tools, and giving them the right to have a sense of ownership over the outcome as well as developing the principles and practices to support continuous participation (Muller et al., 1991; Reich et al., 1996; Sanoff, 2000; Bjögvinsson, Ehn, and Hillgren, 2012; Muller and Druin, 2012; Robertson and Simonsen, 2012; Greenbaum and Loi, 2012). Especially designing for individuals with special needs, such as communicative, cognitive, and physical impairments, require different ways of interaction and communication depending on their physical, mental, intellectual, and sensory capabilities and abilities in order to have a better understanding of their lives in the design process, which is not possible through non-participatory design methods since they do not provide the adequate information and data to the designers. Healthcare systems, facilitating and medical environments, and assistive technologies, such as communication, orientation, and therapeutic devices, and planners, are quite important for these individuals in maintaining their lives; however, they are often excluded in the design of these environments, technologies, and devices, which may be functionally enabling and assisting but not always socially and emotionally supportive or empowering (Moffatt et al., 2004; Wu, Baecker, and Richards, 2005; Neuhauser et al., 2009; Zisook and Patel, 2013) Therefore, participatory design ensures the empowerment of these individuals through enabling and encouraging them to engage in participatory activities and the increased awareness of these individuals' presence in the society.

Regarding their impairments caused by the disorder, children with autism are among the users with special needs, who are hard to empathize, interact, and communicate with through non-participatory design methods. Within this context, children with autism and their caregivers have started to be involved in various design projects, mostly in the design of technology. These projects focus on developing products, models, or design principles to work with children with autism with the aim of reducing the negative effects of the disorder, enhancing their impaired skills, and providing them the opportunity to have an impact on shaping their own material environment for their empowerment, emancipation, satisfaction, and increased sense of ownership (Pares et al., 2005; Keay-Bright, 2007; van Rijn and Stappers, 2008; Millen, Cobb, and Patel, 2011; Frauenberger, Good, and Keay-Bright, 2011; Benton et al., 2012; Hirano et al., 2010; Malinverni et al., 2014).

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However, the challenges caused by the disorder affect the design process and limit the level of children's involvement (Woodcock and Woolner, 2007; Benton et al., 2011). For instance, children with autism lack communication, interaction, and conceptual thinking skills, which are a part of the requirements for collaboration and idea generation; therefore, they cannot take on the role of designers but can still participate in various roles (Frauenberger, Good, and Alcorn, 2012). Moreover, they get anxious and frustrated easily, when they find themselves in unfamiliar, unexpected, or unpredictable situations, and have a resistance to change in their routines and environment. Therefore, direct knowledge elicitation methods, such as brainstorming, interviewing, sketching, and low-tech activities, may be upsetting and ineffective for some children depending on the severity level and cause anxiety, but gathering data through their actions, e.g. physical activities, verbal expressions or gestures, may be more appropriate (Keay-Bright, 2007). The structure of the participatory sessions may be well-planned but may require changes in the method or the flow of the session any time due to children's distraction, emotional condition, and the like (Millen, Cobb, and Patel, 2011). These challenges bring about the need for tailoring the methods and tools to the varying conditions and abilities of children.

3 CASE STUDY

The case study was conducted in a public special education, application, and vocational educational center in Izmir, Turkey, with eight children with autism with different severity levels, seven parents, seven teachers, and eight industrial design students. The sessions involving the children took place at the school mainly for three reasons: (1) to avoid the distraction and anxiety of the children because of any changes in the environment, (2) to understand their daily lives in their own surroundings and how they interact with it, and (3) the children's familiarity with the people at the school. It was also critically important not to make any changes in the setting; therefore, there were not any spatial rearrangements as well as placing no camera for continuous recording.

3.1 PARTICIPANTS

Eight children with autism, referred as 'children', participated in the study with the consent of their parents (Table 1). They varied in their interaction, communication, and learning skills, patterns of behaviors and interests, and sensory sensitivities as well as the level of intensity of their autistic conditions and accompanying disorders/impairments.

CHILDREN	GENDER	AGE	DIAGNOSIS	ACCOMPANYING CONDITIONS	TIME SPENT AT THE SCHOOL
1	F	4.5	Atypical Autism	-	Full day (only afternoon twice a week)
2	M	5	Autism	Mental Disability Physical Disability	Full day
3	M	5	Autism	-	Only afternoon

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4	F	7	Autism	-	Full day
5	M	9	Autism	Epilepsy Hyperactivity	Only afternoon
6	M	11	Autism	-	Full day
7	M	14	Autism	-	Full day (only morning twice a week)
8	M	14	Autism	-	Full day (only morning twice a week)

Table 1 – General profile of the participant children with autism

The families of twenty-three registered children, aged between 4.5 and 17, were invited to the school for a meeting to inform about and explain the objectives of the study. Six parents attended to the meeting, two of whom were the mothers of twins, and two parents were met in another visit. Seven out of eight parents gave consent for the participation of eight children in total. These children's parents and teachers also participated in the study.

Although the selection was based on the voluntariness of the parents, the sample group was possible to be clustered in three developmental age groups with approximate number of children:

— 2-5 ages: Three children at the age of 4.5 and 5
— 6-11 ages: Three children at the age of 7,9, and 11
— 12-18 ages: Identical twins at the age of 14

Eight industrial design students, referred as 'designers', chosen by the researcher regarding their skills in design, interpersonal communication, and willingness to work with children with autism, participated in the study as well.

3.2 APPLICATION OF THE METHOD

The study consisted of four phases, involving some or all participants in each with applying various methods (Figure 1).
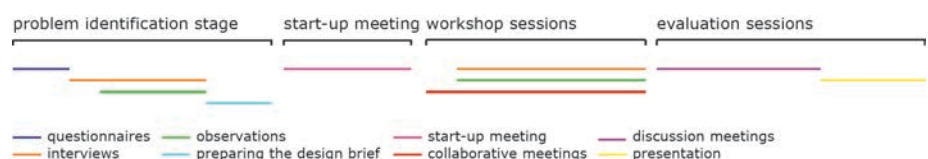

Figure 1 –The structure and the methods of the study.

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3.2.1 **Problem Identification Stage**

At this stage, it was aimed to identify a design problem and structure the workshop sessions. This stage did not involve the designers and was conducted by the researcher.

Questionnaires

Questionnaires were applied to the parents and teachers for receiving direct responses about the children in order to collect primary data for problem identification. After a 15-minute informative meeting, the questionnaires were handed out to the parents (Figure 2). The teachers were asked to fill the questionnaire after receiving the written and signed parental consents. Questionnaires consisted of fourteen items related to the children's diagnosis and accompanying conditions, the most significant daily life problems, objects they use the most and/or obsessed with, any problem when using these objects, ways of personalization, specific interests and/or talents, and consent for participation. The questions were open-ended. The teachers were asked to give responses in relation to the children's school life, since they only have experience with the children at the school, but the parents were not limited with any context, e.g. home or school. Some respondents filled the questionnaire individually whereas others preferred to be asked by the researcher due to their limited time for participation.

Figure 2 –Parents filling out the questionnaire.

Interviews

Informal conversational interviews were conducted with the parents, teachers, and the administrative staff to gather information about autism, the registered children, and the site before and after the application of the questionnaires. These interviews were recorded by the researcher and used as a guide to clarify the focus of the study.

Observations

To support and build on the data collected through the questionnaires and interviews, the researcher made exploratory observations during her subsequent visits by attending the class and sport activities, lunch hours, and special day events with the permission of the school principal, to shape the future research of the research by learning more about the disorder, and the ways of interaction and communication with them as well as the site and the children individually. These observations led the researcher towards a more specifically defined research direction including the identification of the design problem, the preparation of the design brief and the instruments for the following phase.

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Preparation of the Design Brief

During the problem identification stage, it was recognized that the most of the children were strongly interested in the trampoline, which provides many benefits, such as a whole body workout, improving gross motor skills and vestibular and proprioceptive systems, increasing spatial awareness, and relaxing and regulating the body systems through repetitive up-and-down movements (ReboundTherapy.org, 2014). The data collected at the school also indicated the need for more safety to reduce the risks of the trampoline use. Therefore, the designers were briefed to reconsider the conventional trampoline design and develop diverse solutions for an improved bouncing activity providing alternative ways of use that are both beneficial and enjoyable for children with autism.

3.2.2 Start-Up Session

After the problem identification, the researcher scheduled a start-up meeting with the designers to explain the purpose of the study. She made a short introduction to autism, and the objectives and structure of the study, and introduced the participant children by showing the selected videos and photographs and sharing the questionnaire and observation results. Regarding the widely-accepted autism intervention methods, the workshop sessions were decided to be run one-on-one by assigning each designer to one child. The designers drew a name from a bowl to be assigned to the children. A list of informative websites, short videos and films about autism, and product examples were also shared with the designers in order to get them prepared to the workshop sessions by learning more about the disorder and its relation to product design.

3.2.3 Workshop Sessions

The workshop was scheduled to successive four days and each designer worked with the assigned children one-on-one for three days depending on the children's weekly schedule of gym classes. Child 1, 2, and 6 had gym classes only twice week but were observed for three days as well during their in-school activities. It was possible to capture the children's current behavioral patterns, interests, and attitudes related to the trampoline use in a three-day observation and through interviews due to their restricted interests, despite the fact that a longer period would have provided more accurate data in the study.

A small room separated by windows in the hall was set for the designers during the workshop. It was located across the classrooms and near the gym, making it possible to observe everyone during the day, even in the breaks, as well as ensuring the transparency of the process to all participants and enabling them to involve and contribute any time.

Interviews

The designers held unstructured interviews and subject-related conversations with the parents and teachers in order to understand the underlying reasons and motivations of the participant children's behaviors, actions, and preferences (Figure 3). Since each child had different patterns of behaviors and interests, designers' own progresses determined the direction and content of their interview questions. The designers took interview notes in a personal log during and after the interviews and shared them with the other designers in

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collaborative meetings to cumulate the knowledge and information about the disorder and the children with autism both in general and specifically (Figure 4).

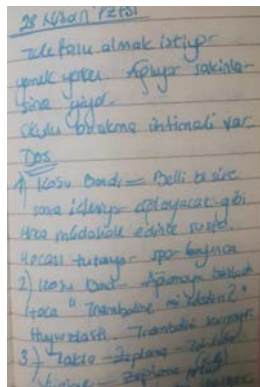*Figure 3 –Designers' interview with one of the parents.*

Figure 4 –Example of a personal log.

Observations

The designers made structured and unstructured observations during children's gym and in-school activities during their daily routine to support the data collected from the parents and teachers. The observations were overt and they were effective to collect data since most of the children were non-verbal.

During the structured observations in the gym, the designers filled the observation form, divided into three focus areas: sport activities, the trampoline activity, and designers' insights. It consisted of eighty-two items in total, mainly related to the class structure, engagement and interest, interaction and communication, support and intervention, concentration, physical development, patterns of behaviors and activities, safety issues, and designers' personal insights.

Both structured and unstructured exploratory observations were recorded through observational and reflective notes, photographs, and especially videos, since the design problem was strongly related to behaviors, movement, and physical interaction, as well. Videos provided data about how the physical activities and behaviors of the children took place while photographs supported videos by providing detailed close-up snapshots of the activities. The designers recorded the activities by using mobile devices instead of a fixed camera for continuous recording and were able to stop any time when recording, especially from a close position, caused frustration or distraction. Written records in personal logs, on the other hand, supported the visual records by describing the

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observed conditions and/or actions, experienced striking moments, and the designers' feelings and insights in relation to them. Moreover, considering that each designer had a chance to observe all participant children in some way at the school, participant sheets reflecting the children's characteristics and trampoline use were prepared for each child and hung on the wall for all designers' contribution (Figure 5). Parents and teachers were encouraged to contribute as well.

Figure 5 —Participant sheets on the wall.

Collaborative Meetings

In the first meeting, warm-up questions were asked to designers to share their expectancies from the process and previous experiences with people with special needs. Following meetings were held periodically for group discussions among the designers and provided a collaborative source of information. The designers shared their experiences and insights, identified the design problems collaboratively, and developed suggestions by building on each other's ideas. In order to provide continuous feedback for the designers, the key points of the meetings, such as new information, observation and/or interview notes, striking moments, and fast-visualized ideas, were listed and clustered on the wall by using post-it notes (Figure 6 and 7).

Figure 6 —Warm-up questions asked to the designers.

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Figure 7 –Post-it clusters for problem identification and brainstorming ideas.

3.2.4 *Evaluation Sessions*

Two sessions were set for evaluation in order to evaluate the design process and its outcomes.

Discussion Meeting

Designers worked individually outside the school to improve their design suggestions for three weeks after the workshop and shared their ideas through sketches and scenarios, gave critiques to each other, and decided on the ideas to develop further in a discussion meeting. They decided to call the process as 'Benimle Tasarla' ('Design with Me') to be used in the presentation. This meeting was sound-recorded by the researcher. After the discussion meeting, the designers continued to improve and refine their designs and prepared visuals for the presentation.

Presentation

All participants and non-participant children, parents, and teachers were invited to the presentation organized at the school. The researcher conveyed an overview of the study and the workshop process and acknowledged the participants. Then, each designer presented their final conceptual trampoline design ideas, after which the audience was asked to give feedback and encouraged to comment on the ideas (Figure 8). Each designer's talk was limited with 5 minutes in order to keep the presentation short regarding the distractibility and short attention span of the children. The researcher video-recorded the presentation and the audience's feedbacks.

During the presentation, the designers filled the product-assessment sheet, including items about the clarity and focus of the design problem and the visibility and reflection of the participants' involvement as well as the clarity, originality, elaborateness, appropriateness, utility, adaptability, aesthetic quality, and creativeness of the idea, to be evaluated on a 5-point Likert scale. They also

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filled the self-assessment sheet, including items about the level of participants' involvement and the level of interaction and communication between the designers and participants to be evaluated on a 5-point Likert scale and open-ended questions on their insights and suggestions about the workshop.

Figure 8 –Presentation at the school.

4 FINDINGS

The findings of the study were grouped into three in relation to the participants: (1) children with autism, (2) parents and teachers, and (3) designers.

4.1 IN RELATION TO THE CHILDREN WITH AUTISM

The children were uncomfortable with the presence of the researcher and designers in the beginning of the study; however, their disturbances, distractions, and anxiety started to decrease after spending time with them and with the support of the parents and teachers in facilitating interaction and managing the children's behavior. The interaction between the designers and children was more than it was expected but establishing verbal/non-verbal communication in between was difficult.

During the sessions, Child 3, 6, 7, and 8 were exceptionally comfortable whereas Child 5 was very aggressive and rejected even his parents. Nevertheless, he did not resist spending time in the gym with Designer 5. Child 7, who was among the children with the least severe autism at the school and has good verbal communication skills, constantly tried to build dialogues with Designer 7. Child 8 was verbal as well but did not like to have conversations; however, he was open to physical interaction and enjoyed holding hands with people. Although he was much more familiar with his teachers, he preferred holding hands with Designer 8 for relaxation when he cried in the sessions. Child 6 did not physically interact in the same way, but enjoyed being with Designer 6 and wanted to be hugged or kissed by her as a reward when he completed his tasks. He also liked to go to the room allotted to the designers and spend time there.

None of the children expressed any ideas or made creative contributions during the sessions. Only Child 7 verbally stated that he enjoyed the trampoline and listened the presentation with less distraction compared to other children. He unexpectedly interrupted Designer 3's presentation by repeatedly asking, "What do you think it means?". However, it was not related to the design but to a word that the designer used while talking. Other children did not listen or show any interest in the presentation at all. In the last designer's presentation, a non-

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participant child tended to physically attack to a crying child and the presentation had to be ended. Even though the duration was kept limited with 5 minutes, the total duration of the presentation was very long for the children and it was not interesting and enjoyable for them to follow.

4.2 IN RELATION TO THE PARENTS AND TEACHERS

The participants' unfamiliarity with the context and the method of the study caused a lack of trust in the beginning of the study and they did not show any interest in the informative meeting at first. However, the father of Child 6, who was very talkative and dominant among others, voluntarily made an effort to persuade the others to how academic and scientific studies can contribute to their children's future. Then, all parents completed the questionnaire and gave consent for their children's participation, except one. The teachers were more willing to participate; however, it was difficult to engage both the parents and teachers in responding the questions when the children were around. Therefore, most of the respondents preferred to be asked by the researcher.

During the sessions, the lack of communication between the teachers and parents, in terms of sharing knowledge and information about the children, was realized. For instance, the teacher stated that Child 5 hated the trampoline and was unable to jump on the floor as well. Designer 5 learnt from her interview with his parent that the child actually loved the trampoline; however, after gaining weight, he started to be scared but still used his own smaller house-type trampoline at home. Another important realization about the teachers was that they were not educated or experienced in the special education of children with autism. They had only completed a course to receive a certificate after retirement or a certain period of experience in preschool or primary school. Moreover, most of the parents were not fully educated and trained about autism and how to take care of their children appropriately. For instance, one of the parents expected this study to cure her daughter without knowing that autism is a lifelong disorder. These realizations were shared with the school principal with the aim and expectancy of contributing to the improvement of the communication between the school and families and increasing the awareness of the lack of knowledge, education, and training.

During the sessions, the parents and teachers managed the children's behaviors and prompt their interaction with the designers. All participant and non-participant teachers and parents stated their satisfaction with the outcome and that they would love to participate in future studies. Non-participant teachers commented on the trampoline ideas, sometimes more than the participants did, during the presentation as well.

4.3 IN RELATION TO THE DESIGNERS

The designers were anxious about meeting the children because of having no previous experience with individuals with autism at first, but became self-confident and comfortable after spending time with them. They expressed this experience as being emotional, touching, unique, and educative for them. Moreover, they stated that they felt themselves important for doing something beneficial for these children and realized that design is a means of increasing awareness on such issues through practice and making these children's lives easier.

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The design brief focused on providing an improved bouncing activity and increasing the measure of safety. The designers' observations supported the need for improving the product and the activity it provides as well. The class teachers stated that all children liked the trampoline and it was used as a reward; however, it was realized that it was used for therapy/physical education more than as a reward and some children, who also rejected any encouraging attempts, had no interest in the trampoline. Some of the children interacted with their teachers while jumping and waited for verbal direction and/or physical support to start/stop the activity. The children sometimes performed activities, such as lying, rolling, and bouncing on knees, on the trampoline. Ball-playing activities were also integrated in the trampoline activity by the gym teachers for physical development as well. As well as these observations, the designers made interviews with the parents and teachers and also took support from them during the sessions to interact and communicate appropriately with the children. They also worked in collaboration among themselves and got feedback from each other, which was stated as being very effective for them.

The designers turned these findings and each child's characteristics into design input and developed eight trampoline design ideas in total. Below are the examples of the design concepts (Figure 9, 10, and 11):
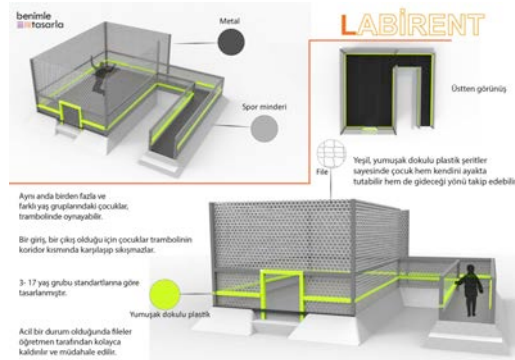

Figure 9 – LABİRENT (LABYRINTH): Trampoline with a physical therapy aisle in order to improve fine and gross motor skills and providing safe jumps for multiple users.
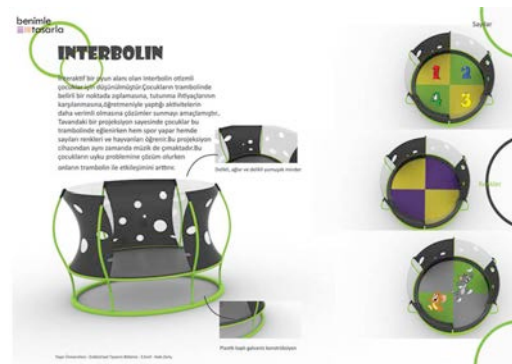

Figure 10 – INTERBOLIN (INTERPOLINE): An interactive play area providing audio-visual stimuli and ball-playing activities with specially designed safety nets.

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Figure 11 – IŞILDAYAN KARELER (ILLUMINATING SQUARES): A ground-level trampoline having illuminated frames as a means of encouragement for interaction for children with fear of heights and that are fascinated by light.

5 CONCLUSION

In this study, it was important not to focus on the children's incapabilities but rather on the potential of their behaviors, actions, and experiences as a design input and how these children can be emancipated by the design process. Therefore, the findings are discussed in terms of the methods used, the interaction and communication among the participants, their attitude towards and interest in the participatory process, and the potential benefits of the design process and ideas.

The application of the methods were challenging in the study. Establishing a trustful relationship took some time and it was partially overcome by the researcher and designers especially through informal conversations to build a healthy communication with the parents and convince them to the importance of their participation for their children's benefit. It was also realized that the questionnaires that were asked in person were more effective both in the sense that it created a ground for having sincere conversations and the answers could require further questions or explanations. In terms of interaction and communication, the intervention of the parents and teachers was required especially when the children were frustrated, distracted of misbehaved. Regarding the ways of participation and involvement of the participants, it was observed that the children were involved as informants, whereas the teachers and parents participated as caregivers, facilitators, informants, and evaluators and the designers as researchers, observers, learners, idea developers, and evaluators in the design process (Table 2).

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Different conditions and physical abilities of the children and unexpected behavioral changes and occurrences caused by the nature of the disorder throughout the design process affected the designers' progress. However, managing their own processes and collaborative sessions, flexible in time management and duration, enabled designers to work more flexibly, which helped collecting and processing the data without any interruption in the process. The designers focused on the experiences to understand the interaction of the children with their surroundings, especially with the trampoline. Since the design task was about movement and physical activities and the product at issue was appropriate for a wide range of users, the heterogeneity of the sample group provided the opportunity to see the diverse effects of autism on children's physical activities. These findings were translated into design concepts that aimed to increase the children's engagement and interest in the trampoline activity and decrease their distraction.

This study shows how designers can learn from children with autism through participatory methods that were chosen regarding the design problem identified in the problem identification stage and the conditions of the children. Therefore, a different design task might have required different methods depending on the product at issue. Different conditions of the children might have caused different choices of participatory activities, such as using more generative techniques with children with better communication, imagination, conceptualization, and abstract thinking skills or carrying out sensory activities with children with more severe sensory impairments in order to observe and understand their reactions to certain stimuli. Due to the large scale of the design task, time constraints, and lack of funding, the study was limited with generating concepts and did not include a prototyping and prototype testing phase. Despite the limitations, the application of the methods was successful and the findings of the study were fruitful, pointing out a new direction in product design. Considering the great value of the reflections of the participation of children with autism and their caregivers, it is hoped that this study will open up new discussions and inspire researchers to investigate new inclusionary ways to work with this special user group.

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