A PARTICIPATORY PRODUCT DESIGN PROCESS WITH CHILDREN WITH AUTISM SPECTRUM DISORDER

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Approval of the Graduate School of Social Sciences

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ABSTRACT

A PARTICIPATORY PRODUCT DESIGN PROCESS WITH CHILDREN WITH AUTISM SPECTRUM DISORDER

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This thesis aims to explore the ways of involving children with autism in participatory product design processes by giving them a central role and a voice to their teachers and parents, who are also affected by the disorder, in the design process. Since children with autism have impaired skills, such as interaction, communication, sensory processing, and learning, caused by the disorder, understanding the nature of autism and how these children interact with their social and material surroundings as well as the problems they struggle with in their daily lives is of great importance in the design process. Considering this, a case study was conducted with eight industrial design students, eight children with autism, seven parents, and seven teachers at Güzelbahçe Special Education, Application, and Vocational Training Center, in İzmir, Turkey. Regarding that the design task, which was to reconsider the conventional trampoline design with respect to the benefits it provides, was based on the patterns of behaviors, actions, and movement, observations, interviews, and questionnaires were applied as well as holding collaborative meetings and discussion meetings. Through the case study, several findings on conducting a participatory process with children with autism, the roles of the participants, interaction and communication among them, their attitude towards and interest in the participatory design, and the potential benefits of the design process and ideas for the children with autism were obtained.

Keywords: participatory design, children with autism, product design

ÖZET

OTİZM SPEKTRUM BOZUKLUĞU OLAN ÇOCUKLAR İLE

KATILIMCI ÜRÜN TASARIMI SÜRECİ

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Bu tez, otizmli çocuklara tasarım sürecinde merkezi bir rol vererek ve bu bozukluktan etkilenen öğretmen ve ebeveynlerin de süreçte söz sahibi olmalarını sağlayarak, otizmli çocukların katılımcı ürün tasarım süreçlerine dahil edilme yollarını keşfetmeyi amaçlamaktadır. Otizmli çocukların, bu bozukluklarından kaynaklanan etkileşim, iletişim, duyu işleme ve öğrenme gibi becerilerinde bozulmalar olması dolayısıyla, otizmin doğasını, bu çocukların kendi sosyal ve materyal çevreleri ile etkileşimleri ve günlük yaşamlarında karşılaştıkları problemleri anlamak tasarım süreci için büyük önem taşımaktadır. Bu düşünceden hareket ile, sekiz endüstriyel tasarım öğrencisi, sekiz otizmli çocuk, yedi veli ve yedi öğretmen ile İzmir'de yer alan Güzelbahçe Özel Eğitim, Uygulama ve İş Eğitim Merkezi'nde bir durum çalışması gerçekleştirilmiştir. Geleneksel trambolin tasarımının sağladığı faydalar ışığında yeniden değerlendirilmesini hedefleyen tasarım konusunun davranışsal ve eylemsel örüntüler ve harekete dayandığı göz önünde bulundurularak, gözlem, görüşme ve anket uygulaması yapılmış, ortak toplantılar ve tartışma toplantıları gerçekleştirilmiştir. Durum çalışması sayesinde, otizmli çocuklarla tasarımcı süreç gerçekleştirilmesi, katılımcıların rolleri, aralarındaki etkileşim ve iletişim, katılımcı tasarıma karşı tavır ve ilgileri ve tasarım süreci ile fikirlerinin otizmli çocuklar için potansiyel faydalarına dair bulgular elde edilmiştir.

Anahtar Kelimeler: katılımcı tasarım, otizmli çocuklar, ürün tasarımı

To Sufferers of Autism

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CHAPTER 1

INTRODUCTION

This study analyzes the literature of autism and participatory design in order to relate them with each other by understanding the nature of autism, including its causes, characteristics, and intervention methods, and its relation with product design as well as the participatory practices conducted with special user groups, specifically with children with autism, with the aim of fulfilling a gap in the field of product design.

This introductory chapter aims to introduce the aim and scope of the thesis in relation to the importance of involving children with autism in the design process with the aim of making their lives better and to the exploration of the ways of working with this user group. The research questions and hypotheses of the thesis as well as its structure are presented in this chapter.

1.1 AIM AND SCOPE OF THE THESIS

Participatory design enables the involvement of children with autism, who are often marginalized and 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 their use and increasing their wellbeing through design. Understanding their lives that are full of unique experiences, their social, cognitive, physical, psychological, and sensory impairments, patterns of

behaviors and interests as well as the underlying causes of these behaviors is of great importance for designing for and with children with autism. However, it is nearly impossible to empathize with or receive direct responses from them, since they lack social interaction and communication skills and express themselves in the way that typically developing people do. Therefore, participatory design helps designers learn more about children with autism through living, experiencing, feeling, sharing, and making with them while encouraging their participation to achieve the highest possible inclusion of these children and giving them the opportunity to influence the design decisions affecting their lives and environments.

There is only a limited number of participatory projects and academic studies on design with children with autism, which mostly focused on human-computer interaction, interface, and technology design (Pares et al. 2005; Keay-Bright 2007; Millen, Cobb, and Patel 2011; Frauenberger, Good, and Keay-Bright 2011; Benton et al. 2012; Hirano et al. 2010; Malinverni et al. 2014). However, there are hardly any applications for participatory methods in the field of product design (van Rijn and Stappers 2008). Therefore, this study is different in the sense that it aims to investigate the ways of working with children with autism, who lack skills in interaction, communication, conceptualization, and abstract thinking etc., in participatory product design processes and how the design process evolves when participants have special conditions. In order to fulfill this aim, it is required to understand the nature of the disorder first, and then the interaction of children with autism with their surroundings as well as the problems they face with to determine their needs. With this in mind, a literature review was done to understand how autism and participatory design relate with each other and a case study was held using participatory methods to work with children with autism in order to draw some conclusions on conducting such product design projects with this special user group.

The core of this study is to understand the children with autism, how social mechanisms for children with autism function, and then search for ways to include their opinions as well as

that of their teachers and parents in the design process regarding their material environment. This study also objects to aid designers, who want to work children with autism in the future product design projects, to shape their research directions and studies and lay the opportunities and constraints of working with this special user group before those designers.

1.2 RESEARCH QUESTIONS AND HYPOTHESES

Research Questions (RQ)

RQ1. How can designers work with children with autism in a participatory product design process?

RQ1a. What is the role of participants (designers, children with autism, parents, and teachers) when working with children with autism in a design process?

RQ1b. How can designers, who have not had a contact with before people with autism, interact and communicate with children with autism during a design process?

RQ2. How do children with autism interact with their material surroundings in their daily routines?

RQ2a. What are the most significant problems of children with autism with their material surroundings in their daily routines?

RQ3. How can design contribute to the lives of children with autism and their wellbeing?

Hypotheses (H)

H1. Participatory design processes are beneficial to understand the individual and specific problems of children with autism in their daily lives and proposing design solutions.

H2. Working with children with autism requires flexibility and spontaneous changes due to unexpected behavioral changes and occurrences caused by the characteristics and special conditions of children throughout the design process.

H3. Personal interests, skills, and talents of children with autism aid designers while developing design solutions.

1.3 STRUCTURE OF THE THESIS

This thesis consists of five chapters:

The first chapter introduces the importance of the involvement of children with autism in the design process and presents the aims and scope of the thesis, and the research questions and hypotheses of the thesis.

The second chapter dwells upon the literature of autism and provides a background on the definitions and classifications of autism based on two international classification systems. The epidemiology and general characteristics of autism, based on the diagnostic criteria, and the intervention methods are also investigated in order to understand the nature and challenges of autism. The chapter continues with the examination of educational and therapeutic tools, equipment, and environments for children with autism.

The third chapter provides a theoretical framework for the study and focuses on the notion of participatory design and the participatory practices done with special user groups, specifically children with autism. It brings together and discusses various definitions and approaches of participatory design and gives an historical overview of the approach. Then, participatory design with special user groups, who are often regarded as minorities in the society and excluded in the design process, is examined thoroughly in order to understand the importance of their involvement and how they are enabled to participate in the design process. Participation of children with autism, which is the focus of the study, is also investigated in detail and an overview of selected participatory projects is presented.

The fourth chapter introduces the case study conducted in Güzelbahçe Special Education, Application, and Vocational Training Center. The site, setting, sample group, and participants of the study are explained in detail as well as the method of the study. The findings of the study are also presented and discussed in this chapter.

The fifth chapter provides an overview of the overview of the study and revisits the research questions. The limitations of the study and recommendations for further studies are presented as well.

CHAPTER 2

AUTISM SPECTRUM DISORDER

This chapter dwells on the definitions and classifications of autism and the epidemiology, general characteristics, and intervention methods of the disorder in order to provide a solid background for the participatory case study that would be conducted with children with autism. It was of great importance to understand the disorder, in terms of the conditions and challenges it brings forward, in order to act upon in the study as well as the current state of autism in Turkey, since the case study would be conducted in İzmir, Turkey. Therefore, the prevalence of autism and the opportunities provided to the children with autism in Turkey are investigated in this chapter as well.

2.1 DEFINITIONS AND CLASSIFICATIONS OF AUTISM SPECTRUM DISORDER

Autism Spectrum Disorder (ASD) is a congenital and lifelong neurodevelopmental disorder that reveals itself in the early childhood with various signs and symptoms affecting individuals' social functioning and communicative skills accompanied by restrictive repetitive behaviors, interests and activities; and often coexists with other disorders and medical conditions as well (WHO 2010, 2014; APA 2013). Impairments in interaction, communication, and behaviors affect all areas of lives of people with autism in a negative way, since these impairments limit their positive and beneficial experiences of the world. In addition to the core diagnostic features of autism, these individuals have multiple impairments and co-occurring health conditions, such as eating disorders, severe anxiety

and depression, sensory impairments, hyperactivity, and motor disabilities (Howlin 2004; Bogdashina 2006; WHO 2010; APA 2013). Although the signs and symptoms of autism are more easily identified in children, some people with lower functioning autism do not receive an ASD diagnosis until adolescence or adulthood, but the symptoms have inevitably existed since their early childhood. Therefore, as well as psychiatric and psychological examinations, the history of the development of mental abilities, language skills and behavioral patterns is of great importance for diagnosis (Bogdashina 2006).

Autism is diagnosed, regarding the signs and symptoms with different intensities from mild to severe, on the basis of the diagnostic criteria of *International Classification of Diseases (ICD)* and *Diagnostic and Statistical Manual of Mental Disorders (DSM)*, which are the two major diagnostic guidelines (Happé 2005; APA 2013; WHO 2010). These internationally recognized classification systems have both similarities and differences; however, they have been continuously revised and modified in relation to the other with a deep examination in order to provide a well-organized and concise system for accurate diagnosing of diseases and disorders (Volkmar and Klin 2005; Bogdashina 2006).

2.1.1 Definition and Classification of Autism Spectrum Disorder in the International Classification of Diseases

The International Classification of Diseases (ICD) is a medical classification system for diagnosing diseases and related health problems with a detailed coding system for clinical and epidemiological purposes (WHO 2014b). The World Health Organization (WHO) published the first edition of ICD in 1900, and revisions were done in 1909, 1919, 1929, 1938, 1948, 1955, 1965, 1975, 1989 (WHO 2005), and 2010.

The current edition, ICD-10, was prepared in 1989 and approved by the World Health Assembly in 1990 (WHO 2005). It has gone through annual revisions due to new scientific knowledge and clinical findings through improved technology and fieldworks. In ICD-10, the WHO classifies ‘Autistic Disorder’, also known as ‘Childhood Autism’, ‘Infantile Autism’,

‘Infantile Psychosis’, or ‘Kanner Syndrome’, as one of the eight disorders under the category of Pervasive Developmental Disorders (PDDs), and characterizes it by two areas of abnormalities with additional disorders and disturbances: (a) developmental abnormalities noticed in the first three years of childhood, and (b) atypical psychopathological functioning, including reciprocal social interaction and communication, and stereotypical and repetitive patterns of behaviors (WHO 2010). The disorders falling under Pervasive Developmental Disorders in ICD-10 are ‘Childhood Autism’, ‘Atypical Autism’, ‘Rett Syndrome’, ‘Other Childhood Disintegrative Disorders’, ‘Overactive Disorder Associated with Mental Retardation and Stereotyped Movements’, ‘Asperger Syndrome’, ‘Other Pervasive Developmental Disorders’, and ‘Pervasive Developmental Disorders, unspecified’.

ICD-10, with regular updates on a yearly basis, is still in use clinically. However, the World Health Organization is planning to publish the 11th edition of ICD, which is still in the revision process, in 2017. It contains some major changes in classification and coding, and one of the most noteworthy changes is in the classification of autism and its diagnosis. Regarding the ICD-11 Beta Draft Version that is available online, the category of Pervasive Developmental Disorders is renamed as ‘Autism Spectrum Disorder’ under the broad category of Mental and Behavioral Disorders. The definition of Autism Spectrum Disorder is revised as a neurodevelopmental disorder that becomes evident in early childhood through developmental delays in reciprocal social interaction and communication accompanying by restricted repetitive behaviors, interests and impairments in sensory perception, of which their severity may change in time (WHO 2014a). Autism Spectrum Disorder is divided into subcategories depending on whether the disorder is with or without any deficit in intellectual development and communication. These impairments may be in varying degrees, which identify the severity of the disorder. The subcategories of ASD in ICD-11 Beta Draft Version are categorized depending on whether the ASD is with or without any impairments in intellectual and structural language development. According to the draft, ASD may be either without any intellectual or language impairment or with either of these impairments or both. Structural language impairments are also specified depending on being marked, pervasive,

complete, or limited but unspecified. ‘Other specified ASD’ and ‘unspecified ASD’ are the other subcategories of the disorder that do not fall under the subcategories with previously specified impairments in ICD-11 Beta Draft Version.

It should be remembered that the ICD-11 classifications are only the proposed modifications for the upcoming edition. Even though the changes in definition and classification of the diseases and disorders are now available online, the ICD-11 Beta Draft Version has not yet been finalized and approved by WHO (WHO 2014b), and cannot be used for clinical diagnosing purposes until then. However, it contributes to this study in terms of indicating what is the evolved and more detailed definition of ASD that provides the opportunity of a more accurate diagnosis. Since ICD and DSM are interrelated with each other and share the classification codes and many criteria, ICD-11 is involved despite being a draft version in order to show it is being revised in parallel with DSM-V, which is the current edition of DSM launched in 2013.

2.1.2 Definition and Classification of Autism Spectrum Disorder in Diagnostic and Statistical Manual of Mental Disorders

Diagnostic and Statistical Manual of Mental Disorders (DSM) is published by the American Psychiatric Association (APA) as a guide containing clinical classifications of mental disorders for diagnosis (APA 2013), using ICD codes. The first manual was published in 1952, and revised several times in 1968, 1980,1987, 1994 (Mesibov, Shea, and Adams 2002), 2000, and 2013. Although the latest edition, DSM-V, was published in 2013, the previous edition and its revised version, DSM-IV and DSM-IV-TR, are the basis of the most of the practical and academic works until now. Therefore, it is important to introduce and refer to the information and knowledge provided by DSM-IV in order to understand how it has evolved into DSM-V in terms of defining and classifying autism as a neurodevelopmental disorder and why the changes throughout this evolution process have occurred.

APA (1994; 2000) previously classified autism as ‘Autistic Disorder’ under the broad category of Pervasive Developmental Disorders in DSM-IV and DSM-IV-TR. It was one of

the five subcategories: 'Autistic Disorder' (classic autism, early infantile autism, childhood autism, or Kanner's autism), 'Asperger's Disorder', 'Rett's Disorder', 'Childhood Disintegrative Disorder' (*Heller's syndrome*), and 'Pervasive Developmental Disorder Not Otherwise Specified'. Autistic Disorder in DSM-IV was characterized by 'the presence of markedly abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activity and interests' that vary depending on the age and developmental level of the individual (APA 1994, 66). The diagnostic criteria of Autistic Disorder in DSM-IV was based on the above-mentioned impairments; and the diagnosis required at least six items from these three core areas of impairments – at least two social interaction impairments, at least one communication impairment, and at least one restricted repetitive and stereotyped patterns of behavior, interests, and activities – that are specified in detail. In addition to these indicative characteristics, 'delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play' should have been specified (APA 1994, 71). It was also expected that Rett's Disorder or Childhood Disintegrative Disorder would fail to explain the disturbance in order to make Autistic Disorder diagnosis based on DSM-IV.

However, significant changes and revisions have been made in DSM-V with the aim of ensuring more accuracy in diagnosing mental disorders by improving the sensitivity and specificity of the diagnostic criteria (APA 2013). The five above-mentioned pervasive developmental disorders that were previously classified in DSM-IV are now covered by the 'Autism Spectrum Disorder' under the category of Neurodevelopmental Disorders in DSM-V. The reason why the separately defined pervasive developmental disorders are now classified together as a spectrum with no subcategories is that they show similar symptoms in diagnosing, but only with different levels of severity (APA 2013). The diagnostic criteria of ASD have been revised accordingly; and hence, the manual provides a more specific definition of ASD, including 'specifiers' for specifying current severity. In DSM-V, two areas of impairments are indicated for diagnosing Autism Spectrum Disorder. ASD is characterized:

> "…by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relationships. In addition to the social communication deficits, the diagnosis of autism spectrum disorder requires the presence of restricted, repetitive patterns of behavior, interests, or activities. Because symptoms change with development and may be masked by compensatory mechanisms, the diagnostic criteria may be met based on historical information, although the current presentation must cause significant impairment." (APA 2013, 31-2)

To be able to make ASD diagnosis, it is required for the individual to have at least two restricted repetitive behaviors, interests, and activities accompanying social interaction and communication deficits. Unlike DSM-IV, DSM-V includes sensory perceptual deficits as a subcategory under restricted repetitive behaviors, interests, and activities. Any intellectual or language impairments the individual has accompanying with medical or genetic conditions, environmental factors, other disorders or catatonia should also be specified for diagnosis, if there are any. Moreover, severity levels are determined by depending on how much need the individual has for support for social communication and restrictive repetitive behaviors in all contexts (APA 2013).

2.2 EPIDEMIOLOGY OF AUTISM

Factors affecting the occurrence and prevalence of autism are investigated in this section in order to understand how these factors are interrelated with each other and affect the frequency of autism in different contexts. Moreover, co-occurring conditions that accompany autism are also examined as well with the aim of understanding how they affect people with autism in terms of the recognition and severity of the disorder.

2.2.1 Causes and Risk Factors

Naturally, the first thing parents usually want to know is what causes their children to born with autism. They often feel guilty about their children's condition and even consider themselves to be the cause. It is a misbelief that bad parenting may cause the children's condition (Happé 2005; APA 2014), since autism is congenital and children are just born with it. However, parents' awareness, support, and relationship with their children are crucially important for children's development and improvement, even though it is not a cause for the disorder.

Causes of autism still remain unknown; but yet, the environment and genetics are found out to be contributing to the occurrence of autism as the highest possible risk factors regarding the research studies that have been done (APA 2014; NIMH 2014; CDC 2014a). Vaccines have also been considered to cause autism, probably since many vaccines are given to children in their early childhood just when autism symptoms are started to be noticed; but the research has disproven it by showing no reliable association between vaccines and the disorder (Price et al. 2010; DeStefano, Price, and Weintraub 2013; NIMH 2014).

Environmental factors, i.e. nongenetic, are one of the greatest risk factors affecting children to born with autism. Maternal conditions before, during and after pregnancy, parental age, birth order, and medical familial patterns appear to be highly associated with the disorder. The research has shown that prenatal, perinatal, and neonatal conditions, such as complications or infections during pregnancy, using medication with certain chemicals, and injuries or traumas during birth, increase the risk of autism (Gardener, Spiegelman, and Buka 2009, 2011). Advanced age of parents increases the risk as well. Children, who are born to families with mothers older than 35 and fathers older than 40, is the group carrying the highest risk of autism; and along with the advanced parental age, first-born children of these parents are more likely to born with the disorder (Durkin et al. 2008; Gardener, Spiegelman, and Buka 2009). Moreover, family history is also important for the increased risk of autism. If autism has already been diagnosed in one of the family members before, the risk occurs to be higher for the other family members. For instance, second- or third-born children are likely to be affected, if the older sibling has the disorder. Considering twins, the risk of autism to be diagnosed in both fraternal twins increases up to around 10%, whereas the ratio is nearly 90% for identical twins, who are more likely to meet the diagnostic criteria (Bailey et al. 1995; APA 2013; NIMH 2014).

Autism is more common among people with certain chromosomal or genetic conditions, such as fragile X syndrome and tuberous sclerosis, or genetic mutations (APA 2013; CDC 2014a; NIMH 2014). Even though genes are agreed to be a cause of autism and put importance to

be researched in order to reveal the exact genes affecting individuals, it is not yet clear that which genes have a role in the disorder. Autism seems to be associated with more than one gene, and these genes probably occur to be in different combinations in different people; moreover, various environmental factors increase the risk of autism along with the effect of genetic variations (APA 2013; NIMH 2014). Therefore, autism occurs in individuals depending on various interrelated and co-occurring factors, both environmental and genetic.

Although there is evidence of the above-mentioned factors for causing autism, it should be stated that they are still at the theoretical level and being researched, and have not been fully proven yet.

2.2.2 Demographic Factors and Prevalence

Demographic characteristics of populations are important to evaluate the patterns of diagnosis in different regions and to understand whether there are any relations in between. Differences in cultural norms and values, socioeconomic conditions, gender, race and ethnicity etc. may affect the recognition and/or diagnosis of autism in different populations (APA 2013), and change the reported frequency of the disorder. For instance, since certain behaviors, use of words, and nonverbal communication vary across different cultures, what is required to observe in an individual to make a diagnosis, by following up whether the individual accomplishes certain tasks or not, may differ accordingly. Therefore, even screening and assessment tools should be developed and improved with paying regard to these potential differences in cultural contexts.

Considering age and gender-related issues, it is claimed that autism is observed four times more common in males compared to females, and females are more likely to have autism with a higher severity due to the intellectual disability that is more frequently observed in females as an accompanying impairment (Yıldırım Doğru 2009; APA 2013). Age, on the other hand, does not have an effect on the occurrence of the condition, since autism is congenital. However, the increased number of early diagnosis may indicate an increased

prevalence among children. Early diagnosis may be more frequently seen in countries or communities with a greater awareness about autism or with a more developed healthcare systems and services due to higher economic standards (Fombonne 2005). On the contrary, in different regions, where socioeconomic conditions are low and accessibility of healthcare services are limited, it is highly possible that autism is underdiagnosed and the prevalence is low, especially in some race and ethnic groups (CDC 2014a).

There is a gradual increase in the frequency of autism in recent years; however, it has not been proven that whether it is the result of greater risk factors, an increased awareness, early and more accurate diagnosis, or different methods of studies (Volkmar et al. 2004; APA 2013; NIMH 2014). The prevalence numbers often appear to be constantly changing because of a variety of factors, such as geographies with different demographics and altering diagnostic criteria; therefore, the prevalence cannot be determined exactly, but there is evidence that it is higher compared to the past (Volkmar et al. 2004; Wing, Gould, and Gillberg 2011; CDC 2012, 2014a; NIMH 2014). Even though the prevalence of autism is not exact, Won, Mah, and Kim (2013) point out that it has been accepted as approximately 1% worldwide, based on the many reports on the prevalence numbers of different populations in different countries.

The Centers of Disease Control and Prevention (CDC) has conducted several research studies with children at the age of 8 in order to estimate the prevalence in various states in the USA in 2008, and stated that the most common problems they had faced during research were the altered diagnostic criteria that was more inclusive and being dependent on behavior and development observations because of the absence of medical tests to diagnose autism accurately (CDC 2012). The results of CDC's research show that 1 in 88 children were affected by autism and that there had been a 78% increase in the prevalence of autism since 2002 until 2008; however, the ratio has increased up to 1:68 and the prevalence in male/female ratio has increased from 4:1 up to nearly 5:1 in the results of the same research repeated in 2010 (CDC 2012, 2014). These studies lay bare some

estimations of autism prevalence among children; however, the results cannot be generalized to all populations either in the USA or different parts of the world, since varying results that lead to varying estimations may be obtained in different geograhies due to demographic characteristics (Fombonne 2005; APA 2013; CDC 2014a). For instance, the prevalence estimations in 2006 and 2007 show that the ratio was approximately 1:150 for children at the age of 8, whereas it was 1:160 for children at the age of 6-12 in Avustralia and 1:100 for children at the age of 9-10 in England, even though the ratios changed in different geographies within the same country (Otizm Vakfı 2012).

Unfortunately, there has not been any scientific data on the prevalence of autism in Turkey yet. However, Kılıç Ekici (2013) states that, according to the informal records, the estimated number of individuals with autism in Turkey is over 600.000, incorporating 200.000 children between the ages of 0-14, based on the worldwide prevalence rates. More specifically, it is estimated that there are 6.000 children with autism at school age, only 291 of whom have the opportunity to receive special education from public autism-specific institutions, in İzmir (Kasım Koç, pers. comm.).

2.2.4 Comorbid Conditions

The situation of a person having at least two different diseases, disorders, medical and/or genetic conditions are defined as ‘comorbidity’ (Valderas et al. 2009). In the case of autism, impairments in social interaction, communication, and behavioral patterns, often followed by intellectual impairments and structural language disorder are noticed in people with autism, as it is indicated in the diagnostic criteria of the disorder (APA 2013). However, additional impairments along with the disorder are highly common among affected people. In addition to the autism diagnosis, they are often diagnosed with other psychiatric, behavioral, and developmental disorders as well, mostly including genetic syndromes, sensory impairments, metabolic disturbances, anxiety and depression, epilepsy, dyslexia, Obsessive-Compulsive Disorder (OCD), Semantic-Pragmatic Language Disorder, and Attention Deficit Hyperactivity Disorder (ADHD) (Mesibov, Shea, and Adams 2002; Howlin 2004; Bogdashina 2006; APA

2013).

When autism is associated with other disorders and medical or genetic conditions, it is critically important to diagnose each one separately (APA 2013; Bogdashina 2006) in order to choose and apply appropriate interventions. The existence and intensity of co-occurring impairments may change throughout the development of the individual from early childhood to adolescence and adulthood; however, it should be taken into consideration that all behavioral and developmental characteristics of autism are in relation with comorbid disorders and disturbances; and each of them may trigger or suppress the other (Howlin 2004). Therefore, treatments and therapies are important to overcome these difficulties and conditions, and to enhance individuals' lives.

Not as an impairment but as a condition, savantism is observed among people with autism as well. As a result of atypical brain functioning, they possess innate exceptional skills, which are not creative but imitative, whether in music, art, calendar calculating, lightning calculating or mechanical and spatial thinking (Snyder 2009; Treffert 2006). There is a misconception about the frequency of savant syndrome among people with autism. Since movies and books often represent autism as a mental disorder with unusual talents, such as *Rain Man* (1988) and *Mozart and the Whale* (2005), it is stereotypically considered that all people with autism have certain savant skills. However, the fact is that although savant syndrome is more likely to be seen in people with autism compared to people with other neurological disorders or within the general population; it only covers the 10% of the group and is only seen in people with relatively mild autism (Fitzgerald 2004; Happé 2005; Treffert 2006). It should also be noted that instead of trying to cure this condition, it is worth putting effort into improving the skills and enabling these individuals to use their savant skills for their own benefit, even as an occupation.

2.3 GENERAL CHARACTERISTICS OF AUTISM

Regarding the definitions and classifications of autism in ICD-10 and DSM-V, it is evident that autism causes various impairments that are social, cognitive, behavioral, and sensory.

These impairments constitute the general characteristics of the disorder, even though each individual with autism has different characteristics that may change or disappear over time. In this section, these characteristics of the affected individuals are investigated.

2.3.1 Social Interaction

Neurotypical people have the ability of interpreting social cues, understanding others' behaviors, emotions, facial expressions, tone of voice, and why and in what situations these occur. It provides a ground for forming relationships with other people and maintaining these relationships. However, people with autism fail to understand and interpret social cues and behaviors of others, and social rules; therefore, they fail to interact properly by performing appropriate social behaviors in response. The interpretation and the use of nonverbal social cues that cause the lack of understanding each other's intentions, maintenance of relationships and intimacy (Carter et al. 2005; APA 2013) are the widely seen deficits in social interaction. They are unable to make sense of other people's actions and their own social surroundings due to their impaired social interaction skills, which make life distressful for these individuals.

People with autism fail to understand what forming a social bond or a friendship means; therefore, it results in serious difficulties in fitting in the social world and showing commitment to peers or family members (Tager-Flusberg 1999; Mesibov, Shea, and Adams 2002). However, it is worth noting that the problems and lack of interaction do not only arise out of the unwillingness or the incapability of people with autism. They have, indeed, a need and strong desire to form social relationships; however, they find other people's ways of interaction and what is expected from them quite strange (Bogdashina 2006). This lack of empathizing between people with and without autism increases the social gap in between.

Spontaneous conversations and unexpected situations forcing people with autism to interact with others, especially with strangers, are very distressing for them, since they do not understand the other's intention or have predictions about how to establish a dialogue. It is

an uncertain and unpredictable situation for them; therefore, they do not show any interest in involving in peers or groups socially. In order to prompt social involvement, familiarity and routines appear as the key factors (Lord 1993 cited in Tager-Flusberg 1999). In that manner, structured environments and familiar activities carried out with familiar people are crucial for comforting people with autism by reducing the unpredictability of the social world and avoiding unexpected situations. Routines and structures provide predictable ways of behaviors and activities that make them feel safer. Adopting rigid and structured programs in therapies and treatments also helps them learn social rules and ways of interaction, and to adopt them to different social contexts. Once they learn it and feel secure, they become more likely to engage with other people, but still in a different way than neurotypical people do (Tager-Flusberg 1999). For instance, they may follow their routine and involve in a social activity within that routine, but may still avoid being in a close social contact with other people as much as they can, and show the least possible social interaction even when they are responsive.

The level of social interaction depends on age, developmental level and severity level of the individual with autism (Mesibov, Shea, and Adams 2002; APA 2013). Regarding the fact that age is an important factor in social development of people with autism, in many situations, it becomes easier to involve in social dialogues and relationships over time due to developmental changes (Carter et al. 2005). For instance, children with autism have difficulty in playing with peers and participating in cooperative plays, but rather engage in passive activities or prefer to play with toys with repetitive movements on their own (Tager-Flusberg 1999; Loveland and Tunalı-Kotoski 2005), because they do not learn through observation and imitation as neurotypical children do. They need some time and guidance to learn. When they grow older, those children become more developmentally mature and may learn to participate in plays, e.g. pretend play and reciprocal games. However, it should be remembered that although the social skills of people with autism may develop over time, even many adults with a mild level of autism have difficulty in social relationships (Volkmar and Cohen 1985 cited in Carter et al. 2005; APA 2013) and involving in social activities with

other adults. On the other hand, the severity level of autism also affects the level of social interaction. Whereas people with moderate or severe autism may show little or no interaction with other people, others with less severe autism may be more engaged in social relationships (APA 2013). The higher the severity level is, the more support and directive guidance is needed to prompt interaction. Nevertheless, no matter on what level the individual with autism is, adequate support and guidance is highly essential to encourage social involvement and participation.

2.3.2 Communication and Language

Neurotypical people are responsive to the outside world and communicate with other people by using their verbal and non-verbal communication skills. Words and body language are the means of direct communication, and interaction as well, for expressing the self, conveying information, and so on. However, people with autism cannot conceptualize the notion of communication and understand the importance of it in socializing and expressing the self; therefore, they cannot "use language appropriately in social contexts" (Tager-Flusberg 1999, 5). It is not only their own intentional preference, but also the result of their impaired brain functioning, and it is seen at all people with autism at all ages and with all severity levels. Communication deficits include the difficulties with speech, grammar, understanding of meaning, the use of knowledge, and comprehension (Howlin 2004; Farrell 2006). These language and communication deficits affect all areas of life and relationships of people with autism when engaging in social contexts. Bogdashina (2006, 86) states that the "deficits may be very severe and may make the person very vulnerable and dysfunctional in certain situations". This is usually the reason of the social isolation of people with autism, because their way of communication that is different from that of neurotypical people is incomprehensible, illogical, and often bothering to people without autism.

People with autism in the early years of their childhood may mumble, but then show developmental delays in language and sometimes never show any signs of verbal skills. These delays in the language development and communication skills are often the first signs

that parents notice in their children before the autism diagnosis (Short and Schopler 1988 cited in Tager-Flusberg, Paul, and Lord 2005). Many children with autism seem to be deaf and/or mute, since they do not talk or give any reaction to what they hear. However, most of the time, it is only because they do not understand the meaning of what they hear or that the communication attempt is towards them. Verbal skills may also be delayed even when writing and reading skills develop normally in people with autism. They may even learn to read and write without any help at an earlier age compared to neurotypical children, since many of them are highly interested in letters and words (Loveland and Tunalı-Kotoski 1997 cited in Tager-Flusberg, Paul, and Lord 2005), but still cannot communicate verbally.

People with autism do not respond when their names are called (Chawarska and Volkmar 2005; Foss-Feig, Heacock, and Cascio 2011; NIMH 2014). This is because they do not have self-awareness and cannot understand that they should respond. Even if their attention is caught by other people, they give either short answers or no answers at all when they are asked questions or tried to be involved in a dialogue as well as having difficulties in extending a conversation by making relevant comments or adding new relevant information (Tager-Flusberg 1999). Even people with autism with relatively more developed language skills have problems with reciprocal conversations. There are researchers, who argue that when people with autism talk, they cannot simply talk about anything else but rather dominate the conversation by lecturing on their own interests, and neither give others to respond nor change the subject, whereas other researchers, on the other hand, argue that conversations on a topic of interest may increase the motivation and engagement of people with autism (Tager-Flusberg and Anderson 1991 cited in Tager-Flusberg 1999; Mesibov, Shea, and Adams 2002; Nadig et al. 2010). Therefore, the topic of a conversation is that of their own interests or not, people with autism cannot chat or appropriately engage in spontaneous back and forth conversations.

One of the widely seen behaviors, related with the communication deficits, of people with autism is ‘echolalia’. Tager-Flusberg, Paul, and Lord (2005, 346) defines echolalia as the “repetition, with similar intonation, of words or phrases that someone else has said”, which

may either be an immediate repetition or repeating the remembered words and phrases that are learnt in the past. However, the condition of echolalia does not mean that they understand the meaning of the words or phrases they repeat. People with autism, even with a higher level of verbal skills, only have a literal and concrete understanding, and literal use of language (Joanette, Goulet and Hannequinn 1990 cited in Loveland and Tunalı-Kotoski 2005; Farrell 2006; APA 2013), meaning that they only understand words and phrases when they are used with their literal meanings. They have difficulty in interpreting the intended non-literal meanings of what they hear or read, such as ironies, humor, idioms, and stories (Tager-Flusberg 1999; Howlin 2004; Farrell 2006). Another problem in verbal communication is in using an appropriate linguistic structure and choosing proper words or phrases. For instance, people with autism have no understanding of speaker-listener relationship, which means that they do not understand that the personal pronouns, such as 'I' and 'you', should change in a conversation according to who is speaking (Tager-Flusberg 1999; APA 2013). Even when they talk about themselves, they usually do not use the word "I", but rather use their names by referring themselves as the third person. In addition to misusing the pronouns, people with autism rarely choose the right words or phrases and combine them in order to form meaningful sentences. This is because of the lack of understanding of the meanings of words, how they function in language, and also the function of the language itself (Farrell 2006).

Non-verbal communication skills are also impaired in people with autism. They do not use gestures (pointing to objects, making eye contact, etc.), facial expressions (showing emotional signs, smiling, etc.), or tone of voice properly, and cannot understand what they mean when other people use them (Mesibov, Shea, and Adams 2002; APA 2013; NIMH 2014). Non-verbal language, as well as verbal language, is also essential in social relationships, since many social cues are understood through non-verbal signs. Bogdashina (2006, 84) argues:

> "Sometimes they are not aware of the social cues because of the same perceptual problems which affect their understanding of other aspects of the environment. For example, visual processing problems may prevent the person from learning to recognize and interpret facial

> expressions. They may have to develop a separate translation code for every person they meet. Even if they can tell what the cues mean (because they have learned them theoretically), they may not know what to do about them."

Therefore, social interaction and communication are closely related with each other. Verbal and non-verbal communication deficits result in lack of social interaction, and limited social interaction likewise limits the communication of people with autism with other people. Both of these deficits make the daily lives of people with autism more complicated and difficult to manage and cope with, since they cannot express themselves through socially accepted ways of communication. When they realize that they are incapable of expressing what they want, what they need, or what they are uncomfortable with at that moment, they begin to show inappropriate behaviors. Although many children with autism may be taught other ways to express themselves and make progress in communication as they grow older, the difficulties in communication in social contexts remain at some level (Loveland and Tunalı-Kotoski 2005; APA 2013; NIMH 2014). Therefore, they are more likely to have depression and anxiety disorders because of this social lack and their increased awareness of it by age (White et al. 2009).

2.3.3 Behaviors, Interests, and Activities

Stereotyped behaviors, overly focused interests, and restricted activities are one of the core features of autism for diagnosis (APA 2013; WHO 2010). People with autism show repetitive and unusual patterns of behaviors, such as hand-flapping, rocking the body, and staring at the spinning parts of objects, which are noticed with a variety of levels of severity (Howlin 2004; Loveland and Tunalı-Kotoski 2005). Some behaviors of people with autism may be extreme whereas some may be nearly unnoticeable. Restricted repetitive behaviors, which may either be lifelong or disappear in time, are mostly noticed in the early childhood after infancy, and are observed more in younger children with more severe autism compared to more developed children, adolescents, and adults (Volkmar et al. 2004; Esbensen et al. 2009; Leekam, Prior, and Uljarevic 2011). Although the severity of these restricted patterns of behaviors and interests may diminish later in life, Howlin (2004) states that especially individuals with higher functional ability tend to be more preoccupied with the routines,

stereotyped behaviors, and interests with age, which causes their lives to become more distressful and chaotic, if they do not develop skills on these areas and use its advantage.

People with autism have narrow and intense unusual interests in things, especially that do repetitive movements or with rigid structures. For instance, children with autism insist on playing with the same toys every time, and often play with them in an unusual way, such as lining them up, moving them back and forth repetitively, or spinning their parts to watch, and may engage in the same act for a long time (Mesibov, Shea, and Adams 2002; Baron-Cohen 2008). Moreover, since their attention is highly and overly focused on things they are interested in, they are obsessed with their interests (Howlin 2004; APA 2013), such as learning and memorizing all details about football matches, dates, or simply carrying the same objects all around all the time. As the other symptoms of autism, restrictive interests differ from individual to individual; however, many of them are often interested, and some are also talented as well, in music, arts, linguistics, maths, science, and all kinds of patterned activities (Grandin 2006; Tammet 2014; Williams n.d.).

Being very committed to their daily routines with structured activities, any changes or unexpected things happened in their routines make people with autism upset and may cause tantrums, even though those individuals may learn to cope with their special condition as they grow older (Mesibov, Shea, and Adams 2002; Howlin 2004; Grandin 2006). It is hard to manage for parents, teachers, and peers and requires treatment that helps reducing the severity of stereotyped behaviors of children with autism (Loveland and Tunalı-Kotoski 2005). These special treatments increase the quality of life by prompting social adaptation.

Problems with sensory sensitivities, *hypersensitiveness* and *hyposensitiveness*, in people with autism are considered to be one of the reasons for performing stereotyped behaviors (Doman 1984 cited in Bogdashina 2003; Foss-Feig, Heacock, and Cascio 2011; APA 2013), which function as a means of defense, self-stimulation, compensation, or sensorial pleasure (Bogdashina 2003, 2006; Tsatsanis 2005). Abnormal sensorial sensitivity causes problems

of sensorial stimulation; therefore, repetitive behaviors arise out of the lack of self-expression or self-stimulation. It can be reduced by directing individuals to engage with other stimulators that may interest them. Sensory therapies and interventions in related activities and environments are also beneficial to reduce sensory perceptual deficits, and hence, related stereotyped behaviors (Bogdashina 2003; Ashburner et al. 2014).

2.3.4 Sensory Perception

For an individual to make sense of the world, all sensory systems should function properly. Neurotypical people have sensorial awareness of their surroundings; therefore, they interact with it, respond to it, and take a social part in it. However, people with autism "do not respond in the way we expect them to, because they have different systems of perception and communication" (Bogdashina 2003, 20). They typically have impairments in sensory systems that cause them to fail to develop an awareness of their surroundings and behave accordingly in response. Insufficient processing of sensory input results in lack of social adaptation and participation in daily activities because of the inadequate perception of the outside world and developing unusual responses to these inputs; however, deficits in sensory processing is only one of the various factors affecting the daily lives of people with autism regarding the complexity of the disorder (Tsatsanis 2005; Ashburner et al. 2014).

Bogdashina (2003) indicates seven sensory systems: sight (vision), auditory (hearing), olfaction (smell), gustation (taste), tactile, vestibular (related to balance), and proprioceptive (related to body awareness – positioning and movement) systems. Sensory impairments are often seen in more than one of these sensory systems with different combinations; and "different sensory modalities may be differentially affected" (Foss-Feig, Heacock, and Cascio 2011, 338). Even though deficits in sensory systems are not only specific and indicative for autism alone, problems with sensory sensitivity, perception, and interpretation are one of the core disturbances of people with autism. Since the brain functioning of people with sensory perception impairments is not able to transmit the sensory input and organize it (Yıldırım Doğru 2009), they cannot develop appropriate verbal or behavioral responses through

perceived senses. They may have sensory insensitivity or difficulties in coping with being overstimulated, or have unusual sensory interests that other people find odd. They may insist on being exposed to certain stimuli for pleasure or may try to avoid any slightest sensory input. Many people with sensory impairments also suffer from perception distortion or fragmentation, and so on. As a result of all these impairments, people with impaired sensory systems are more prone to hurt themselves; because abnormal sensory experiences may be overwhelming, distressing, and even painful for the individual and may cause tantrums and/or injuries. For instance, hypersensitive people may become anxious and show outbursts because of sensory stimuli that they find threatening whereas hyposensitive people may injure themselves because of being unable to understand the consequences of their injurious behaviors and do them continuously (Bogdashina 2003; Yıldırım Doğru 2009).

Even though the sensory processing capability can be increased, as individuals grow older, sensory abnormalities in behavioral responses and interests, including fascinations and different modes of reactions, are highly common (APA 2013). Examples of these abnormalities include:

> "...empty gaze; visual fascination with patterns and movements; failure to react to sounds/appearing deaf; hyposensitivity to pain, cold, or heat; hypersensitivity to taste; and inappropriate use of objects (e.g., interest in the sensory aspects of objects, such as licking/mouthing, peering, or interest in texture)." (Tsatsanis 2005, 366)

Below is the list of possible sensory experiences of people with sensory deficits along with autism, based on the "possible patterns of sensory experiences in autism" listed and explained by Bogdashina (2003, 162-164), which are the basis of the 'Sensory Profile Checklist' developed by her for assessing an individual's sensory processing in daily life:

- Gestalt perception (inability to differentiate foreground and background information)
- Intensity of the sensory experience (hyper-sensitivity and/or hypo-sensitivity)
- Disturbance (sensitivity to) and/or fascination by certain stimuli
- Inconsistency of perception (fluctuation between hyper-, hypo- and normal)
- Fragmented perception (partial perception; stimulus overselectivity)
- Distorted perception
- Sensory agnosia (difficulty interpreting a sense and attaching meaning)
- Delayed perception (delayed processing of sensory stimuli)
- Vulnerability to sensory overload
- Mono-processing (number of channels working at a time)

- Peripheral perception (avoidance of direct perception)
- System shutdowns (losing the normal functioning of some or all sensory channels)
- Compensating for unreliable sense by other senses
- Resonance ('Losing oneself' in stimuli)
- Daydreaming
- Synaesthesia ('cross-sensory perception')
- Perceptual memory
- Associative ('serial') memory
- Perceptual thinking

Although impaired sensory perception makes individuals' lives difficult, it is possible to improve the senses to function properly. Therefore, appropriate therapies are essential to enhance sensory processing as much as they are to reduce all negative effects of and impairments caused by autism.

2.4 INTERVENTION FOR AUTISM

Autism does not have a known medical cure that totally recovers the disorder but rather needs a lifelong intervention for the improvement of affected individuals (Happé 2005; Myers and Johnson 2007; APA 2013). However, there are various therapies, treatments, and special education methods that are developed for children with autism with a variety of special needs, abilities, and disabilities in order to provide them an easier life with a higher standard. It is important to note that none of these interventions, either medical or non-medical, have been proved to be valid for all children with autism due to the heterogeneity of the population of people with the disorder (NRC 2001; Levy and Hyman 2008). Therefore, selecting an appropriate intervention and careful planning regarding the needs and conditions of the individuals are critical for them to benefit from these interventions.

It is also highly critical to understand the importance of treatments, therapies, and special education to be on a regular basis and be dedicated to maintain the strict schedules and structured programs (Mesibov, Shea, and Schopler 2004). Although it is very hard and stressful to raise a child with autism, families' acceptance of the condition of their children and putting effort to be knowledgeable about the disorder and different possibilities and opportunities of interventions as well as the laws and regulations of special education and services that are available can be helpful for families to live with a child with autism

throughout their lives (NRC 2001; NIMH 2008). Therefore, educating parents and the indulgence and appropriate involvement of families, in addition to that of therapists and special educators, is very important for the development of children with autism (NRC 2001; Myers and Johnson 2007).

In this section, medical and non-medical intervention opportunities are investigated in order to understand how to deal with the challenges coming along with autism and the methods as well as their impact on the affected individuals.

2.4.1 Medical Interventions

Even though autism does not have a medical cure, comorbid conditions accompanying autism, such as epilepsy, anxiety and depression, hyperactivity and attention deficits, may require medication treatment in order to eliminate the causes and/or severity of the symptoms of autism, when they cause self-injuries, learning difficulties, and the like. (Happé 2005; Leskovec, Rowles, and Findling 2008). It is not scientifically a primary intervention for people with autism; however, appropriate medication treatment helps to take co-occurring deficits, disorders and/or diseases under control and makes it possible for them to benefit more from other therapies, treatments, and education, and to enhance their lives (Myers and Johnson 2007). Medications can only be prescribed by professionals; such as neurologists or psychiatrists, who know the condition and medical history of the individual with autism (NIMH 2008).

2.4.2 Non-Medical Interventions

Although it may gradually progress, the most effective intervention for autism has been agreed to be a well-structured combination of educational, behavioral, and developmental interventions as well as other supportive therapies and treatments (NRC 2001; Myers and Johnson 2007; Levy and Hyman 2008). It is recommended to plan an appropriate intervention as soon as the child is diagnosed with the disorder in order to get the most benefit out of the intervention (NRC 2001; CPS 2004). Depending on the child's age,

developmental level, skills, and needs, individualized intervention programs, which often takes 25-40 hours a week throughout a year, should be planned by professionals and families collaboratively and the child's progress should be monitored on a regular basis. A well-planned systematic intervention can reduce the symptoms and effects of autism, help individuals to reach the developmental level of their peers as much as possible, especially when started in childhood after an early diagnosis (CPS 2004; APA 2013).

There is a wide range of non-medical interventions with various aims, mainly including educational, behavioral, developmental, cognitive, interactive, and sensory approaches aiming to teach, develop, and improve appropriate behaviors, social interaction and communication skills, academic learning skills, emotional regulation, and sensory integration (Mesibov, Shea, and Schopler 2004; Happé 2005; Prizant et al. 2006; Bogdashina 2006; Myers and Johnson 2007). They can be applied at special education schools, inclusive classes, in which typically developing children and children with autism are taught together, at public schools, rehabilitation centers, vocational training centers, homes etc. are the places that non-medical interventions may be applied (Kılıç Ekici 2013). Even though these are the intervention opportunities for children with autism in Turkey as well, the majority of the children cannot benefit from the right of receiving special education, therapies etc. due to the lack of appropriate schools and centers, lack of qualified special educators and therapists focused on autism, and lack of funding from the government. Since there are only a limited number of autism-specific institutions and qualified experts, only 2114 children with autism are able to benefit from public special education schools and rehabilitation centers in Turkey whereas the number of these children is 291 out of 6.000 in İzmir (Otizm Platformu 2008; MEB 2014). Moreover, public institutions offer free full-day education; however, private institutions offer 8-hour intervention in a week, which is not adequate, and the government funds only a small part of the intervention fee, which is the 12-hour of the overall intervention in a month; therefore, there is a need for funding, increased number of special institutions, and more graduate education programs for training qualified special educators and therapists in order to ensure providing more opportunities of appropriate and adequate

interventions and complementary therapies to children with autism (Kılıç Ekici 2013; Otizm Platformu 2008).

In this section, the most adopted evidence-based intervention models and approaches are examined.

2.4.2.1 Applied Behavior Analysis (ABA)

ABA, also known as *Lovaas Model*, is based on developing and maintaining socially desirable behaviors and eliminating inappropriate behaviors in children with autism as well as teaching new skills and how to adapt and generalize them to different situations by using various reinforcement and punishment mechanisms (NRC 2001; Myers and Johnson 2007). Depending on the characteristics of the disorder, imitation, play, social, communication and self-care skills are among the behaviors to be developed and improved whereas tantrums and stereotypical repetitive patterns of behaviors are to be eliminated. Socio-environmental settings and interactions within these settings are also essential to be analyzed objectively in this method in order to understand and solve problem behaviors; therefore, maintaining and teaching how to generalize the increased appropriate behaviors in different contexts is important to enhance daily life skills and social adaptation (Ryan 2011).

The main purpose is to ensure that children with autism reach the developmental level to attend to inclusive education programs with their peers. Compared to other education methods, ABA is the only method that has scientific evidence of being successful in increasing intellectual functioning, when applied continually and appropriately (Lovaas 1987; Rogers and Vismara 2008); however, it is still argued that the behaviors learnt through this intervention is not always easily transferred to different contexts (Bogdashina 2006).

ABA mainly uses two teaching techniques: *discrete trial training* (DTT) and *incidental teaching*, both techniques involve structured and systematic activities broken into several components. DTT is a child-centered and structured one-on-one teaching technique focusing on teaching new skills by dividing tasks into several simple steps and using children's

interests, motivations, and preferences as rewards for desired reactions and target behavior (NRC 2001; Smith 2001; Ryan 2011). Incidental teaching, on the other hand, is focused on teaching and improving verbal and non-verbal communication skills, i.e. extending the use of language and developing spontaneous speech. It takes place in natural settings, such as kitchen and classroom, and use of children's interests and preferences for reinforcement, discrete trial training (NRC 2001; Ryan 2011). For instance, the teacher shows a toy, blocks the child's access to it, asks the child to name or point the toy, and lets the child to take it if he/she gives the target verbal or non-verbal response (Lovaas Institute 2007). Clues are used in both teaching techniques for directing children; and these clues are removed gradually in time, when the child starts to adapt the behavior or skill.

2.4.2.2 Treatment and Education of Autistic and Communication Handicapped Children (TEACCH)

Compared to ABA, TEACHH is a less intensive and a life-long intervention philosophy, which advocates the 'culture of autism' and acknowledges the nature of the disorder (Mesibov, Shea, and Schopler 2004; Williams and Wright 2004; Bogdashina 2006). Rather than being an educational model on its own, it uses a combination of several existing intervention methods depending on the children's current conditions. It favors structured learning and suggests organizing physical environments, structuring predictable sequence of events and/or activities, and visual support, such as visual cards and schedules (Mesibov, Shea, and Schopler 2004; TEACCH Autism Program 2014). This approach is based on individualization of the structured activities and greatly emphasizes building on individuals' interests and skills, social interaction, and group activities during these structured events and activities as well (NCR 2001).

2.4.2.3 Social Communication, Emotional Regulation, and Transactional Support (SCERTS)

Regarding the fact that social environment has a strong effect on children's development in everyday life, SCERTS has been developed as an intervention model for children with autism in order to enhance their functional social communication skills, emotional regulation,

and skills to cope with everyday difficulties through interpersonal and learning support (Prizant et al. 2003, 2006). SCERTS provides an assessment process to determine the child's condition and monitor his/her progress, and then plan an intervention accordingly. Similar to TEACCH, SCERTS is a philosophy rather than an intervention method by itself and requires the collaboration of families and teachers, since it is not a school-based approach.

2.4.2.4 Developmental, Individual Difference, Relationship-Based Intervention (DIR)

DIR is a developmental-emotional intervention model developed by that aims to help children develop symbolic thinking and establish social relationships and enhanced emotional bonds by using the *Floor Time* technique, which focuses on the interaction with the child in a free-play environment and improving his/her social interaction skills and emotional development playfully and through enjoyment (Wieder and Greenspan 2003; Myers and Johnson 2007). Since this intervention model is based on social interaction and emotional regulation, it is more effective to use this model as a complementary of behavioral intervention models.

2.4.2.5 Other Interventions

Psychiatric therapy, speech and language therapy, occupational therapy, sensory integration therapy, art and music therapy, animal-assisted therapies, physiotherapies, and motor interventions are among the widely preferred complementary interventions, which can be undertaken individually or integrated into other interventions, for people with autism (Simpson et al. 2005; Greenspan et al. 2008; Autism Society 2014).

Since the majority of people with autism have psychiatric disorders along with autism, such as anxiety, attention deficit hyperactivity disorder (ADHD), and obsessive-compulsive disorder (OCD), these disorders require professional intervention, psychiatric therapies, in order to reduce the severity of the symptoms of autism, increase the effectiveness of educational and behavioral interventions, and therefore, to improve the quality of life (Autism Speaks 2014).

Speech and language therapies are used in order to improve the individuals' verbal and non-verbal communication skills, including basic verbal conversations and gestures. These therapies may include games, electronics, facial exercises, and pictorial communication (WebMD 2013). For instance, PECS (The Picture Exchange Communication System) uses picture symbols to teach how to establish a dialogue (CDC 2014b).

Occupational therapy aims to increase the independence and the quality of life of the individual as much as possible with the therapeutic use of daily life activities, i.e. occupations, to support individuals to be socially integrated, participate, perform, and function appropriately in any social setting, such as home, school, work, and community. It includes any performance in daily life, e.g. physical, behavioral, sensory, cognitive etc., including self-care training, such as eating, bathing, and dressing (AOTA 2013; CDC 2014b).

Sensory integration therapy is often used as a part of occupational therapy with a sensory diet, which is a well-planned and scheduled program of sensory activities, in order to enable the nervous system to process all sensory input normally, such as avoiding mono-processing, increasing sensitivity, or desensitizing. The sensory diet is individualized and involves various techniques, which are playful and pleasurable, such as body-brushing, bouncing, and rolling (Bogdashina 2003).

Art and music therapy are helpful especially for improving sensory integration by providing tactile, auditory, and visual stimulation. Art, as a communicative and imaginative therapeutic activity, provides a medium for symbolic and non-verbal expression of the self and emotional regulation (Evans and Dubowski 2001). Music has an emotional therapeutic effect as well. Songs and improvisational music support the development of speech and improvement of cognitive skills as well as increasing self-motivation and stimulating feelings (Trevarthen et al. 1998).

Animal-assisted therapies are often integrated with occupation therapy and mostly refer to dolphin-assisted therapy and therapeutic horseback riding. These therapies provide sensory and motor challenges to the individuals and support their cognitive development, social functioning, sensory sensitivity, and emotional development (Sams, Fortney, and Willenbring 2006; Bass, Duchowny, and Llabre 2009). Even though animal-assisted therapies are appreciated widely, there is no scientific proof on the effectiveness of these therapies yet, but the research still continues (Marino and Lilienfeld 2007; Fiksdal, Houlihan and Barnes 2012). Interaction with animals and having pets also have therapeutic effects on people with autism due to the strength of the human/animal bond (Fine and Beck 2010).

Physiotherapies and motor interventions help to reduce self-stimulating repetitive behaviors and increase the overall health and well-being of people with autism as well as contributing to the development of social, communication, learning, and sensory skills by encouraging and providing regular participation in physical activities and focusing on postural, motor, and functional delays (Micacchi et al. 2006; Atun-Einy et al. 2013). The physical activities may involve moving the whole body or certain parts of the body depending on the individual's physical condition. As a form of physiotherapy, Rebound Therapy, using trampolines to provide therapeutic exercises and movement, was developed by Eddy Anderson in 1970s. It is used for enhancing movement and balance, therapeutic positioning, relaxation, sensory integration, improving tolerance to physical exercise, and increasing/decreasing muscle tone as well as increasing concentration, communication and cognitive skills (ReboundTherapy.org 2014).

The aim of all above-mentioned interventions is enabling individuals with autism maintain their own self-care, enhancing their skills, and increasing their social adaptation by learning to apply what they learn to new situation they face with. As it is for all intervention methods, therapy programs and schedules are required to be planned as early as possible after the diagnosis and be individualized for each individual with autism in order to benefit from the intervention.

2.5 EDUCATIONAL AND THERAPEUTIC TOOLS, EQUIPMENT, AND ENVIRONMENTS FOR CHILDREN WITH AUTISM

There is a wide range of tools, equipment, and environments for educational and therapeutic purposes for children with autism. These may include products and environments aiming to improve auditory, visual, tactile, vestibular, and proprioceptive senses, fine and gross motor skills, and enhance independence, social interaction, communication, and cognition. Since they are interrelated with each other, these products and environments are not specific to any particular intervention method, but can rather be used for various methods with multiple purposes.

2.5.1 Visual and Audial Materials for Behavioral and Developmental Education and Therapies

Behavioral and developmental education and therapies often use visual and audial materials during interventions, since children with autism learn and understand from visuals better and verbal directions or sounds help them learn and remember educational or daily tasks as well.

Flashcards with realistic pictures, symbols or illustrations, visual prompts etc. are the materials that are mostly used for improving learning skills, speech and language therapies, and behavioral education. They initially aim to teach basic social interaction and communication skills, verbal and gestural expressions, words and idioms, and behaviors, and the like. Moreover, since children with autism seek for strict schedules with expected and familiar activities, visual schedulers are used in special education and in their daily lives. Visual materials are also supplemented by audial materials, such as timers and voice recorder buttons. Timers are generally used for reminding activities or self-care training, e.g. toilet training. Voice recorder buttons, on the other hand, are also useful for speech therapies as well as supporting verbal and visual instructions during activities, teaching interaction skills through games, and the like.

In order to support special education and therapies, reinforcer toys are used to motivate or reward the children. For instance, tactile, musical or spinning toys, providing sensory pleasures, can be motivating reinforcers for children with autism. Offering a variety of reinforcers during an activity is often more preferable, since it encourages children to have multiple options.

2.5.2 Sensory Products and Multisensory Environments for Sensory Integration

Sensory integration plays an important role in the development of children with autism and helps them make sense of the social and material world around them as well as enhancing their cognitive abilities, self-maintenance, and independence. In order to increase or decrease the sensory sensitivity and regulate the body systems, there is a wide range of sensory products, varying from calming to stimulating, for children with autism with different sensory impairments. For instance, products that provide pressure, such as body-socks, weighted vests and blankets, swings, and squeezers, which improve sensory processing and body awareness, are both pleasurable and calming for sensory seeker children. Body-brushes, tactile panels, tactile disks, and musical instruments, on the other hand, are other examples of sensory products aiming to increase sensitivity to certain stimuli. They are not only useful for teaching to differentiate textures and sounds, but also to match similar textures or objects, improve imaginative and group play skills, the sense of rhythm, and such.

There are also multisensory environments, challenging children with multiple simultaneous sensory stimuli, such as sensory rooms and multisensory hydrotherapy swimming pools. These environments are mainly used for sensory integration therapies. Sensory rooms consist of various sensory products that can also be used separately whereas hydrotherapy swimming pools make use of aromatherapy and relaxing sounds as well as providing physiotherapy to children.

2.5.3 Tools for Motor Development and Recreational Equipment and Environments for Physical Education

The majority of children with autism have underdeveloped fine and gross motor skills and need physical education or physiotherapy. Table tennis, play-foam and play-dough, finger strengtheners, and similar toys and tools help them improve fine motor skills. For children with oral motor problems, chewable objects, bubble blowers, and whistles are also available, which are used for sensory, occupational, and speech therapies.

Recreational equipment and environments also have a critical role in physical education for children with autism. They improve children's fine and gross motor skills as well as regulating body systems, providing relaxation, and improving tolerance to physical activities. These may include fitness equipment, climbing walls, soft play environments, ball pools, and trampolines. Additional activities, such as turn-taking games and ball throwing, can be integrated with the use of these equipment and environments.

As mentioned earlier, all educational and therapeutic means do not only serve for a single purpose and are beneficial for children with autism in various aspects. Enhancement of impairments affects an individual positively and this enhancement leads to an increase in the level concentration, cognitive and physical abilities, and imaginative skills etc., i.e. overall wellbeing of a child.

CHAPTER 3

PARTICIPATORY DESIGN WITH PEOPLE WITH AUTISM

This chapter provides a theoretical framework for the study that is based on the involvement of children with autism in the design process. It dwells on the definitions and emergence of the participatory approach and continues with participatory design with special user groups. Then, it presents an overview of the participatory design projects conducted with children with autism. Since there is a limited amount of resources on participatory product design, this study draws on the literature from other design fields with the aim of examining the nature of the approach and its applications.

3.1 DEFINITIONS OF PARTICIPATORY DESIGN

Participatory design is a democratic, empowering, and inclusive practice involving people in the design process not as passive users but rather active participants encouraged and enabled to contribute and influence their social and material environments they are living in. The application of the methods and the design process may take longer time compared to non-participatory design methods; however, it ensures an in-depth investigation of the task being focused on and more sustainable design solutions as well as providing social benefits by immersing in participants' lives, valuing each participant's ideas, abilities, and skills, and incorporating their everyday experiences and latent needs. Sanoff's (2007) description of participatory design is inclusive of the perspectives of all disciplines adopting a participatory approach:

> PD [participatory design] practitioners share the view that every participant in a PD [participatory design] project is an expert in what they do, whose voice needs to be heard; that design ideas areas in collaboration with participants from diverse backgrounds; that PD [participatory design] practitioners prefer to spend time with users in their environment rather than ‘‘test’’ them in laboratories. Participatory design professionals share the position that group participation in decision-making is the most obvious. They stress the importance of individual and group empowerment. Participation is not only for the purposes of achieving agreement. It is also to engage people in meaningful and purposive adaptation and change to their daily environment. (Sanoff 2007, 213)

Participatory design is not only a design approach but also a research methodology, based on the idea of research and knowing by design (Spinuzzi 2005). The approach has its roots in the research traditions of participatory research and participatory action research, which regards research subjects as active participants throughout a research process, while a deep understanding is obtained during the collective action leading a political or social change through equal engagement of participants towards the problem and objectives defined by them (Couto 1987; Blessing and Chakrabarti 2009; Greenbaum and Loi 2012). Participatory research mainly concerns with “research, knowledge production, and empowerment related to the position of oppressed people, poor people, people with political or economic disadvantage” and regards all participants, both local people and researchers, as equal and as both researchers and learners (Couto 1987, 84).

The applications of the participatory approach range from simple to complex contexts, in which the process and the outcome of that process are shaped at the same time. It advocates the direct involvement of people, who are affected by the outcome of a design process or even by the process itself, in the design of products, environments, organizations, institutions etc. through various participatory methods and tools as well as developing the principles and practices to support participation continuously (Reich et. al 1996; Bjögvinsson, Ehn, and Hillgren 2012; Muller and Druin 2012; Robertson and Simonsen 2012). The idea of participation lies behind the involvement of people, especially those who are ignored and excluded, to enhance social progress within a community for, with, and by them through democratic, emancipatory, and transparent practices, and giving them the right to have a sense of ownership over the design (Muller et al. 1991; Sanoff 2000; Greenbaum and Loi 2012). In participatory design, design process, either the design of a single product or

building or a design of a community, is a social process that extends beyond designers' activities, who are no longer considered superior to non-designers, and draws on diverse perspectives of non-designers as well regardless of how large the scale of a project in any field of study and practice (Reich et al. 1996; Luck 2003).

As a set of application theories and practices of engaging users in design activities, participatory design is mainly emphasized with its democratic, empowering, and emancipating aspects in various contexts, such as urban planning, architecture, industrial design, geography, information technology, and business organizations (Sanoff 2007; Björgvinsson, Ehn, and Hillgren 2012; Muller and Druin 2012). It holds a human-centered attitude and aims to make a design, no matter what the context is, more responsive to human needs by giving right to future users, who use and/or are affected by a designed product, system, or service, to contribute to the decision-making process, either directly and/or by representatives, for the development and/or improvement of it (Simonsen and Hertzum 2010). The design context and the profile of participants in relation to the context may change. Therefore, "participatory design is contextual [as well and] participation varies in type, level of intensity, extend, and frequency" depending on the participant and the situation (Sanoff 2000).

Participatory design is an appropriate methodological approach in order to understand users by revealing their insights and serves to set the requirements and shape the future of a design by eliciting knowledge of the issues, e.g. skills, practices, context etc., related to the design task in a design process (Maguire 2001; Olsson 2004). Lahti and Seitama-Hakkarainen (2005) support the adoption of participatory design in a design process as well; however, they specifically underline the involvement of knowledgeable users, i.e. users having the adequate knowledge about the design issue, to be able to contribute to the process. However, except their experiences and opinions, all participants may not always have the detailed information or knowledge about the overall context, such as the infrastructure of a system or technical knowledge; therefore, the level of interest and

expertise of participants vary, so does the level of involvement, and specialists from other disciplines for training may be preferred to give support and consultation for increased effectiveness and efficiency (Sanoff 2000).

Participatory design is not a linear result-oriented practice, but rather a reciprocal process-oriented research and practice focusing on the empowerment of participants in a design process. Robertson and Simonsen (2012) define 'participation', within the framework of participatory design, as a mutual and continuous learning process, both for designers and non-designers, during which they engage in collective activities of exploring, reflecting upon, understanding, establishing, developing, and supporting that process and its outcomes. Mutual learning provides information and increased knowledge about existing situations, practices, and opportunities and future possibilities. Participation does not only serve for the betterment of products, systems, or services, but also enables participants to learn in the process of doing, which empowers and strengthens them by learning more about themselves (Couto 1987; Sanoff 2000).

In terms of its understanding and methodologies, participatory design definitely differs from non-participatory design processes both in theory and practice. Participatory design, in contrast to non-participatory design, promotes the active participation of and collaboration among stakeholders, such as designers, customers, and manufacturers, in the design process at all stages and ensures a deep understanding of the limitations that constrain innovations through various negotiating and reconciling perspectives (McNeese et al. 1995; Reich et al. 1996). Within this perspective, the importance of collaboration and innovation as well as the participation of all stakeholders affected by a design process rather than only users is underlined. In non-participatory design, designers or producers decide what the users' needs are and develop designs accordingly and users are regarded as merely consumers, not as a co-designer and a source of information, and involved only after the design process is completed for determining the success of the design in the market, not during the process for expressing themselves (Reich et al. 1992; 1996). However,

participatory design acknowledges and promotes collectivity during a design process, in which creativity is expressed as a collective act through participatory methods and tools. Participation, in that sense, serves for the decentralization of the authority by breaking down the hierarchical power structures of non-participatory design, which attributes creativity only to the designer instead of acknowledging that everyone has at least some level of creativity, by giving the opportunity to users to express their creative abilities to bring a design into its real existence and give meaning to it through active participation (Sanders 2001; Sui 2003; Lahti and Seitama-Hakkarainen 2005). Sanders (2001, 317) argues that the non-participatory design process is dominated by the designer and it is necessary to democratize it by adopting "participatory design [that] makes everyday people, such as users, an integral part of the design process, especially at the early front end". However, depending on the objectives and the plan of the participatory process of a project (Sanoff 2000), practical skills of participants are valuable for a design process in the making and/or implementation of a design as well (Björgvinsson, Ehn, and Hillgren 2012). Therefore, participants may partially or fully participate in different roles and contributions of each participant are acknowledged and equally valued in participatory design, since it relies on the mutual respect of all participants. Even though the level of involvement varies and users may be engaged in the process only at certain stages, Kuhn (1996) highlights the importance of the participation of end-users in a design process at all stages. Regardless of which stage of the process the users are involved in, the involvement should be well-managed in order to increase the effectiveness and efficiency of a comprehensive and evolving design process (Şener and Van Rompuy, 2005). A well-planned and well-managed participatory process is also more likely to be sustained and result in solutions that are flexible to the changes over time, since multiple voices are heard and decisions are made with a consensus of participants (Sanoff 2006; Robertson and Simonsen 2012).

Reich et al. (1996, 165) consider non-participatory design as a constraint that limits participation because of pragmatic, economic, and/or organizational concerns, and regard participatory design as being "the antithesis of traditional design in which designers are

expected to exhibit their expertise". However, participatory design does not reject or ignore the importance of expertise but rather favors specialized experience as a source of competency for technical and interpersonal consultancy and acknowledges the collaboration among designers and non-designer participants for a design process to reach success (Schuler and Namioka 1993). Sustainable and adaptable processes and designs that have the acceptance of the majority of participants and involve their preferences, expressions, values, and expectations provide a commercial advantage to companies in the market as well. Due to the core principles of participatory design, organizations that adopt participatory design as a method and involve their existing and/or potential consumers, customers, and other stakeholders in the design, development, or improvement of their products, systems, or services ensure a competitive advantage and reduce the risk of consumers'/customers' acceptance of those products, systems, or services beforehand (Laurel 2003; Şener and Van Rompuy 2005; Sleeswijk Visser et al. 2005). There are also various consultancy firms, e.g. IDEO and SonicRim, which develop participatory methods and tools and use them in a wide range of fields, offering design services and providing consultancy and professional support to both private and public sectors.

3.2 HISTORICAL OVERVIEW OF PARTICIPATORY DESIGN

Giving a voice to people in political decision-making processes through participation has been acknowledged as a democratic attitude since Ancient Greece, but often favoring men and neglecting slaves and women, who were regarded as the minorities in the society (Plato & Grube 1992 cited in Sanoff 2006; Ehn 1992; Glenn 2003). Participatory democracy involving all citizens, who are affected by a decision made, in the making of those decisions has also been adopted as the main feature and political participation has been accepted as the strength of the political systems of developed countries (Dalton 2008; Verba and Nie 1972 cited in Dalton 2008). Due to the growing population in modern societies, direct participation of all citizens in decision-making became difficult and representative democracy has come to scene, in which the interests of both the majority and minorities have started to be heard by selected representatives (Ehn 1992; de Tocqueville 1959 cited in Sanoff 2006).

Sanoff (2000) states that even though the notion of participation in building and planning dates back to ancient times, community participation, which is concerned with involving and encouraging local people in social development and for improving social services, has a more recent origin influenced by the democratic movements in 1950s and 1960s. Beginning with the people's realization of their potential in contribution to social development, formerly in the US in 1960s, various social and political citizen movements increased in number and started to be seen in different contexts, such as civil rights, women's liberation, anti-war, alternative cultures and low-income populations, and urban planning (Castells 1983 cited in Sanoff 2000; Sanoff 2000; Robertson and Simonsen 2012). Davidoff (1965) presented a new model of planning that he proposed as a way of enabling all social groups in the society to be directly involved in urban planning. Davidoff's advocacy model of planning aimed to foster a positive change in the society by overcoming the struggles of minority groups, such as low-income rates, racism, and alternative cultures, and giving them the opportunity to be heard in order to represent the most possible largest population in decision-making processes. Many designers and planners acknowledged his advocacy model and showed reaction to the existing model that neglected those citizens, who were influenced throughout the process and by the outcome, by participating directly in the activities and/or investigating the ways of relating the understanding to their own practices especially in community arts projects (Sanoff 2000; Robertson and Simonsen 2012). Community design centers were established in the US to get the citizens involved in the planning of their physical environments through community improvement and citizen action programs (Davidoff 1965; Sanoff 2006). The aim was to hear the voices of everyone as much as possible to make strategic plans collectively, provide technical assistance and support for financing of projects, acquisition, and management of community housing and facilities, and take a collective action rather than only determining and acting on the interests of a small group of people within a population (Sanoff 2000; 2006).

As the ongoing movements and practices were taking place in the US in 1970s, workers and worker unions started an industrial democracy movement towards computerization in

workplaces that put their control over their work at risk, formerly in Norway, Scandinavia, and participatory design of computer-based systems was a part of it with a focus on democracy and balanced power relations in workplaces leading mutual learning and improvement by appropriate tools and techniques (Kensing and Blomberg 1998; Greenbaum and Loi 2012). Beginning with questioning the introduction of the information technology, workers that would use that technology started to be involved in the process of developing and implementing the computer systems with the idea that they had the right to have a say in the process in order to prevent deskilling and loss of managerial control of workers and possible work reductions that the full-computerization of work tasks might cause (Kensing and Blomberg 1998; Robertson and Simonsen 2012; Björgvinsson, Ehn and Hillgren 2012). Bødker, Grønbæk, and Kyng (1993) state that the participatory projects in 1970s in Scandinavia were 'first generation' projects that aimed to develop an appropriate platform in order to increase workers' influence on the use of technology in the workplace whereas 'second generation' projects in 1980s were mainly focused on users' perspective for developing computer-based systems further through designing new kinds of computer support based on skills and product quality.

In 1980s, the Scandinavian approach of participatory design of information technologies and interfaces that does not only value technological change but also social change and development inspired other projects and practices in North America and European countries (Gregory 2003). Participatory projects draw on various disciplines, such as design fields and diverse design approaches, architecture, political and social science, and communication studies. Diverse experiences and knowledge, such as of local people, institutions, and special user groups are also of great importance (Muller and Druin 2012; Gregory 2003).

With an increase in the adoption of the participatory approach, various consulting and research associations, groups, and firms have been founded starting from the 1990s. The International Association of Public Participation (IAP2), IDEO, Participatory Geographies Research Group (PyGyRG), and SonicRim are among the examples of those collectives.

IAP2 was established in the USA in 1990, with the aim of spreading the participative perspective in nations throughout the world and advancing the practice of public participation in decision-making processes by increasing the awareness of the public through various practices and sharing how they might affect the decisions, and offering professional support to the industry, governments, universities, civil society organizations, and the like (Sanoff 2006; IAP2 2014). They support international research and offer consulting and training services on diverse sectors, such as transportation, policymaking, urban development/planning, health, education, finance, public utility, and environment. In 1991, a global design consultancy firm, IDEO, was founded in the USA and applied design thinking to various fields together with the participation of related communities or groups of people in order to develop and/or improve human-centered products, systems, and services (IDEO 2014). Research and application areas are almost similar to the diversity of the fields of practice of IAP2, and in addition to these, product design, communication design, interface design, business and organizational designs etc. for social innovation are among the expertise of IDEO. In 2005, PyGyWG, which has later on become the Participatory Geographies Research Group (PyGyRG) in 2008, was established within the Royal Geographical Society/Institute of British Geographers (RGS/IBG) in the UK (Sanoff 2006; Kindon 2010). The aim of PyGyRG is to promote the use of participatory methods, tools, and principles in geographies. Their research studies and applications mainly focus on participatory and collective actions based on the idea of empowerment through engagement, mutual and continuous learning, self-critical reflection of practitioner experts, inclusion of neglected people in communities, challenging beliefs and power relations disadvantaging certain groups and/or individuals, and reliability and ethics (PyGyRG 2014). As the last example, SonicRim, which is a global design consultancy firm as well, was founded in the USA in 2008, using participatory generative, evaluative, and experiential research (SonicRim 2014). The firm's researchers have different backgrounds including economics, politics, sociology, anthropology, psychology, marketing, branding, communication, computer sciences, and design.

Compared to non-participatory design, participatory design is more democratic and humanistic and reflects it with its encouraging and emancipating approach. There is also a social motivation behind it to give the opportunity and courage to the excluded user groups, who are so-called the minorities in the society, in order to enable them to have a say in the design process and decisions they are affected by. Therefore, the motivations behind the participatory practices involving special user groups are investigated in the following section.

3.3 PARTICIPATORY DESIGN WITH SPECIAL USER GROUPS

Prompting participation in order to identify problems, gathering participant-led design input, and generating solutions to these problems enables developing more suitable designs to participants' needs that are different depending on their work roles, relations to the design task, life stages, physical/cognitive conditions, and various other elements and aspects (Muller and Druin 2012). Special user groups are among the target users of inclusionary design practices, who require a better understanding of their lives and need increased quality of life. However, non-participatory design methods are not always suitable to apply when working with these user groups, since they do not always provide the necessary or required information and data to designers. In a non-participatory design process, users are not directly involved in the process and designers' own experiences, preferences or predictions are considered as representing real user needs and desires, and the like. However, even though designers may have experiences as users in some situations, special user groups are often hard to empathize with, unless the designer belongs to one of those groups. Although special user groups refer to the marginalized and ignored user groups and include people with various conditions, e.g. socioeconomic or health, elderly people, people with disabilities, and children, who are regarded as minorities and are often excluded from the design processes, are focused on within the context of this thesis, on the basis that different ways of interaction and communication and alternative design methods are needed to ensure their involvement and empowerment through participation.

3.3.1 Participatory Design with Elderly People

Since, the elderly population has been increasing in number, especially in Europe, facilitating elderly people to be self-sufficient through design, especially design of assistive products developed with new technologies and housing and care services, has been gaining more importance (Lines and Hone 2004; Demirbilek and Demirkan 2004). Various professions are concerned about universal design for the ageing population, promoting freedom of choice and lifestyle, increased safety, usability, and attractiveness, and providing independent living both physically and psychologically (Demirbilek and Demirkan 1998, 2004).

Ignoring the physical, psychological, social, emotional, and cognitive needs of elderly people results in failure in design; therefore, it requires designers to be aware of and sensitive to the requirements, experiences, needs, and desires of these people (Lines and Hone 2004; Joyce, Williamson, and Mamo 2007). Participatory design ensures thorough investigation of their daily lives and experiences as well as enhanced design solutions. Studies show that involvement of elderly people in the design process through participatory methods, such as interviews, personas, brainstorming, scenario building, sketching, prototyping, deployment matrix, and focus groups, promoting social interaction and collaboration increase the awareness of the self and satisfaction of these individuals by being influential on design decisions (Demirbilek and Demirkan 2004; Zaphiris, Sustar, and Pfeil 2008; Lindsay et al. 2012).

3.3.2 Participatory Design with People with Disabilities

People with disabilities are another special group of people, who are often marginalized, yet can be empowered through design. The social model of disability advocates that disability is a barrier that the society creates against people with ‘impairments’ and inappropriate design as a disabling mechanism in the society is the result of the disability (Lindsay et al. 2012). Moreover, Oliver (1992, 105) states that research on people with disabilities have been often seen “as a violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances and quality of life” by these people. Therefore, their participation

can be empowering and emancipating for this challenging specific user group and design can be helpful to improve their life standards as well.

Healthcare systems, facilitating and medical environments, and assistive technologies, such as communication, orientation, and therapeutic devices, and planners, are quite important for people with disabilities in maintaining their lives (Moffatt et al. 2004; Wu, Baecker, and Richards 2005; Neuhauser et al. 2009). However, these people are often excluded in the design of these environments, technologies, and devices, which are great in number and variation, yet not adapted appropriately for different user groups with disabilities and have limited success in application (Moffatt et al. 2004). They may be functionally enabling and assisting but not always socially and emotionally supportive or empowering (Zisook and Patel 2013). For that reason, people with disabilities should be included in the research activities and the design process that influence their lives either as participants or even co-researchers and have a sense of ownership (Radermacher 2006). Moreover, the participatory approach gives designers the opportunity to gather detailed information by sharing the unique experiences of people with disabilities with them and use them as a resource in design. It also offers different ways of communication depending on participants' physical, mental, intellectual, and sensory capabilities and abilities, which are quite challenging in the design process.

Within this perspective, participatory design ensures the empowerment of people with disabilities through their active involvement in identifying their problems and needs by simply providing them with generative tools and methods and encouraging them to engage in participatory activities as well as increasing the awareness of these individuals' presence in the society, their strengths and creative potential with their different viewpoints of the world.

3.3.3 Participatory Design with Children

Children are one of the special user groups, whose contributions are valuable and inspiring in a design process. Children perceive a design problem given to them very differently when

compared with adults, since they have a high imaginative potential. However, it requires developing appropriate tools and methods for designing for and with children. Designers are less likely to involve users when they are confident about empathizing with the user group they are dealing with and having the necessary knowledge about them; however, children's participation is needed in a design process, since it is not always possible for adults, either designers or parents, to represent children or recall their own childhood memories (Druin 1999; 2002; Sanders 2000). Although parents and teachers can give valuable information about their children, active participation of children is necessary and also inspiring for designing and developing innovative technologies, since children, as technology users, have their own way of expressing their thoughts that can only be revealed through direct participation by using their creative and imaginative potentials (Druin 2002; Jones et al. 2003). In order to ensure their participation and achieve as many insights from them as possible, Sanders (2000) states that it is critically important to develop different research skills and generative tools and Druin (1999) supports the need for tools of expression for children to overcome their lack of verbal expression as well.

Children can be involved in the design process in various roles. Druin (2002) defines four main roles defining the level of involvement of children in the design of technology: user, tester, informant, and design partner. In the role of 'user', the technology has been already developed and distributed for the use of children and its impact on children has been observed for future designs, whereas they are the evaluators of the initial prototype of the technology generated by adults before launching the project in the role of 'tester'. Children as 'informants', engage in the process in various stages and through various methods before, during, and after the prototype development until the designed technology is distributed. 'Design partners', however, is the most ideal role and children are provided with the equal opportunity to contribute to the design throughout the whole process as adults can do. This opportunity is empowering in the sense that children have more impact on the technology compared to the technology's impact on children. Developing new methods and participation models as well as adapting the existing ones is needed to support children to become design

partners. As an alternative model to that of Druin's, 'Bonded design', in which children are in a role that falls between informant and design partner and work in an intergenerational team, is proposed, even though it is questionable whether or not an equal cooperation can be established because of the imbalanced power relationship between children and adults (Large et al. 2006). Bonded design also reveals the need for adult guidance in terms of organizing sessions, setting the agenda, and managing children's behaviors and engagement during the sessions when necessary.

3.4 PARTICIPATORY DESIGN WITH CHILDREN WITH AUTISM

Experiences of children with autism are considerably different from that of designers and participatory design is an appropriate methodological approach to adopt when working with this user group, since these individuals 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. Considering the democratic and social aspects of the participatory approach, 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 social, cognitive, and physical 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).

However, involving children with autism in the design process comes with its challenges caused by the disorder, which affect the design process and limit the 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. Moreover, children with autism get anxious and frustrated easily, when they find themselves in any unfamiliar, unexpected, or

unpredictable situation. Therefore, direct knowledge elicitation methods, such as brainstorming, interviewing, sketching, and low-tech activities, may be upsetting, inappropriate, and ineffective for some children depending on the children's conditions and cause anxiety (Keay-Bright 2007). Even though the structure of the sessions are well-planned, there might be a need to change 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). This challenge brings about the need for tailoring the methods and tools to the varying conditions and abilities of children, with the awareness of the need for flexibility in adapting each one to the children any time when needed, in order to have an increased empathic understanding and to gather data that can be translated into design input and product ideas more rationally (van Rijn and Stappers 2008; Frauenberger, Good, and Alcorn 2012).

Keay-Bright (2007) states that neither quantitative nor qualitative data can be gathered systematically when working with children with autism; therefore, it is important to gather those data through their actions, e.g. physical activities, verbal expressions, or gestures. The lack of social and cognitive skills of the children and their resistance to change, both in their routines and environment, bring about the need to structure the design process with a clear definition of their roles depending on their conditions. Children with autism should not be expected to take on the role of designers directly, but can participate in various roles (Frauenberger, Good, and Alcorn 2012).

With the aim of involving children with special needs in designing technology, Guha, Druin, and Fails (2008) developed an inclusionary model based on educational inclusionary principles and Druin's Cooperative Inquiry (1999) method. The model consists of three layers: (1) Druin's level of involvement, (2) the nature and severity of the disability, and (3) the availability and intensity of support. The first layer, as the basis of the model, requires determining the level of involvement and the role of children, i.e. user, tester, informant, or design partner, in the design process, regarding time, access to participants, and funding. The second layer indicates the effects of the nature and the severity of the disability on

involvement. Children with more severe disabilities, e.g. low-functioning autism, often have a more limited role, such as 'tester', whereas children with less severe disabilities, e.g. behavioral disorders, can be involved in more active roles, such as 'design partners' with less support. Lastly, the third layer suggests that the level of involvement of a child with a limited role can be increased by giving more support to that child. For instance, a child with low-functioning autism can be involved as a design partner with appropriate tools and adequate adult guidance. Williamson (2003) emphasized the advantage of including adults as informants as well in order to define the limitations, especially in the early stages of the design process.

As might be expected, the frameworks of all projects involving children with autism have their bases on the autism literature. Two of the research studies are grounded on the autism intervention programs in terms of structuring the activities (Frauenberger, Good, and Keay-Bright 2011) and setting the criteria (Benton et al. 2012). In ECHOES, the learning activities are determined within the SCERTS framework whereas the IDEAS process is analyzed against the TEACCH criteria to develop a set of principles: (1) ensure the children are familiar or can identify with the design topic in some way (*concept of meaning*), (2) identify the special interests of each child and incorporate these within examples and discussions to engage the child (*distractibility*), (3) be prepared for very direct criticism, give clear explanations (*concrete vs. abstract thinking*), (4) ensure the children know what activities to expect during each session and represent these in a visual way wherever possible (*organizing and sequencing/visual vs. auditory learning*), (5) involve an enthusiastic member of teaching staff, who knows the children well and is able to reinforce the support structure and improvise where necessary (*excessive anxiety/prompt dependence*), (6) use the personal strengths of each child to build up their confidence in the sessions (*strong impulses*), (7) involve researchers from a range of backgrounds, as it is important to have adult team members with technical skills as well as the psychological (Benton et al. 2012).

Other projects suggesting a design framework for participatory design with children with autism are the ReactiveColours and LINKX. Keay-Bright (2007) proposes a four-stage model, Research-Inspire-Listen-Develop, to apply to all stages of the design process in the ReactiveColours, from the feasibility phase to the implementation and dissemination phases. On the other hand, for the LINKX project, which is an interactive language-learning toy, van Rijn and Stappers (2008) proposes a design guideline to be used in further research studies by designers. This guideline includes giving children the feeling of being in control, providing a structured situation as well as enabling them to create the structure themselves, making use of their special interests, facilitating their excellent memory, rewarding them with sensory experiences, facilitating their eye for detail, and letting them use their whole body.

The participatory projects with children with autism mostly involve children with autism as both testers of the prototypes and informants (Pares et al. 2005; Keay-Bright 2007; van Rijn and Stappers 2008; Frauenberger, Good, and Keay-Bright 2011; Benton et al. 2012; Hirano et al. 2010; Malinverni et al. 2014) whereas some as only testers (Millen, Cobb, and Patel 2011) due to the impairments, conditions, and poor imagination skills of the children that limit their participation in some way. As presented in Table 3.1, which provides an overview of few participatory projects, children with autism are involved in generative and creative sessions depending on their severity levels and conditions as well as testing low-tech or flash-based prototypes in ECHOES, IDEAS, LINKX, ReactiveColours, MEDIATE, vSked, and Kinect Game; however, they are only involved as testers in COSPATIAL. The methods used in these projects vary depending on the aim and content of the projects as well as the conditions of the participant children, but mainly include observing behaviors, paper prototyping and prototype testing, drawing, and group discussions.

Moreover, the number of participant children with autism in each project is very limited changing between 3 and 8, except that MEDIATE is tested by 90 testers and the sample size is not mentioned in Kinect Game. It is worth noting that that children with autism is a quite specific user group that needs to be handled from various aspects and investigated deeply,

which requires time and collaboration, and it is more feasible with small groups. Besides the participation of children with autism, ECHOES and COSPATIAL involved typically developing children in the design process as well in order to focus on the adaptation of the methods to children with autism. Except ECHOES, MEDIATE, and Kinect Game, the teachers and parents (in IDEAS and vSked) or only the teachers (in COSPATIAL, LINKX, and ReactiveColours) of the children with autism are also involved in the process and seen in the role of proxies, facilitators, and informants in different stages of the projects and support interaction and communication as well as managing children's behaviors as their caregivers. IDEAS, vSked, COSPATIAL, and ECHOES are also multidisciplinary projects, drawing on various disciplines, e.g. human-computer interaction, artificial intelligence, neuroscience, developmental psychology, and visual arts.

Since the projects are mainly in the field of human-computer interaction and technology design, more appropriate methods are needed in product design to work with children with autism, regarding the design task and context. Moreover, compared to participatory design with typically developing children, participatory design with children with autism is quite challenging due to their impairments, which affect the level of their participation, and the need for searching for alternative ways of involvement. With the aim of taking participatory practices with children with autism a step further in the field of product design, a case study was conducted with children with autism, their teachers, and parents. The methods that were used in the study were chosen in the light of the literature and the results of the preliminary research that had been done on the site. The following chapter explains the study and the findings in detail.

Table 3.1 Examples of Participatory Projects with Children with Autism

PROJECT	AIM	PARTICIPATION OF CHILDREN	PARTICIPATION OF ADULTS	METHODS	MODELS / GUIDELINES FOR FUTURE STUDIES	MULTI-DISCIPLINARITY	THEORY IT IS GROUNDED ON
IDEAS (Benton et al. 2012)	Through a math-based tutoring software project trial, developing a new method to support the involvement of children high-functioning autism (HFA) and Asperger Syndrome (AS) in the design of technology by providing support for communication and collaboration	2 groups with 3 children with autism in each as testers and Informants (11-13 years of age)	Teachers Parents	Group discussions, Technology demonstration, Paper-based templates for idea generation, Paper prototyping, Flash-based prototyping for evaluation, Questionnaires for evaluation	1. Ensure children's familiarity with or ease of identification of the design topic 2. Identify and incorporate children's special interests in examples and discussions for engagement 3. Give clear explanation and be prepared for direct criticism 4. Ensure that children know the next activity during the sessions and provide them visual representation of the activities 5. Involve teaching staff, who knows the children well, to support the structure and improvise when necessary 6. Use children's personal strengths for their confidence in the sessions 7. Involve researchers from various disciplines with technical skills, psychological knowledge etc.	Teaching staff members from the children's schools, university researchers (one with a computer science, on with a developmental psychology background)	Every session had a clear goal based on specific TEACCH characteristics.
vSked (Hirano et al. 2010)	Designing a collaborative visual scheduling tool allowing group interactivity with the content generated through end-user programming	4 children with autism as testers and informants (9-10 years old)	Teachers Parents	Observations, Interviews, Focus groups, PD activities with teachers and staff members, Prototype evaluation (focus group discussions and then interventions)	4 design principles for interactive visual supports, specifically, for use in classrooms for children with autism: 1. Ease the transition to new tools by mimicking old ones 2. Reduce teacher burden 3. Automatically generate records and reports 4. Design for flexibility and robustness	Teachers, neuroscientists, autism specialists, assistive technology specialists, private therapists	

Table 3.1 (continued)

PROJECT	AIM	PARTICIPATION OF CHILDREN	PARTICIPATION OF ADULTS	METHODS	MODELS / GUIDELINES FOR FUTURE STUDIES	MULTI-DISCIPLINARITY	THEORY IT IS GROUNDED ON
COSPATIAL (Millen, Cobb, and Patel 2011)	Developing educational technologies in the form of shared active surfaces and collaborative virtual environments to support the enhancement of social skills for children with autism	6 typically developing children as testers (10-11 years old) 5 children with autism as testers (16-17 years old) 3 children with autism as testers (13-14 years old)	Teachers	Questionnaires, Interviews, Task analysis, Observation, Brainstorming, Focus groups, Storyboarding, Scenario designs and personas, Mind-mapping, Technology demo, Wizard of Oz prototype review		Technology developers, design engineers, educational psychologists, teachers from mainstream and autism specialist schools	Main focus was on the cognitive characteristics of the disorder.
LINKX (van Rijn and Stappers 2008)	Designing an interactive toy to help children with LFA learn their first 100 words	3 children with autism testers, informants, and co-researchers	Teachers	Observation, Expert interviews, Context mapping techniques (toolkits of expression, script providing tools) 3D prototype testing	1.Give them the feeling of being in control 2.Provide a structured situation 3.Let them create a structure themselves 4.Make use of their special interests 5.Facilitate their excellent memory 6.Reward them with sensory experiences 7.Facilitate their eye for detail 8.Let them use their whole body		
Kinect Game (Malinverni et al. 2014)	Developing a set of motion-based playful learning experiences that support children with autism to acquire simple social interaction and communication skills	Unmentioned number of testers and Informants	None	Fictional inquiry, Observation, Drawing, Role-playing, Directed design, Storyboarding, Recalling storyboard, Low-tech prototyping, Wizard of Oz prototype review			Practices from art and expressive art therapies

Table 3.1 (continued)

PROJECT	AIM	PARTICIPATION OF CHILDREN	PARTICIPATION OF ADULTS	METHODS	MODELS / GUIDELINES FOR FUTURE STUDIES	MULTI-DISCIPLINARITY	THEORY IT IS GROUNDED ON
MEDIATE (Pares et al. 2005)	Designing an interactive and transportable multisensory environment to promote creativity, exploration, and enjoyment in non-verbal children with low-functioning autism (LFA)	90 children with autism testers and unknown number of informants (6-12 years of age)	None	Interaction-driven design, Literature research, Unspecified PD activities, Evaluation			
REACTIVE COLOURS (Keay-Bright 2007)	Defining a methodology for inclusion in the development of technology promoting relaxation, encouraging spontaneous play, and supporting learning for children with LFA	6 children with autism testers and informants (4-7 years of age)	Teachers	Focus groups, Observation, Interviews, Brainstorming, Low-fi workshops (storyboards, drawings), Workshop with prototypes, Formal evaluation	The model offers a 4 stage iterative cycle: RESEARCH / INSPIRE / LISTEN / DEVELOP The project has 4 main stages: 1. Feasibility 2. Design 3. Implementation 4. Identifying further possibilities and inviting collaborators *The model is applied to all stages of the project.		
ECHOES (Frauenberger, Good, and Keay-Bright 2011)	Developing a technologically enhanced learning (TEL) environment to support young TD children and children with HFA (aged 5-7) in exploring and acquiring social interaction skills	30 typically developing children at the age of 6 and 3 children with special needs (2 HFA) as testers and informants	None	Sensory workshops, Storytelling, Digital prototype testing, Existential phenomenology, Internal testing and formative evaluation at each stage		Developmental psychology, visual arts, human-computer interaction, artificial intelligence, education, and several cognate disciplines	The learning activities are based on SCERTS.

CHAPTER 4

THE CASE STUDY

A case study is an intensive investigation and a descriptive and exploratory, rather than experiential or confirmatory, research of a phenomenon, such as social groups, situations, events, and activities, in a natural context bounded by space and time by using multiple sources of information systematically through a series of methods in order to understand, identify, or categorize the phenomenon being studied (Hancock and Algozzine 2006). Within this perspective, a case study was conducted in order to understand how children with autism interact with their material surroundings with the aim of exploring the ways of involving them in the design process through participatory methods.

The study was conducted at Güzelbahçe Special Education, Application, and Vocational Training Center, in İzmir, Turkey, with eight industrial design students, eight children with autism, seven parents, and seven teachers. The design task given to the designers was to redesign the conventional trampoline, an equipment of physical activity that many children with autism enjoy and provides various benefits to children with autism. The selection of the 'trampoline' was due to the literature (see Section 2.4.2.5 and 2.5.3) and the parents' and teachers' responses to the questionnaires confirmed that the trampoline was used both as a reward and a physiotherapy equipment at the school, which had the potential to be improved in order to provide activities in addition to jumping for children's development and improvement as well as bringing about some problems related to the use of it because of the inadequate measure of safety that increases the risk of injury. The physical features and the

current condition of the trampoline available at the school pointed out the need for increased safety as well. Regarding the guidelines and principles suggested in IDEAS, LINKX, and ReactiveColours, providing structured activities and sensory experiences to the children, identifying and using their special interests and personal strengths, establishing trustful relationship with the participants, and ensuring familiarity were paid great attention.

In this chapter, the site and the physical features of the setting, in which the study was held, are presented. Then, the study is explained in detail, starting with the problem identification stage and followed by a start-up meeting, workshop sessions, and evaluation sessions. After the description of the method of the study, the findings are presented and discussed.

4.1 SITE

Güzelbahçe Special Education, Application, and Vocational Training Center (Fig. 4.1) is one of the three public special education centers established in İzmir, in 2014, according to the list of special education centers for children with autism released by the Ministry of Education. It is located in Güzelbahçe and provides educational service to children from Üçkuyular, Balçova, Narlıdere, Güzelbahçe, Seferihisar, and Urla.

The school aims to provide free full-day education to children with autism at three four-year levels with a curriculum approved by the Ministry of Education as well as providing preschool education. The first level covers the primary education, starting from the 1^{st} to 4^{th} grades, whereas the second level covers the 5^{th}-8^{th} grades. The third level includes vocational training to the students in 9^{th}-12^{th} grades. The curriculum includes gym classes as well. The classes are between 9.30 am-2.30 pm. As the teachers state, the curriculum is not based on any widely accepted autism intervention method, such as ABA or TEACHH, and is inadequate for the students.

It has a capacity for providing special education up to 84 students between the ages of 3 and 23 and has incorporated 26 students and 10 teachers by December 2014. There are 20

classrooms dedicated to student groups with maximum 4 students in each with a teacher. Moreover, there are also shared spaces including an atelier, a conference room, a library, a gym, and a dining hall.

Fig. 4.1 The building of Güzelbahçe Special Education, Application, and Vocational Training Center

4.2 SETTING OF THE STUDY

Three public special education centers in İzmir and Tohum Autism Foundation in Istanbul, which is the most widely known autism foundation in Turkey, were visited. Private special education and rehabilitation centers were left out of the scope on purpose. The main reason for this exclusion is that they provide half-day education to children whereas full-day education provides the opportunity to observe children more deeply in their school activities. Among the visited schools that meet these requirements, Güzelbahçe Special Education, Application, and Vocational Training Center had agreed to collaborate in this study with full participation of the registered students, parents, and teachers.

All stages of the study were conducted at the school, Güzelbahçe Special Education, Application, and Vocational Training Center. It was the most practical and appropriate place

to meet with the participants, since the children were familiar with the school and their own schedules, which the workshop was scheduled accordingly, and they could be observed in their own contexts without being disturbed by any spatial changes. The children were also familiar with the teachers and parents at the school, who were mostly present there or could be able to come when invited.

In the scope of the design brief, the observations were done mainly in the gym (Fig. 4.2), where the designers could explore the children's sport activities and use of the trampoline. In order to get to know the children in every aspect, classrooms and dining hall were the other mostly observed spaces at the school, where the interviews were often conducted as well. A small room separated by windows in the hall was set for the designers to gather and work collaboratively during the workshop sessions. It was located across the classrooms downstairs and near the gym, which made it possible to observe the children and the action flows constantly 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.

Fig 4.2 A view from the gym at the school

It was critically important not to change the setting during the study, since the children with autism get nervous and distracted if any changes in their settings or routines occur. Therefore, the settings of the observed spaces were not rearranged, but rather kept in their standard arrangements. There was no camera placed in the settings for continuous recording. However, each designer recorded the children they were responsible for separately during their observations.

4.3 SAMPLE GROUP

Eight children, who were diagnosed with Autism Disorder in the first three years of their childhood, participated in the study. Considering that the participation of adults in the participatory design projects conducted with children with autism prompt interaction and communication between designers and children as well as managing children's behaviors and comforting them, as it is seen in the similar studies mentioned in the previous chapter, teachers and parents were decided to be involved in the case study with children with autism and designers. There were 23 registered children with autism at the school, whose ages ranged from 4.5 to 17, by the time the research had started. Following the preliminary meetings with the school principal, families were contacted through the administration. Because of the time constraints and lack of accessibility, all families were invited to the school in order to convey a detailed explanation and objectives of the study in an informative meeting and choose the participants on a volunteer basis. Six parents attended the meeting, two of whom were the mothers of twins, and two parents were met in another visit. Seven out of eight parents gave written and signed consent for the participation of eight children in total as well as the use of the outcomes of the case study, including all visuals. As well as these seven parents, five class and two gym teachers, who were the teachers of the participant children, participated in the study.

Even though the selection of children was based on the consent and voluntariness of the parents, the chosen 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' in the thesis, participated in the study as well. Four of them were the second year and four of them were the third year students in the Department of Industrial Design at Yaşar University, İzmir, Turkey. They were chosen by the researcher regarding their skills in design and interpersonal communication, and willingness to work with children with autism.

4.4 PARTICIPANTS OF THE STUDY

There were 31 participants in total in the study. The designers, children with autism, parents, and teachers participated in the process in the different stages of the study through various methods used by the researcher and the designers. In this section, general profile of these participants, time they spent at the school, and their relations with each other are explained.

4.4.1 Children with Autism

Eight children with autism participated in the study with the consent of their parents. The number of participant children was small as it is in similar studies in the literature. However, it provided the opportunity to investigate the children's lives, behaviors, needs, and the like, through finding the answers of more focused and in-depth questions during the study.

Two children were full-day students; four children were half-day students twice a week, but full-day for the rest of the week; and two children were only half-day students among the participant children. The information about each child was obtained from the questionnaires and interviews conducted with their parents, teachers, and through observations before and during the workshop week and it was clear that the children varied in their interaction, communication, and learning skills, behavioral patterns and interests, sensory sensitivities, and interaction with the product at issue as well as the level of intensity of their autistic

conditions and accompanying disorders/impairments (Table 4.1).

Table 4.1 General Profile of the Participant Children with Autism

CHILD	GENDER	AGE	DIAGNOSIS	COMORBID 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
4	F	7	Autism	–	Full day
5	M	9	Autism	Epilepsy Hyperactivity	Only afternoon (previously full day)
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)

Child 1

She is a 4.5-year-old girl with autism. She does not talk and is not very responsive. In class, her teacher works on teaching basic directions, such as ‘come’ and ‘sit’, for her to follow. The most significant problem of her is the problem with toilet training and self-care. She usually puts her fist fully in her mouth and bites it or bites other people. Staying still or sitting in one place for a long time is really difficult for her and causes her to cry. She has a lack of interest in toys in general, but she likes to listen to music and her favorite object at school is the colorful toy clock with music. She plays it over and over again while playing with puzzles, which she likes to play with too much as well. Besides her interest in music, electronic devices preoccupy her a lot. She knows how to turn all electronic devices and light switches on and off, and is very curious about computers although she has not learnt to use it yet. She likes to be on the trampoline but not jumping on it. She only enjoys lying on it and walking near to the edges in circles. While lying on the trampoline, she makes continuous noises by scratching the base of the trampoline or touches the net around the trampoline as she walks in circles. Even though she rejects it, her gym teacher gives physical support to her in order to encourage her at least to bounce on the trampoline but she always tends to bend down on to her knees. Moreover, she sometimes runs away and is never aware that she leaves her

mother somewhere. She usually ignores to interact with people, even with her mother and teacher, who are the most familiar people to her, and has no interaction with peers.

Child 2

He is a 5-year-old boy with autism with the highest severity level among other children at the school. Because of his physical and mental disabilities, he has a physiotherapist and psychiatrist. His problems caused by physical restrictions and his incapabilities in self-care are very significant. He is a very fast runner, but he cannot walk without help, because he let himself fall down to the ground after 3-4 steps. In that sense, gym classes are very important for his physical development. He likes the trampoline but is not able to use it on his own. His gym teachers give physical support to him to jump on the trampoline. He likes Legos and plastic toy pieces; however, he is unable to put the pieces together on his own. He rather spins the pieces, as well as toy cars, on the ground. He does not understand how to use objects. Moreover, he has an obsession with listening music. His mother prefers radio instead of television in order not to make him become addicted to televisions. He has a biting habit, which has been decreasing in frequency recently. He does not interact or communicate with other people and hardly follows the given directions. Unlike the other subjects of the study, his repetitive behaviors are not very apparent or significant. His verbal communication skills have not been developed, and he lacks non-verbal communication as well.

Child 3

He is a 5-year-old boy with mild autism. He is the only child among others at the school, who attends to an inclusive nursery class. His learning skills are comparably better. His most significant problem is with toilet training, because of which he carries a timer that is set to 20 minutes. He does not have any problems with using daily objects, but only with the toilet seat because he does not want to use it. He likes to sing and knows many Turkish and English songs, including the Turkish National Anthem, which he sings repeatedly. He is very attracted to animals and magazines that contain pictures of various animals. He likes to

imitate their sounds. His teacher sometimes uses these magazines as rewards during the class. Sport activities, especially jumping on the trampoline, are very enjoyable for him, and he has a great inclination to sports. He always tries to jump higher on the trampoline by pulling up his knees and gaining acceleration. He has two very risky moves on the trampoline. The first one is that he has recently discovered that the net of the trampoline is flexible and started to throw himself on to the net and secondly, he suddenly stops while jumping high and throws himself facedown on to the bed of the trampoline. He has also realized the stacked gym mats beneath the bed of the trampoline and started to go under the trampoline and play there. Besides sports, he is interested in painting and playing puzzles on his tablet and helping her mother while cooking. He displays limited verbal communication with people. Even though he does not form full sentences, he sometimes uses a few words. He does not always ignore people and occasionally makes eye contact. He is more prone to interact with others compared to the other children at the school. He begins to act in a spoiled manner, if given close attention.

Child 4

She is a 7-year-old girl with autism. She has eating and sleeping disorders and concentration problems during activities and classes. When she gets nervous or frustrated, she claps her hands wildly or slaps her legs and screams. Sometimes, she laughs on her own for no apparent reason. She loves to be in the gym and very interested in sports. Her class teacher locks the door during the classes in order to prevent her to run out of the class to the gym. Most of the time, she runs directly to the gym in breaks and wants to run around or jump on the trampoline. Her teachers and her father usually use the trampoline as a reward when she accomplishes something or as a means for relaxing her when she is very hyperactive or nervous. She loves to jump high and tries to see the outside over the net. She sometimes lies on the bed of the trampoline on her back or facedown for relaxation. When lying on her back, she likes to move her body in circles by her feet. After seeing Child 4 going under the trampoline to lie and play on the gym mats, she has started to imitate him. She is obsessed with swinging objects or parts of objects, and her personal tablet. After lunch, her father

takes her to their car and she plays with it until the class starts. Repetitive movements, sounds, and behaviors she displays are very apparent. She hardly makes eye contact, responds to her name or accepts to be touched; however, likes to be tickled and laughs or smiles while doing that. Although she shows no peer interaction, she imitates her peers' behaviors if these behaviors are that of her interest. She knows how to take advantage of people to achieve her own purposes and interacts with them on her own free will only when she wants someone to do something that she wants. She understands the directions given by other people, but mostly ignores to follow them. She is non-verbal, but continuously makes strange noises and has recently started to mumble.

Child 5

He is a 9-year-old boy with severe autism along with epilepsy and hyperactivity. He has a very short attention span and serious behavioral problems, including aggression and violence. The main reason for that is his hyposensitivity to tactile stimuli. He does not feel pain and cannot control the pressure he applies. Therefore, it is always necessary to watch him even during his daily activities, since he is prone to injure himself anytime. He has tics and leaves one tic only when he adopts another one. He displays repetitive patterns of behaviors, such as listening the same song over and over again from her mother's mobile phone. He has an obsession for putting things in order, such as dolls or apples during lunch. He usually tests other people's reactions and acts accordingly. If he feels that he is able to be the authority over them, he exploits it. However, he accepts his previous teacher as the only authority at the school. He has difficulties with following directions and cries a lot when he is pushed to do something just as the majority of the children with autism; however, puzzles as a reward encourages him to complete the tasks in the class, since he likes to play with them a lot. He loves being with and taking care of animals. He is non-verbal and makes no eye contact. When he is forced to interact or communicate, he becomes aggressive. He does not allow anyone other than his parents and his previous teacher get close to him. Since he is very resistant to change, he has had adaptation problems to his new teacher, who has not been familiar to him yet. Therefore, his parents have recently preferred to bring

him to the school only for the gym class hours, during when he seems comparably more comfortable. His gym teachers give physical support and verbal directions to him during all sport activities, which he rejects to do. Although all children usually use the massage chair during breaks between sport activities, his gym teachers use it as a reward when he completes an activity. Since he ignores and resists to people, the massage chair also helps to stimulate his senses and relax him without any physical or verbal contact. He rejects to jump the trampoline and his gym teachers do not force him. Regarding his father's statement that he has a small-diameter and low trampoline at home, which has also bars for him to handle while jumping or bouncing, it is probably because the trampoline at the school is comparably very large in diameter and high, which causes him to be afraid.

Child 6

He is an 11-year-old boy with autism. He has difficulties with maintaining self-care and social adaptation. Even though it is limited, he is open to interaction and wants to be paid attention to, but ignores peers and does not develop relationships with them. He cannot communicate verbally, but he occasionally responds to his name and makes eye contact. He needs to be directed verbally to do something or complete tasks, and mostly follows these directions given to him. During gym classes, the most frequent activity that his gym teacher makes him to do is walking on the treadmill. He sometimes does the other sport activities but never uses the trampoline. Whereas his gym teacher believes that he is afraid of jumping and height, his father states that he used to jump on the couches at home but he has started to hesitate to jump on the trampoline after gaining weight. It sometimes takes some time for him to concentrate on things he is doing. He does not display hyperactive behaviors; however, he shouts for no apparent reason while he walks around at the school. He is attracted to lights, as his father states. For instance, he runs towards the light in the dark or stares at LEDs. He does not have any obsession with objects, but he likes puzzles to play with. He is very tender-minded, likes to kiss people and to be tickled. He sometimes seems to get excited, upset or nervous, but displays hardly any facial expressions.

Child 7

He is a 14-year-old boy and one of the twins with autism. He is talkative and usually open to interaction. Although he does not totally ignore other people, he cannot form peer relationships, except his twin brother. He pays great attention to details, but is more likely to miss the big picture. He remembers the things he is once told and likes to ask the same questions to other people to test their knowledge. He loves watching football matches. He knows the names of all players by heart and is very good at imitating sports commentators. He sometimes asks questions to people as if he is holding a microphone. He likes to answer the questions that are asked to other people but they are mostly just random answers rather than logical. However, he sometimes gives logical answers or makes rational comments, especially if the subject of the question or the talk is of his interest. Unlike other children with autism, he usually understands jokes and makes jokes himself. He has strong leadership skills and is especially directive upon his twin brother. He does not have an obsession with objects, but he is obsessed with his twin and wants him always to be around, as his teacher states. He does everything he does for himself for his brother as well; therefore, his brother has become dependent on him. Stereotypical behaviors are rarely seen; if he is warned while showing repetitive mannerisms, he immediately stops and apologizes. He is very responsible and completes the tasks he has started, and realizes his mistakes even without any warning. He sometimes cries if he does not want to do what is told, but he follows directions and gets along with others well in general. His mother and teacher usually hug and kiss him as a reward when he accomplishes something, and it makes him happy. He sometimes imitates the same behavior and hugs, kisses or tickles them, when they give an answer he seeks or do something he likes. He likes computers and tablets as well, which he can use very fast. His fine motor skills are not developed enough; for instance, he has problems with using scissors, zipping, buttoning, and tying shoes. In order to overcome this, his teacher gives him exercises with play dough and his gym teacher makes him do table tennis or ball-bouncing exercises. He and his twin are the ones who show the highest performance during sport activities among the other participant children, since they have less severe autism. Except the activities that require developed fine motor skills, he completes all

activities independently. As he is very open to verbal communication, he enjoys chatting during sport activities as well. He likes the trampoline and verbalizes that he likes it. His gym teacher gives him activities, such as counting numbers, singing, and throwing balls reciprocally, to be done simultaneously with jumping on the trampoline.

Child 8

He is a 14-year-old boy and one of the twins with autism. His verbal communication skills are limited and he lacks interaction with other people compared to his brother. However, he is usually in interaction with his twin, but not with peers. He has echolalia; mostly repeats the same words he says or echoes back when he is told something. He can answer questions that require basic answers, but not too much comprehension. He pays attention to details, but it takes time for him to concentrate. His attention span and concentration skills are less than his twin's, but he is faster to complete the given tasks. It is important to motivate him for the school in the first ten minutes in the mornings, otherwise he stays nervous for the rest of the day. He cries or pretends to cry, when he is pushed to do something. Since he hates picking up toys, his teacher uses it as a punishment. He is conditioned to it; therefore, stops crying and wandering around in order not to tidy up. His stereotypical repetitive behaviors are very apparent. He loves to play games on the tablet and knows the names of computer brands, software, and operating systems. He is very dependent on his twin, since he does everything for him anywhere. He is less responsive, if his brother is around. Even though they had been taught by the same teacher, he has recently been transferred to another teacher in order to encourage him to be more independent from his twin. Most of the children are on medication due to their hyperactivity and lack of concentration at school, but he is very affected by it, loses his energy, and seems to almost fall asleep at around noon everyday. For instance, he even sleeps on the massage chair during breaks between sport activities or after the gym class. He has difficulties due to his underdeveloped fine motor skills. Table tennis and bouncing ball are the activities that his gym teachers make him to do for developing his fine motor muscles. Even though his twin has higher performance, he can complete almost all activities without any help of the gym teachers as well, except table

tennis and bouncing balls. However, he sometimes needs to get verbal directions. He likes to jump on the trampoline and enjoys it more if his gym teacher gives additional activities, such as throwing balls in and out, while jumping. An additional activity also seems to increase his concentration during the use of the trampoline as well, since otherwise, he usually follows his twin with his eyes during his own sport activities. He has no problem with stepping in or out of the trampoline, and mostly jumps on the same spot if he is not throwing balls reciprocally with his gym teacher simultaneously.

It is evident that each participant child with autism in this study has different characteristics in terms of interaction and communication skills, learning abilities, behavioral patterns, interests, and sensory sensitivities. Their autistic conditions and accompanying disorders and/or impairments vary in intensity as well.

4.4.2 Designers

Eight industrial design students from second and third grades participated in the study (Table 4.2). They were randomly assigned to the subjects with no previous information about them. Their previous experiences with children or people with special conditions were asked in the first session of the workshop in order to understand how they approached the study, and it was found out that they had had no experience with children with autism before.

Table 4.2 General Profile of the Participant Designers

DESIGNER	GENDER	GRADE	PERSONAL EXPERIENCES WITH CHILDREN / PEOPLE WITH SPECIAL CONDITIONS
1	F	2	She has 3- and 6-year-old relatives in the family. She also worked with a group of 11 children at the age of 5 for a design project at school.
2	F	2	She once worked with children as a volunteer in a summer camp. When she was at high school, there was also a primary school child with epilepsy at her school. It aroused her interest and she sometimes played games with him.
3	F	2	She knows people, who have family members with epilepsy and Down's Syndrome. She also has a cousin with epilepsy, with who she has been in close contact.
4	F	2	She does not have any experience with children or people with special conditions, but only with her 7-year-old typically developing cousin.

5	F	3	She once attended to a one-day activity that was organized for entertaining abandoned children.
6	F	3	She had a classmate with Down's Syndrome in primary school. She had first been scared and not known how to interact, but then, they had become friends.
7	F	3	She once visited a rehabilitation center within the scope of a playground design project in the previous semester.
8	F	3	She does not have any experience with children or people with special conditions, but loves to play with children.

4.4.3 Parents

Seven parents participated in the study and gave permission for observing and working with their children (Table 4.3). Some of the parents spent their whole day at the school in order to keep an eye on their children and help them with their needs whereas the others only brought their children to the school and picked them up. They helped the designers to interact and communicate with the children when needed. They also gave detailed information about their children's past and current conditions and explained why certain behaviors occurred. They had been met before the workshop week and spent time together during the workshop days as well.

Table 4.3 The Presence of the Participant Parents at the School

PARENT	GENDER	PARENT OF	TIME SPENT AT THE SCHOOL
1	F	Child 1	Full day
2	F	Child 2	Full day
3	F	Child 3	Bringing her son to the school and picking him up
4	M	Child 4	Full day
5	M	Child 5	Full day
6	M	Child 6	Bringing his son to the school and picking him up
7	F	Child 7 and 8	Bringing her sons to the school and picking them up (full day until the workshop week)

4.4.4 Teachers

Eight teachers participated in the study (Table 4.4). Five of them were class teachers, and the other three were gym teachers. One gym teacher had to quit due to job change on the first day of the workshop and could not be involved during the sessions; however, he had participated in the problem identification stage conducted by the researcher. He had been the only gym teacher at that time. After the preliminary research had been completed, one class and two gym teachers, one of whom has started to work in the midst of the workshop week, joined the teaching staff.

Table 4.4 The Participant Teachers Matching with the Children at the School

	TEACHER	GENDER	TEACHER OF
CLASS TEACHERS	1	F	Child 1, 2, and 3
	2	F	Child 6
	3	F	Child 8 (She had been teaching Child 5 and 7 as well before Teacher 5 joined to the teaching staff.)
	4	F	Child 4
	5	M	Child 5 and 7 (He has started to work at the school right after the preliminary research had been completed.)
GYM TEACHERS	6	M	All Children (He has started to work at the school right after the preliminary research had been completed.)
	7	F	All Children (She has started to work at the school on the third day of the workshop week.)
	8	M	All Children (He quitted in the workshop week, but had been involved in the preliminary research.)

4.5 METHOD

The case study consists of four phases: (1) the problem identification stage, (2) start-up meeting, (3) workshop sessions, and (4) evaluation sessions. Questionnaires, interviews, observations, and collaborative meetings for feedback and evaluation were conducted with a focus on the experiences of the children with autism in these phases involving some or all of the participants in each. The phases of the study were in sequence, but did not incorporate a linear process within, since the challenging conditions of the children and the responsibility of the parents and teachers to take care of them required a flexible and non-linear structure. A diversity of techniques was used to collect, share, and analyze the data, and for evaluation.

4.5.1 The Problem Identification Stage

In order to identify a design problem and structure the workshop sessions, questionnaires, interviews, and observations were conducted at the school and the findings obtained from the application of these methods helped shaping the research direction and preparing the design brief. This stage did not involve the designers and was conducted by the researcher.

4.5.1.1 Questionnaires

Since questionnaires are used for collecting primary data from respondents about their attitudes, behaviors, thoughts, facts from a certain period of time of their lives, etc., which are not always possible to capture through observation (Blessing and Chakrabarti 2009), questionnaires were preferred to receive direct responses about participant children with autism from their parents and teachers in the study.

Questionnaires were applied to the parents and teachers with the aim of revealing the common daily life problems of children with autism and their interaction with their material surroundings in daily routines in order to create a ground for problem identification. The questionnaires were handed out to the parents, after a 15-minute informative meeting about the objectives and the future process of the study in the dining hall at the school (Fig. 4.3). After receiving the parental consents and completed questionnaires, the teachers of the children, whose parents gave permission for participation, were contacted and asked to fill the questionnaire. Some of the respondents filled the questionnaire individually whereas the others were asked in person by the researcher due to their limited time for participation.

Questionnaires consisted of 14 items related to the children's diagnosis and comorbid conditions, their most significant daily life problems, objects that they use the most and/or obsessed with, the problems that they have while using them, ways of personalization (if there are any), their personal interests and talents, and a parental consent for their children's participation in the study (see Appendices A1 and A2). Although the open-ended questions

in the questionnaire were the same both for the parents and teachers, the teachers were asked to give responses in relation to the children's school life, since they only have experience with the children only at the school, whereas the parents were not limited with any context of the children's lives, e.g. home or school.

Fig. 4.3 Parents filling out the questionnaires

4.5.1.2 Interviews

Informal conversational interviews, during which spontaneous questions are generated, were conducted with the parents, teachers, and the administrative staff in the problem identification stage in order to gather detailed information about the disorder, children at the school, 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 and shape the further research direction.

4.5.1.3 Observations

In order to support the data collected through the questionnaires and interviews, the researcher made unstructured 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 during the problem identification stage. The researcher did not perform full immersion but rather artificial immersion on purpose at this stage, since the psychological sensitivity of the observed group and therefore the anxiety because of the unfamiliarity were high, that required distance between them and the researcher in the beginning (Blessing and Chakrabarti 2009). These observations provided more information about the disorder, general characteristics of children with autism, and the ways of interaction and communication with them as well as the site and all children at the school individually. The researcher also observed the children by watching the video recordings of the children's various sport activities in the gym, which were shared with the researcher by the gym teacher. These exploratory 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 research of the following phase.

4.5.1.4 Preparation of the Design Brief

During the problem identification stage, it was recognized that most of the children at the school had a great interest in the trampoline, which provides many benefits to children with autism, 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 the repetitive up and down movements it provides (ReboundTherapy.org 2014). The collected data at the school also indicated the need for more safety to reduce the risks of the trampoline use, considering the trampoline that was available for the children at the school.

Regarding the findings of the problem identification stage, the researcher prepared the design brief for the following phase. The designers would be expected to reconsider the conventional design of the trampoline and what other purposes it might serve for by providing an improved bouncing activity that is both beneficial and enjoyable for children with autism. The focus of the project was on developing a diversity of design solutions and exploring the potential uses of the trampoline in order to help children improve their fine and

gross motor skills, sensory systems, body awareness and balance, cognitive skills, concentration, and safety during the bouncing activity as well as providing alternative ways of usage (see Appendix B).

4.5.2 Start-Up Meeting

After the completion of the problem identification stage, the researcher scheduled a start-up meeting with the designers to explain the purpose of the study. The researcher made a short introduction to autism, the objectives and structure of the study, and how to process in the study. Each participant child was introduced to the designers by showing the selected video recordings and photographs of each of them and conveying the information derived from the questionnaires and previous observations.

Regarding the methods that the teachers apply and widely accepted intervention methods, such ABA and TEACCH, it was decided to run the workshop sessions one-on-one. It was also aimed to enable each designer to focus on one child and the design problem they would identify to investigate more deeply. Therefore, each designer drew a name from a bowl to be assigned to one child to work with throughout the process. A list of informative websites, short videos and films about autism, and product examples for people, especially children, with autism were also shared with the designers at the end of this meeting in order to provide them more information about the disorder and its relation to product design before the study started.

4.5.3 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 (Table 4.5). The designers conducted interviews with the parents and teachers as well as observing the children for three days and were consulted by the parents and teachers. Child 1, 2, and 6 had gym classes only twice week but were observed for three days as well during their in-school activities.

Table 4.5 Workshop Sessions

	Monday	Tuesday	Wednesday	Thursday	Friday
Designer 1	Child 1	Child 1	X	X	Child 1
Designer 2	X	Child 2	Child 2	X	Child 2
Designer 3	Child 3	Child 3	Child 3	X	X
Designer 4	Child 4	Child 4	Child 4	X	X
Designer 5	Child 5	Child 5	Child 5	X	X
Designer 6	X	Child 6	Child 6	X	Child 6
Designer 7	X	Child 7	Child 7	X	Child 7
Designer 8	X	Child 8	Child 8	X	Child 8

The children's moods were changing everyday because of their special condition, but since the physical activities and children's interests and conditions in relation to these physical activities were the main focus of the study, there were not any significant daily changes that occurred. Moreover, it was possible to capture the children's current behavioral patterns related to the trampoline use in a three-day observation and through the interviews in this period of time due to their restricted interests and stereotyped behaviors, despite the fact that a longer period would have provided more accurate data in the study.

The designers were allowed to be the shadow of any participant any time throughout the workshop process, although each designer was peered to one child. Therefore, collaborative meetings were held to provide a ground for the designers to share the information they gathered, which increased the collaboration among the designers in terms of collecting and analyzing the data and idea generation.

4.5.3.1 Interviews

During the workshop sessions, the designers conducted unstructured interviews as well as subject-related conversations with the parents and teachers (Fig. 4.4), since conversational interviews allow the conversation to flow naturally with spontaneity and unstructured interviews give interviewers the opportunity to direct the interview depending on participants'

responses and make unexpected discoveries about the situation related to the focus of the study (Blessing and Chakrabarti 2009; Vanderstoep and Johnston 2009). These interviews provided the designers the opportunity to understand the underlying reasons and motivations of the participant children's behaviors, actions, and preferences. Since each child had different characteristics and patterns of behaviors and interests, the designers were allowed to be flexible in forming the questions and schedules. Their own progresses determined the direction and content of their interview questions. The designers took interview notes during and after the interviews in a personal log and shared them with the other designers in collaborative meetings to cumulate the knowledge and information about the disorder and the children with autism both in general and specifically (Fig. 4.5).

Fig. 4.4 Designers' interview with Parent 6

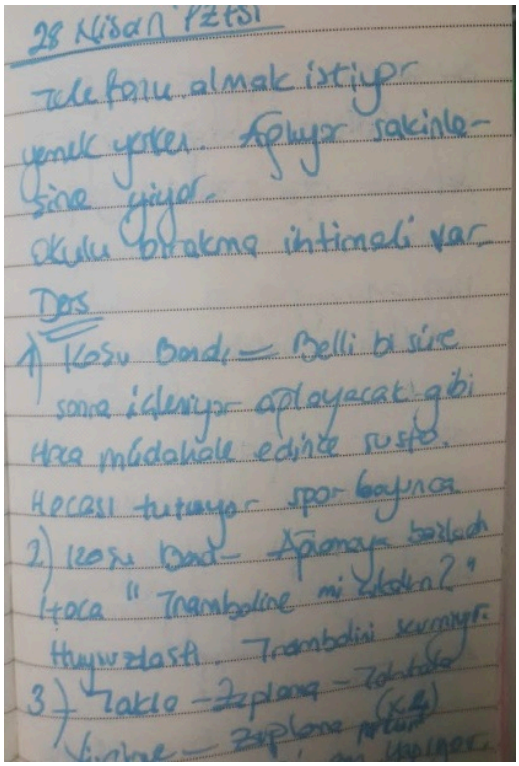

Fig. 4.5 An example of personal logs

4.5.3.2 Observations

Even though the parents and teachers gave information about the children before and during the study, observing the children during their activities was highly important, since the main focus of the study was to understand the behaviors and actions of children with autism as well as the reasons behind those behaviors and actions in order to utilize them as a design input. Moreover, the participant children were non-verbal, except for two of them. Therefore, observation was the most suitable method for the study regarding the advantage of the method for “gathering data on non-verbal behavior” (Corbetta 2003, 235) and eliminating the “reliance on participants’ perceptions” (Vanderstoep and Johnston 2009, 238). As Keay-Bright (2007) states as well, in participatory processes with children with autism, observing the behaviors and physical activities of children is more beneficial compared to direct knowledge elicitation methods.

The designers made structured and unstructured observations during children’s gym and in-school activities to support the data collected from the parents and teachers and have a

deeper understanding about the design context. The observations were overt; therefore, the participants were aware that they would be observed and had been informed about the purpose of the observations before the study was conducted. The designers took the role of observing participants, who "observe and document their own process" (Blessing and Chakrabarti 2009, 259), and kept the record of their observations.

During the structured observations done in the gym, the designers filled the observation form prepared by the researcher (see Appendix C). It was divided into three sections: (1) sport activities, (2) the trampoline activity, and (3) designers' insights. The sections contained 82 items in total: 30 items in the 'sport activities' section, 44 items in 'the trampoline activity' section, and 8 items in the 'personal insights' section. These items were 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 personal comments and insights of the designer as the observer.

Both structured and unstructured observations were recorded through reflective notes, photographs, and especially videos, since the design problem was strongly related to behaviors, movement, and physical interaction. Since photographs capture only a particular moment without reflecting the movement and sequence of events and/or behaviors whereas videos provide recording these missing parts of observations (Murchison 2010), video recording was more advantageous than photographs in the study. Videos provided data about how the physical activities and behaviors of the children took place while photographs supported the videos by providing detailed close-up snapshots of the activities, situations, and environment. The designers recorded the children's physical activities and trampoline use by using mobile devices. Since the children with autism notice any small changes in the environment and are disturbed by any unfamiliar occurrences, it was decided not to place a camera in the setting for continuous recording but rather make recording individually only when possible in order to avoid the children from being distracted and becoming nervous. Another reason for individual recording was that each child performed different activities in

the gym; therefore, it was not possible to capture these activities closely and clearly from a fixed view angle. Although the presence of an observer and recording from a close position might be distracting for the children as well, recording was preferred in order to collect possibly the most effective data.

Since the interaction with the children and immersing in their world were of great importance in the study as well, the designers took observational and reflective notes in a personal log to describe the conditions and/or actions they observed and keep the record of the striking moments they observed and/or experienced, their insights and feelings in relation to them (Blessing and Chakrabarti 2009). It was also useful for the study that written notes support recordings of observations and avoid missing unrecorded important information; therefore, they allow the observer to produce the most complete data (Murchison 2010). The designers were intended to acquire more knowledge about autism and gather information about the children in general as well as gathering information specifically related to their physical activities and trampoline use. Therefore, the observational and reflective notes did not only involve the observations done in the gym, but also the exploratory observations done in the other places at the school during the children's all kinds of activities in their daily routines.

Even though the observations were done individually, all designers more or less had some experience with all participant children and had a chance to observe them in some way at the school. In order to share these experiences, insights, and ideas, participant sheets were prepared for each child and hung on the wall for all designers' contribution (Fig. 4.6). These participant sheets included all information and data derived from the observations and immersions as well as the characteristics of each child and their trampoline use. The designers contributed to the participant sheets with post-its, when they had anything different that they found important or interesting to add in order to take into consideration in designing or any ideas as design solutions. All contributions were also shared and discussed together in the collaborative meetings. The parents and teachers were encouraged to contribute as well.

Fig. 4.6 Participant sheets on the wall

4.5.3.3 Collaborative Meetings

Besides the observations and interviews in the study, the designers came together among themselves periodically in order to convey the information they gathered, identify the design problems in relation to the collected data collaboratively, and develop design suggestions by building on each other's ideas. These meetings provided the designers a collaborative source of information and a ground for having discussions about each other's experiences, personal insights, and ideas, and the relevance of the collected data to product design and the design brief.

In the first meeting, warm-up questions were asked to designers to share their expectations from the process and previous experiences with people with special needs (Fig. 4.7). The following meetings included group discussions among the designers and provided a collaborative source of information. 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 ideas, were listed and clustered on the wall by using post-it notes (Fig. 4.8).

Fig. 4.7 Warm-up questions asked to the designers

Fig. 4.8 Post-it clusters for problem identification and brainstorming ideas

4.5.4 Evaluation Sessions

In order to evaluate the design process and its outcomes, two sessions were set for participatory evaluation. As the first step of the evaluation, a discussion meeting was held among the designers in order to evaluate the design ideas being improved and exchange ideas. The presentation, on the other hand, involved all participants of the study as well as the non-participants, who were also invited to the presentation.

4.5.4.1 Discussion Meeting

The designers worked individually outside the school to improve their design suggestions further 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 take a step further in a discussion meeting. The designers also 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.

4.5.4.2 Presentation

The presentation day was organized at the school and all participant and non-participant children, parents, and teachers were invited by the researcher and the school administration. The presentation took place in the dining hall and was limited with 45 minutes in total, giving word to each designer for 5 minutes, in order to keep the presentation short regarding the distractibility and short attention span of the children. In the presentation, the researcher conveyed an overview of the research and the workshop process and acknowledged the participants. Then, each designer presented their final conceptual designs, after which the participants were asked to give feedback and encouraged to comment on the ideas (Fig. 4.9). The researcher recorded the presentation and the feedbacks during the session.

Fig. 4.9 Presentation of the design ideas to the participants in the dining hall

The designers were asked to fill the product assessment and self-assessment sheets, prepared by the researcher, as the presentation continued (see Appendices D and E). The product assessment sheet included items about the clarity and focus of the design problem, 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. The self-assessment sheet, on the other hand, included 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.

4.6 FINDINGS AND DISCUSSION

This study focused on the potential of the behaviors, actions, and experiences of children with autism as a design input and how these children can be emancipated by the design process rather than focusing on their impairments and incapabilities. 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.

4.6.1 In Relation to the Children with Autism

When the children first met the researcher, they were uncomfortable because of the presence of an unfamiliar person. However, during the problem identification stage, it was observed that they seemed less disturbed by the researcher's presence after each visit. Moreover, the interaction between the designers and children was more than it was expected; however, establishing communication in between was difficult. Most of the children were frustrated and had difficulties with getting used to the presence of the designers, but their frustration and anxiety decreased apparently after spending time with the assigned designer and the support of their teachers in facilitating their interaction and managing the children's behavior. By the time they started to establish close relationships, the children started to become more open to interaction during the designers' presence without or with less distraction. The children's lack of concentration to start an activity or follow the given directions during the activities also started to decrease.

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 as much as he did in the class. 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 everyone and chatted with Designer 7 during the sessions. Child 8 did not like to have conversation although he was verbal. However, he was open to physical interaction during the sessions. He enjoyed holding hands with people, specifically Designer 8 in the sessions, for calming down and relaxation (Fig. 4.10). For instance, it was the first time for Child 7 and 8 that their mother only dropped them to the school and left for the day, which caused fear, frustration, and anxiety, especially for Child 8. Although he was much more familiar with his teachers, it was observed that he called Design 8 and chose to hold hands with her to relax when he cried. Child 6 did not physically interact

in the same way, but yet 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.

Fig. 4.10 Child 8 holding hands with Designer 8 for relaxation

None of the children expressed any ideas or made any creative contributions during the workshops or presentation. Only Child 7 verbally stated that he enjoyed the trampoline. He also listened the presentation much longer, compared to other children. He unexpectedly interrupted Designer 3's presentation with the question, "What do you think it means?", that he continued asking repeatedly. However, it was not related to the design but to a word that the designer used while talking. Despite his lack of conceptual thinking, he applauded each designer and was less distracted than other children, who did not listen or show any interest at all. In the last designer's presentation, a non-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.

4.6.2 In Relation to the Teachers and Parents

Since children with autism have a quite sensitive and special condition, as well as their parents, establishing a trustful relationship with the participants of the study was of great importance in the study. The context and the method of the study were very unfamiliar for the participants, which caused a lack of trust in the beginning of the study. The attendees of the informative meeting were not willing to participate and did not show any interest in the study at first. However, Parent 6, who was very talkative and had a dominant character highly respected by the others, showed an exceptional enthusiasm and voluntarily made an effort to persuade the other parents to the importance of the academic studies to contribute to their children's future. After his small talk, all parents completed the questionnaire and gave consent for their children's participation, except a mother of twins. When their children were around, it was difficult to engage them in completing the questionnaires or interviews and they seemed uncomfortable with the idea that they had to be completed immediately. However, they started to relax when they realized that the researcher showed tolerance to these interruptions and gave them as much time as they needed to take care of their children. Compared to the parents, the teachers were more willing to participate, but being the first actors to take care of the children at the school caused them to have more limited time to respond to the questions. Therefore, they preferred to be asked by the researcher. During the workshop sessions, Teacher 3 and Parent 4 and 6, who were always in contact with the designers and tried to inform and support them with their ideas and knowledge as much as possible, were the most active and helpful participants among the parents and teachers.

During the sessions, it was realized that there had been an apparent lack of communication between the teachers and parents in terms of sharing knowledge and information about the children. For instance, Teacher 6 stated that Child 6 hated jumping on the trampoline and that he could not even jump on the floor, which was also observed by Designer 6. Later on, Designer 6 started to investigate the reasons that might lead the child to hate, reject, or be afraid of the trampoline and jumping. In her interview with Parent 5, she learnt that the child

actually loved the trampoline; however, he started to be afraid of it after gaining weight, but still jumped on a smaller house-type mini-trampoline at home. Another important realization about the teachers was that they were not educated or experienced in special education of children with autism. It was stated that most of the teachers at the school had completed a course for a certificate to be a special educator after retirement or a certain period of experience in preschool or primary school. They also relied on their individual experiences. For instance, Teacher 4 stated that she acts upon her experiences with her daughter with Down's Syndrome when educating and taking care of her students with autism. This lack of experience was evident in their relationships with the children. For instance, Teacher 1, who was very stern with her students, insisted that Child 2 was incapable of understanding and learning how to play with the musical toy in the class whereas Child 2 could easily follow the direction given by Designer 2 to play with the toy (Fig. 4.11). Moreover, many of the parents were not fully aware of their own children's condition and were not informed or trained about the disorder and how to take care of their children appropriately. For instance, in the informative meeting, Parent 1 asked the researcher whether the study would heal her daughter at the end, and it was also observed that the parents sometimes sat together and discussed about how autism can be cured without really knowing that there is no medical cure for the 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 the families and the awareness of the lack of knowledge, education, and training.

During the study and especially after the presentation at the school, all adult participants stated their satisfaction with the outcome as well as the school principal and non-participant parents, who stated that they would be able to participate in future studies. Non-participant teachers commented on and contributed to the presented trampoline ideas, sometimes more than the participants did, as well. After ending the presentation, some participants left the room but the discussion continued unintentionally between the designers and few other participants. Teacher 3 and 7 were dominant in that discussion and suggested combining the ideas of Designer 5 and 6, which they thought it was the most practical one to apply at the

school and that the children could benefit the most. After this discussion, the school principal, on behalf of the teachers, stated their need for educational materials that are specifically designed for children with autism. He also emphasized that they have limited technological hardware and that they need low-tech materials at least in the short term.

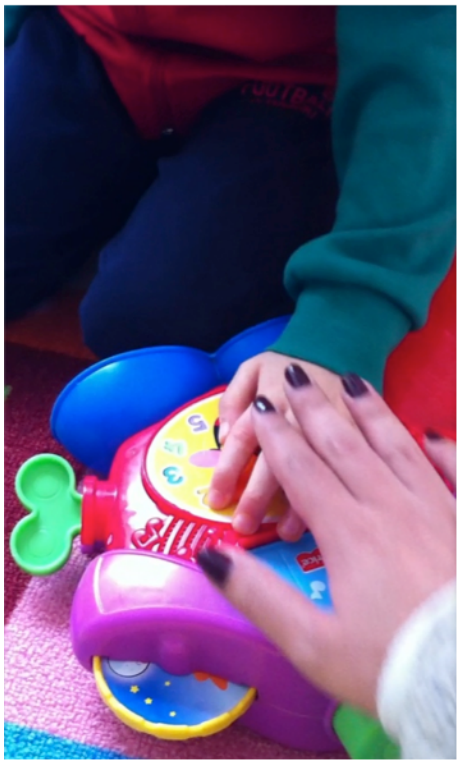

Fig. 4.11 Child 2 learning how to play with a musical toy with Designer 2

4.6.3 In Relation to the Designers

In the beginning of the study, the designers stated their anxiety about meeting the children, since they had not had any experience with children with autism before and that they became confident and comfortable after spending time together. Their experiences with children were expressed as being emotional and touching but also very unique and educative by the designers. They also stated that they felt themselves important for involving actively in a process for the benefit of a special user group and realized that design can increase awareness on issues through practice and that there have been so many things to do to make these children's lives easier through design.

The application of the methods were challenging for the designers in the study. As mentioned before, it was of great importance to establish trustful and close relationships among the participants and it took some time, but yet was partially overcome by the researcher and designers, especially through informal conversations. These conversations enabled them to build a healthy communication with the parents and convince them to the importance of their participation for their children's benefit. In terms of applying the questionnaire, it was realized that it was more effective to ask the questions in person for two reasons. Firstly, it created a ground for having sincere conversations and secondly, the answers sometimes required further questions or explanations. In order to interact and communicate with the children, on the other hand, the designers often took support from the parents and teachers. Even though the children seemed getting used to the presence of the designers, the process required the intervention of the parents and teachers especially at times when the children were frustrated, distracted, or misbehaved. Especially gym teachers were quite helpful throughout the sessions. The designers were also in collaboration among themselves and stated that it was very effective for them to work together and get feedback from each other.

The identification of the main design problem by the researcher and design problems about each child's use of the trampoline by the designers were not predetermined but rather identified through involvement of the participants. The designers' immersion in the children's daily routine, including all activities at the school, enabled them to find out various unidentified and disregarded problems, such as the reasons of children's resistance to jump on the trampoline, their need for the integration of additional activities to the trampoline activity, and even the lack of communication between the teaching staff and families. Therefore, these findings support the main hypothesis of the study, H1, that stands for participatory design being beneficial for understanding the daily life problems of children with autism and proposing design solutions.

As mentioned in H2, it was expected in this study that the participatory process would require flexibility and spontaneous changes because of unexpected behavioral changes and occurrences throughout the design process due to the unstable nature of the disorder. Therefore, despite the structured process that was planned as a framework, the designers were given the opportunity to act freely within this framework and adapt the methods depending on the changes in the mood, behavior, schedule etc. of the children they were assigned to. During the workshop sessions, different conditions and physical abilities of the children affected the designers' progress as expected. However, managing their own process and engaging in collaborative sessions, which were flexible in time management and duration, enabled the designers to work more flexibly. This flexibility helped collecting and processing the data without any interruption in the process. The designers focused on the experiences of the children to understand their interaction with their material surroundings, specifically with the trampoline. Since the design task was about movement and physical activities and the product at issue was appropriate for the use of a wide range of users with or without disabilities, the heterogeneity of the participant children provided the opportunity to see the diverse effects of autism on children's physical activities. It paved the way for different design ideas with a focus on diverse issues depending on the assigned children's personas. As a supportive result for H3, children's interests, skills, and talents also helped designers develop more appropriate design solutions and anything obtained throughout the process were translated into design concepts that aimed to increase the children's engagement and interest in the trampoline activity and decrease their distraction.

4.6.4 In Relation to the Trampoline Design Ideas

The design brief, which was prepared regarding the literature and the responses given by the teachers and parents to the questionnaire, aimed to increase the safety of the jumping activity by using the potential of the trampoline at first. During the workshop sessions, each designer focused on the children they were assigned to, made a deep investigation, and shared their findings with each other. Their observations supported the need for increased safety related to the use of the trampoline as well, although none of the children was injured

during the trampoline activity (Fig. 4.12, 4.13, 4.14, and 4.15). After the workshop sessions had started, it was realized that there were some students, who were afraid of or not interested in using the trampoline and needed motor improvement but could not benefit from the trampoline. However, the process of designing the trampoline was continued, since the focus of the design task was on providing an improved bouncing activity that might enable all children to benefit from the activity rather than only offering another conventional trampoline design. At the end of the study, eight trampoline concepts were generated and presented by the designers, which are also as valuable as the process, since each concept embodies the participants' needs, opinions, and feedbacks.

Fig. 4.12 The trampoline at the school

Fig. 4.13 Unstable legs of the trampoline

Fig. 4.14 The ladder of the trampoline

Fig. 4.15 The entrance of the trampoline

The class teachers stated that all children with autism like the trampoline and it is used as a reward for the children at the school. However, it was realized during the observations that the trampoline was used for therapy/physical education more than it was as a reward and three participant children had no interest in the trampoline activity. These disinterested children were tried to be encouraged to use the trampoline by using their special interests by the gym teachers but they rejected it, whereas others seemed fascinated by the activity. The use of the trampoline was not frustrating or overstimulating but rather observed to be calming for the children that used it.

In terms of interaction and communication, it was realized that none of the children interacted with their peers but four of them interacted with their teachers. Except two children, none of them communicated verbally/non-verbally while using the trampoline and ignored everyone. The gym teachers sometimes gave verbal directions to the children; however, only three of them followed these directions at once whereas two other children followed only when repeated. Four of the children waited for a verbal direction to start or stop

to use the trampoline but did not need any direction to stay on the activity. Three children needed and wanted physical support from the teachers as well. Half of the children seemed to be able to concentrate on the trampoline activity and the children did not seem distracted during the activity, except two children.

Even though the trampoline is suggested to be used by only one person at a time, two or three children, and sometimes accompanied by one of the gym teachers, used the trampoline at the same time. It was rare but still important to be taken into consideration for the designers that the children sometimes performed different activities other than jumping on the trampoline, such as lying, dancing, rolling, bouncing on knees, holding an object, and playing with balls (Fig. 4.16, 4.17, 4.18, and 4.19). It was also an unusual behavior that two children kept going under the trampoline that Child 3 had discovered and imitated by Child 4 (Fig. 4.20). It was asked to the gym teachers whether it was a repeated behavior but learnt that it started to happen only when the observations were done.

Fig. 4.16 Child 1 crawling on the bed of the trampoline

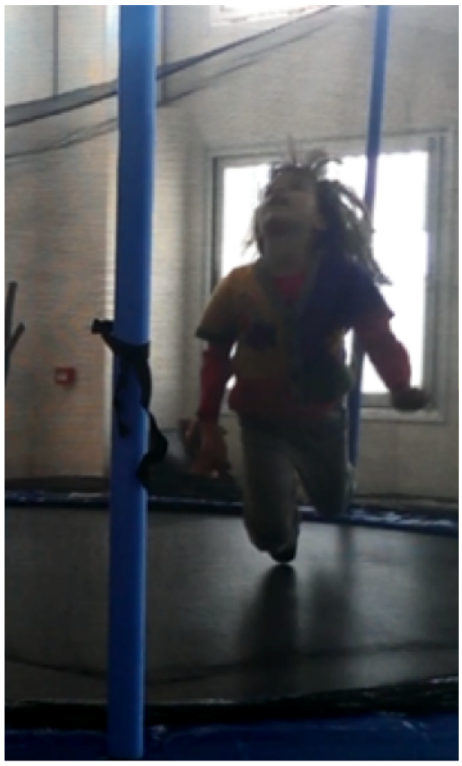

Fig. 4.17 Child 4 jumping on her knees

Fig. 4.18 Child 7 lying for relaxation

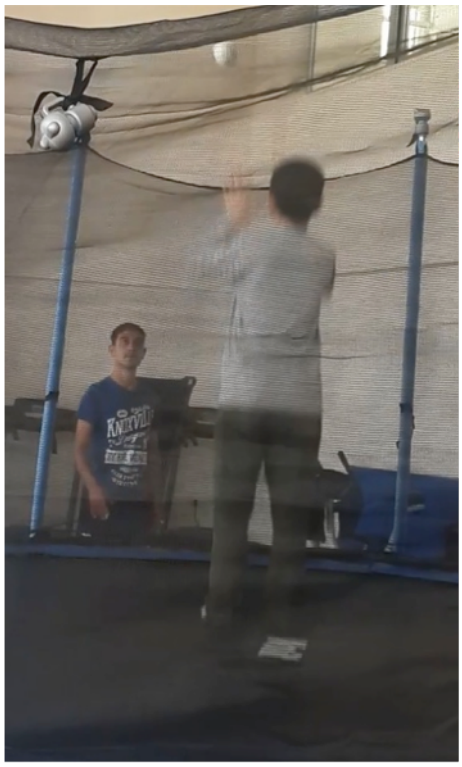

Fig. 4.19 Child 8 and Teacher 6 throwing balls to each other

Fig. 4.20 Child 3 and 4 under the bed of the trampoline and kicking the bed

In the light of the outcomes of the workshop and idea generation, eight trampoline ideas have been developed. Below are the trampoline design ideas of the designers:

TRAMBALON (Trambaloon) by Designer 1

Designer 1 focused on the resistance of Child 1 to jump on the trampoline and tendency to bend on her knees or lie on the bed of the trampoline despite the encouraging attempts of her gym teacher. Starting from this point, TRAMBALON was designed for children with autism, who like to spend time on the trampoline but not jump on it. With the mechanic system of the bubble-shaped base, the aim is to enable the children, who cannot jump on the trampoline, to feel the up-and-down movement that trampolines provide for physical and sensory development and body balance and get used to it (Fig. 4.21).

Fig. 4.21 TRAMBALON (Trambaloon) by Designer 1

LABIRENT (Labyrinth) by Designer 2

Designer 2 worked with Child 2 and focused on his underdeveloped motor skills and need for physical support while jumping on the trampoline, which was used for physiotherapy, as well as reducing the risks caused by two or more people jumping at the same time. In order to provide solutions to these issues, LABIRENT was designed with the aim of enabling more than one child to jump on the trampoline without having any risk of injury and providing activities for physical therapy. The soft green bars enable children to stand alone and follow the way by grasping the bars, which aim to improve fine motor skills as well. It has two entrances in order to avoid bumping into each other. The nets are easy to lift by an adult for direct intervention in case of any emergency. The trampoline meets the standards for the age group of 3-17 (Fig. 4.22).

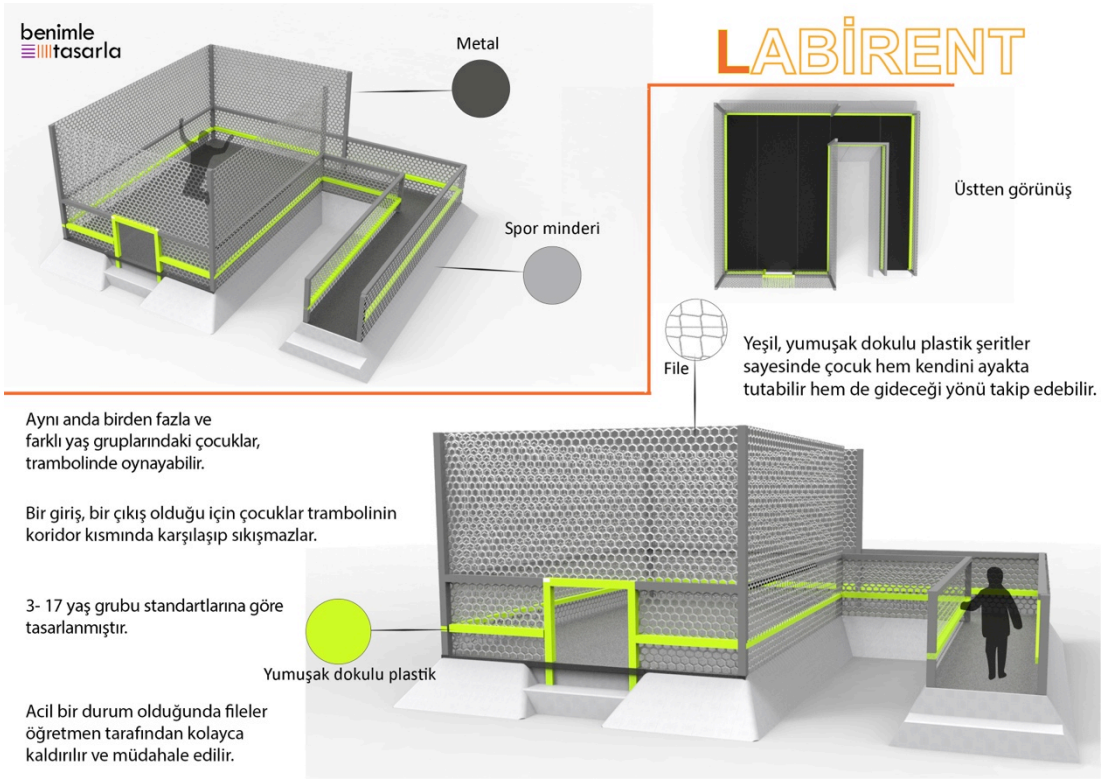

Fig. 4.22 LABIRENT (Labyrinth) by Designer 2

The Trampoline by Designer 3

Designer 3 focused on Child 3, who was one of the children with a great interest in the trampoline activity and enjoyed jumping very high. He had a risky pattern of jumping because he did not stay in the center of the trampoline but rather close to the edges. He often grasped and pulled the nets down while jumping. He sometimes went under the bed of the trampoline to play there. The designer also took the personal interest, such as colors and animals, into consideration. With these in mind, Trampoline was designed for children with autism, who perform risky jumps on the trampoline far from the center. The nets are well-stretched for a feeling of more safety. In order to avoid any object, person or animal to be under the bed of the trampoline, the base is designed accordingly. Colorful graphics are used in the center to catch the jumper's attention in order to ensure that he/she stays in the center during the trampoline activity (Fig. 4.23).

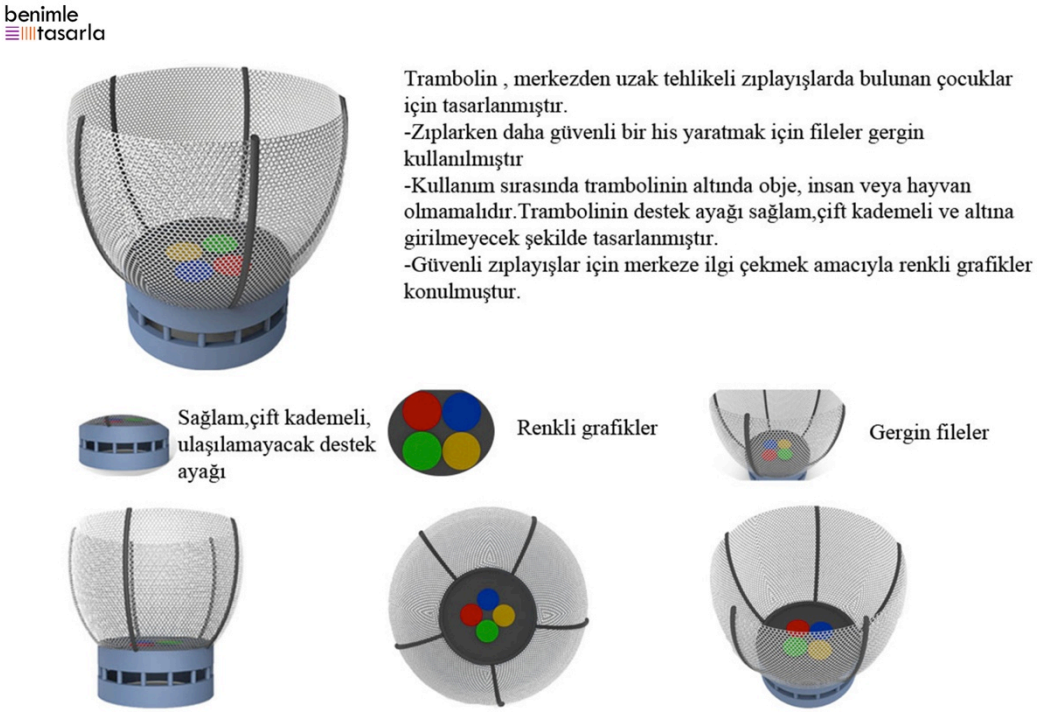

Fig. 4.23 The Trampoline by Designer 3

GÜVENLE ZIPLA (Jump Safe) by Designer 4

Designer 4 observed the hyperactive behaviors of Child 4, both in her gym and out-of-gym activities, and focused on her hyperactive jumping activity on the trampoline as well as the risks caused by the equipment itself. With this in mind, GÜVENLE ZIPLA was designed for children with autism, who jump on the trampoline with high energy, with the aim of increasing the measure of safety to reduce the potential risks. More support legs are added in order to limit the unwanted movement of the equipment. The interlock system of the safety net is redesigned to avoid them from moving from the top of the fixed bars during the trampoline activity. In order to ensure that the safety net is stable and to avoid children to pull the safety net, the bars are curved outside (Fig. 4.24).

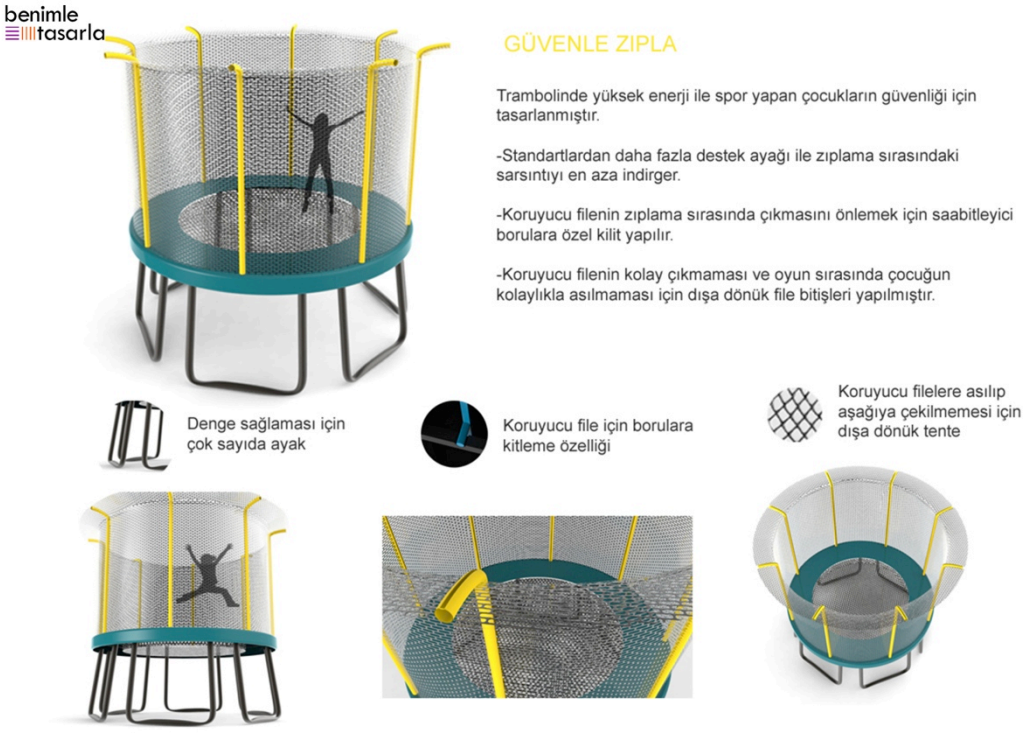

Fig. 4.24 GÜVENLE ZIPLA (Jump Safe) by Designer 4

ZEM1N (Gr0und) by Designer 5

Designer 5 worked with Child 5, who was hyperactive and aggressive and had a high resistance to jump on the trampoline at the school because of his fear of heights, even though he had his own mini-trampoline at home. Regarding the child's fear, ZEM1N was designed as a ground-level trampoline for children with autism, who reject getting on the trampoline because of their fear of heights. The ground is dug to fix it in place (Fig. 4.25).

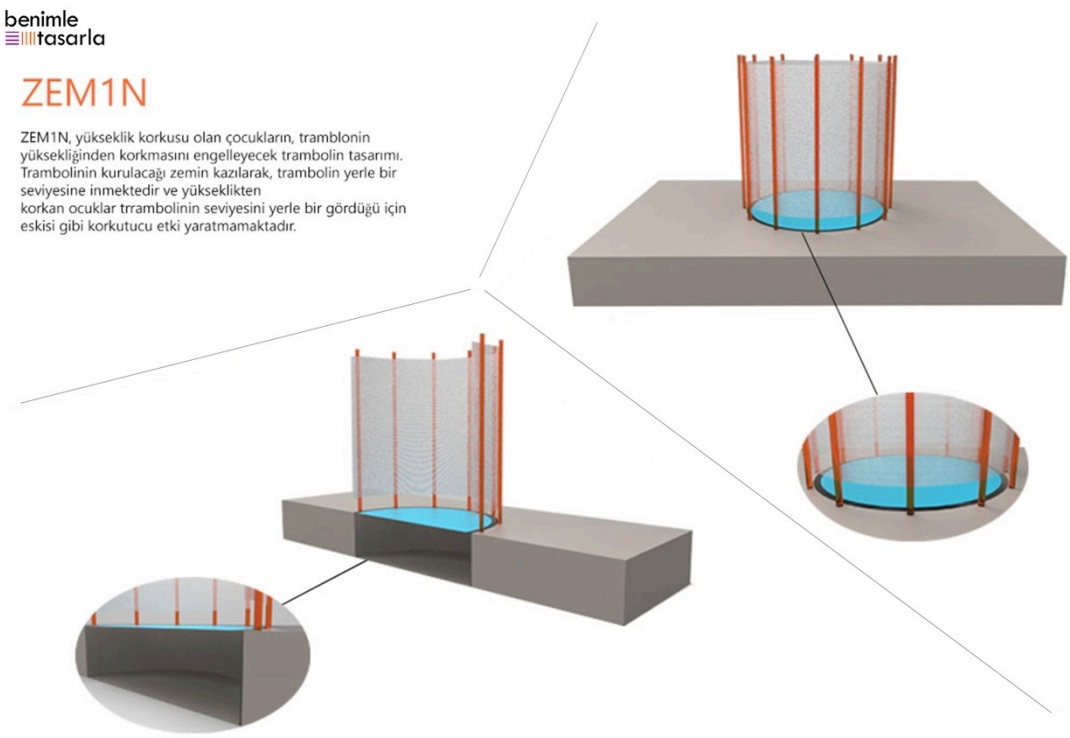

Fig. 4.25 ZEM1N (Gr0und) by Designer 5

IŞILDAYAN KARELER (Illuminating Squares) by Designer 6

Designer 6 focused on the rejection of Child 6 to get and jump on the trampoline that was caused by his weight and fear of heights and his fascination by light as a means of encouragement. Regarding the data and information about Child 6, IŞILDAYAN KARELER was designed for children with autism, who have a fear of heights and are fascinated by light. Each square has a bed with different level of hardness to help children get used to the trampoline activity and the white frames are lit with each jump in order to keep the children interested and concentrated on the activity. Therefore, the children can jump to different heights with the same effort on each and stay on the activity. The nets function as safety nets as well as separators. It is aimed to encourage and enable having interaction with other people through additional activities, such as playing balls over these nets, during the trampoline activity (Fig. 4.26).

Fig. 4.26 IŞILDAYAN KARELER (*Illuminating Squares)* by Designer 6

RAKAMMATİK (Numbermatic) by Designer 7

Designer 7 worked with Child 7, who was verbal and open to interaction, liked numbers, math operations, and the trampoline, and had underdeveloped fine motor skills. Using his interests to increase the concentration on the trampoline activity as well as providing additional physical activities for improving fine motor skills, RAKAMMATİK was designed. It aims to enhance the communication and interaction between the children with autism and their teachers. It also supports the improvement of cognitive and learning skills during the trampoline activity. For instance, the teacher asks basic math operations and the child throws the number out of the net through the holes after he/she finds the answer. The safety nets are specialized for enabling such interactive activities. The activity aims to improve the children's fine motor skills as well by engaging the children in sticking and grasping the numbers. Moreover, the structure of the trampoline is enhanced by wider legs and lower center of height of the base (Fig. 4.27).

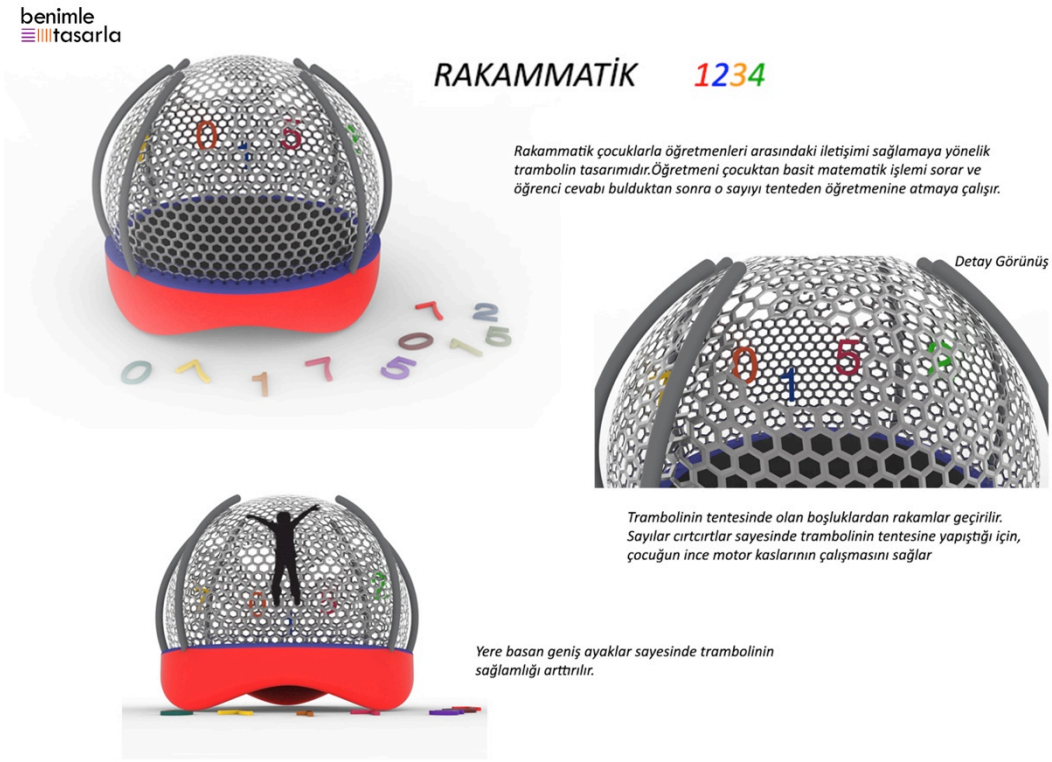

Fig. 4.27 RAKAMMATİK (Numbermatic) by Designer 7

INTERBOLIN (Interpoline) by Designer 8

Designer 8 focused on the interaction and communication skills as well as the interests of Child 8, such as numbers and cartoon characters, in order to use these skills to overcome his resistance to jump on a certain spot on the trampoline and provide activities to energize him and improve his underdeveloped fine motor skills. In addition to the jumping activity, other engaging activities done with the gym teachers were also important in the design process. Starting from this point, INTERBOLIN was designed as an interactive play area for children with autism. The aim is to provide solutions towards making children jump on a certain spot, meeting their need for grasping something, and making the activities they do with their teachers more effective. INTERBOLIN provides both an enjoyable sportive activity and audio-visual stimuli. With the projector on top, various visuals can be projected onto the bed of the trampoline. It keeps the children concentrated and helps them learn colors, numbers, animals, and such. The visuals can be changed depending on the children's interests. It also plays music in order to regulate the children's sleep routines as well as increasing their interaction with the trampoline. The music or sounds can also be in relation

with the visuals to support the children's learning process. The safety nets are also specialized for ball-throwing activity (Fig. 4.28).

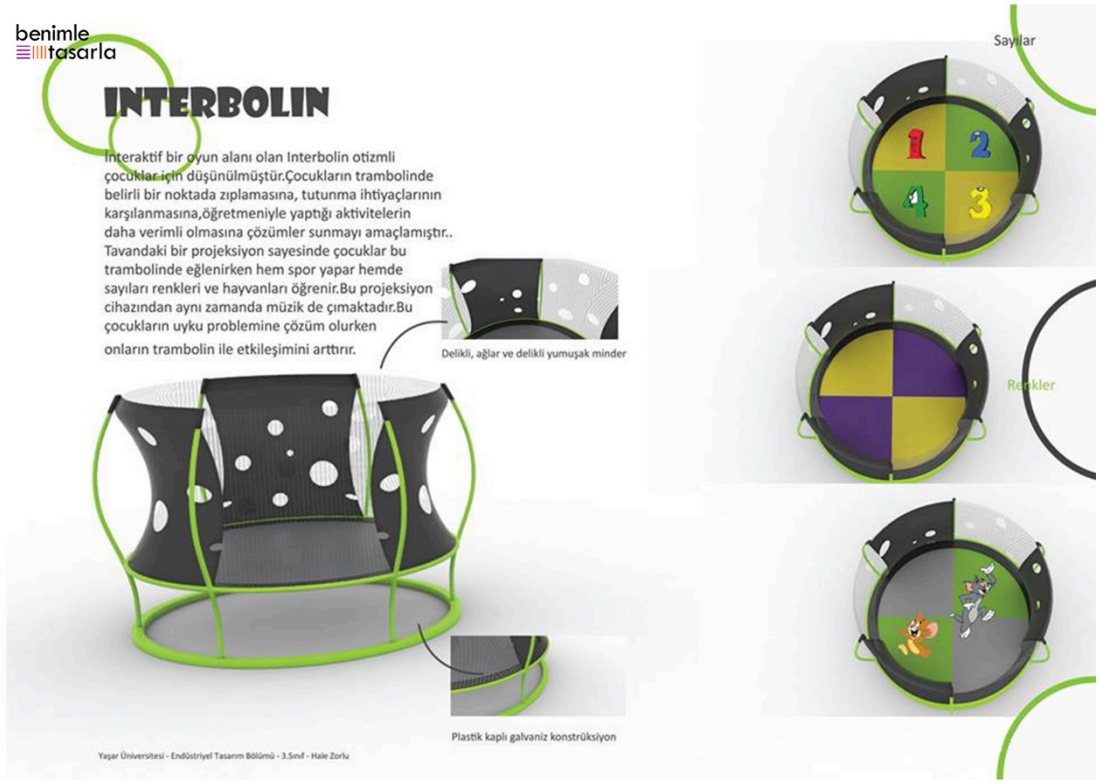

Fig. 4.28 INTERBOLIN (Interpoline) by Designer 8

The design concepts developed by the designers regarding the participant children's characteristics and conditions were the reflection of the workshop process, incorporating the participant children's unidentified and disregarded needs, fears, and preferences in the light of the contribution of their parents and teachers. Regarding the product assessment done by the designers during the presentation of the design concepts, the most precise problem definitions were of IŞILDAYAN KARELER and RAKAMMATİK, which correspond to the scope of the design brief. The problem definitions of IŞILDAYAN KARELER and LABIRENT were the designs that are focused on a specific problem area the most and the design ideas are presented most clearly and straightforward in LABIRENT, ZEM1N, RAKAMAMATIK, and The Trampoline. Moreover, the involvement of the participants was most obvious and reflected on the design in RAKAMMATİK. In terms of the originality of the idea, based on the outcomes of the workshop sessions of the study, TRAMBALON and RAKAMMATİK received the highest rate. According to the designers, the most detailed and well-planned design

solutions belonged to LABIRENT and INTERBOLIN. The solutions that TRAMBALON and INTERBOLIN suggested are the most appropriate solutions to the design problem identified by their designers. INTERBOLIN was found the most logical, useful, and beneficial design solution whereas IŞILDAYAN KARELER was regarded as the most improvable and adaptable design solution for children with autism that have cognitive, behavioral, physical, sensorial, and psychological characteristics specified by their designers. Moreover, the elements of LABIRENT and The Trampoline were rated the highest for their aesthetic quality. Finally, TRAMBALON, RAKAMMATİK, and LABIRENT were found as the most unexpected design ideas that are beyond the conventional trampoline ideas.

Since the trampoline is a product that provides sensory experiences and challenges, the design concepts were also evaluated against the Woodcock and Woolner's (2007) suggested themes for design consideration of a multisensory room for the use of children with autism: (1) accommodating sensory variability, (2) avoiding inappropriate or easily damaged materials and objects, (3) addressing the whole autism spectrum, and (4) providing repetition. Each design suggestion, embedded with the participants' input, aimed to provide at least one sensory experience, e.g. visual, tactile, or audial, to the children, as well as stimulating their vestibular and proprioceptive systems in order to increase their engagement in the activity by decreasing their distraction or providing additional activities, e.g. counting numbers, throwing balls, catching objects etc., and enhancing their interaction and learning skills. In terms of the use of materials and objects, safety issues were also considered in each design suggestion. Especially the designers that were assigned to the highly hyperactive children, who were addicted to the trampoline, paid special attention to this issue. Depending on the concepts, material features were considered by the designers as well. Moreover, the heterogeneity of the participant children in terms of age, severity, and characteristics, provided the opportunity to investigate the subject and the related tasks from various aspects and led to diverse design ideas, which are possible to be used by most of the children on the spectrum and even by typically developing children. Lastly, the trampoline in itself contains a repetitive movement, which does not manipulate or

overstimulate the children with autism but rather provides relaxation and physical improvement.

In this study, it was realized that jumping on the trampoline may not always be an enjoyable activity for all children with autism due to various factors, such as their physical conditions, fears, or disturbances, even though it is fascinating and, at the same time, calming for most of them. The designers revealed these factors that had not been identified before and developed solutions by using participatory methods and turning these factors into input for design in order to enable the children to benefit as much as possible from the trampoline activity. Moreover, it was also important to understand that design has so much to offer to increase the wellbeing of children with autism in the study.

CHAPTER 5

CONCLUSION

This final chapter presents an overview of the thesis and states the limitations of the study before offering recommendations for further studies.

5.1 OVERVIEW OF THE STUDY

The ways of involving children with autism in a product design process is explored in this thesis through a case study within a theoretical framework of participatory design.

Autism, as an inborn and lifelong disorder with impaired interaction and communication skills co-existing with stereotyped behaviors and interests as well as comorbid conditions, limits the affected individuals' daily experiences at all ages. Participatory design, on the other hand, as a democratic, liberating, and empowering research and design approach is beneficial for learning more about these individuals' lives, experiences, and needs as well as increasing their wellbeing and quality of life through their involvement in the process of designing products, services, environments, and the like for their use. It also helps increasing the awareness on the presence of these individuals and their potential and capabilities. Since early intervention is crucial for the development of children with autism, designing appropriate products and environments for intervention are highly important as well.

Participation of children with autism starts with the identification of the problems through exploratory methods. It is also important to decide on the methods to be used in the participatory process, depending on the design problem. With respect to this, questionnaires, interviews, and observations were applied and the design problem was identified accordingly in the case study. After the identification of the problem, the methods were chosen and the rest of the study was structured.

Because of the impairments caused by the disorder, it is difficult for children with autism to fully participate in the design process in the role of designers and contribute to the process through direct knowledge elicitation and generative methods, but rather through observing their behaviors, actions, and expressions (Keay-Bright 2007; Frauenberger, Good, and Alcorn 2012). Therefore, the method of the case study relied heavily on the observations and interviews with the teachers and parents. Observing the physical activities, interaction of the children with autism with the teachers, parents, designers, and peers, and material surroundings was highly effective and contributed to the design process a lot. It was supported with the interviews as well, especially for understanding the underlying reasons of the children's behaviors and actions. Throughout this process, the children with autism were involved as informants, whereas the teachers and parents participated as caregivers, facilitators, informants, and evaluators. They helped the designers during the process and prompted interaction between the children and designer. The designers, on the other hand, were researchers, observers, learners, idea developers, and evaluators at the same time.

Designers' experiences with children with autism are a big part of the learning process. In the case study, the designers had had no experience with children with autism and learned about these individuals during the design process. Even though this lack of experience had caused anxiety in the beginning, reading, watching, and doing research about autism, observing, interacting, and spending time with children with autism encouraged them. Their increased self-confidence helped them be more open to interaction and communication as well as establishing an emotional bond between them and the children. This bond increased

their enthusiasm and prompted them to learn more about autism and the affected children. However, communicating with these children was not an easy task, which required adult intervention as mentioned earlier.

It is also important to note that children with autism have various problems in their daily lives. These problems are not only limited with the problems caused by their impairments, but also covers the problems related to their material surroundings. They use various products and environments, which are not usually specialized for them and cause them struggle while using. Therefore, understanding their needs is of great importance in order to improve and contribute to their material surroundings. In that sense, product design has many opportunities to offer to children with autism both in terms of making their lives easier through design products and empowering and giving voice to them through participatory methods.

The study has an educational value as well, regarding the designers' experiences throughout the study. The designers were 2nd and 3rd grade industrial design students, who had not used such participatory methods or designed for or with children/adults with special conditions in their studio projects. In that sense, this study offered them the opportunity to gain experience in a very specific and unique area in the product design field, which increased their awareness on the potential of design in such cases as well as enabling them to acquire new design skills. Therefore, this study has the potential to be developed further as a studio model in industrial design education.

5.2 LIMITATIONS OF THE STUDY

The participatory process involved children with autism with different severity levels and physical, psychological, and intellectual conditions, even though the study had been planned to conduct a participatory process with high-functioning autism (HFA) or Asperger Syndrome (AS) for the reason that these individuals have greater ability to socialize, communicate, and collaborate compared to individuals with more severe autism. However, it was found out that

this specific group covers only the 30% of people with autism and it was quite difficult to have access to children with autism for the study because of the lack of organizations and associations that gather them together in Turkey. Moreover, the majority of autism associations are not very active and the majority of the children at public and private special education centers are mostly with severe to moderate autism. Therefore, due to the lack of resources, accessible participants, autism associations, and special education centers, the study was conducted with only a small group of participants. However, with more participants, it would have been possible to make comparisons between different groups of participants and different design tasks for more generalizable findings.

It was also difficult to find resources in the product design literature as a guidance to conduct participatory design studies with children with autism. Therefore, the study needed to have an interdisciplinary nature, borrowing from other design disciplines related to the topic. In terms of the participatory methods that were used in the study, they 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.

The design process in the study was limited with generating design concepts and did not involve the prototyping phase of the trampoline, due to time constraints and the lack of funding. Therefore, the design ideas stayed at the stage they had been presented in the presentation at the school, even though it would be better if the design ideas could have been combined and refined regarding the participants' suggestions and tested or at least discussed with mock-ups or prototypes. Another reason for not being able to run the prototyping phase was the large scale of the trampoline that cannot be tested with the

participants by using low-tech prototypes. It might have been possible to make prototypes with the participants and test them during the process, if the design task had been different.

Despite the above-mentioned limitations, the application of the participatory methods was successful and the findings of the study were fruitful, pointing out a new direction in the field of product design.

5.3 FURTHER STUDIES

This study is an example of a participatory design process with children with autism in the field of product design applying various methods to involve the children and the teachers and parents of these children as well as a group of designers to work in collaboration. In order to contribute to this specific field of study, there is a need for an increase in the number of participatory product design projects with children with autism. In further studies, more participants with diverse conditions and severity levels can be involved, as well as experts from different disciplines, such as psychologists and physiotherapists, to ask for opinions and get feedback during the process for evaluation in order to develop more appropriate design solutions. Moreover, the workshop sessions can be extended in time and the methods can be applied to different contexts, including different groups of participants, settings as well as products, in order to make comparisons in between and develop techniques for working on design projects with children with autism.

Regarding the case study conducted within this thesis, the methods and the structure of the workshop sessions can be enriched as the next step of the study with the generative activities that enable the teachers and parents to make more creative contributions during the sessions. The workshop can also be improved by taken the time constraints of the teachers and parents into consideration, since they cannot fully engage in the sessions because of their responsibility to take care of the children constantly. Moreover, the design ideas developed by the designers could not be refined after the presentation in the light of the participants' feedbacks and suggestions due to the time limitations, as mentioned earlier.

Therefore, the trampoline designs can be refined and finalized with prospective collaborative sessions.

Although there are various other considerations that have been left out of the scope of this thesis, it is still evident that the participation of children with autism and their teachers and parents is of great value for product design. Considering the fruitful findings of the study, 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 in the field of product design.

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APPENDIX A1: QUESTIONNAIRE FOR PARENTS

Date: ___/___/_____

This questionnaire aims to identify the problems that children with autism face with in their daily lives to be used in the thesis focused on working with children with Autism Spectrum Disorder in the product design process advised by Assoc. Prof. Dr. Deniz Hasırcı within the Graduate Program of Design Studies at İzmir University of Economics. The data will be used in a design project conducted with the participation of children with autism with the aim of developing design solutions to the identified daily life problems. The questionnaire is the first stage of the study consists of 3 main stages.

Thank you for your participation.

RA. Sevi Merter, sevi.merter@gmail.com, 0 232 4115634 / 0 506 3710241
Assoc. Prof. Dr. Deniz Hasırcı, deniz.hasirci@ieu.edu.tr, 0 232 4117106

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1. STAGE

1. First name / Last name: _____
2. First name / Last name of your child: _____
3. Contact (phone/e-mail): _____
4. What is your child diagnosed with?

- ☐ Autism
- ☐ Asperger Syndrome
- ☐ Rett Syndrome
- ☐ Atypical Autism (Pervasive Developmental Disorder Not Otherwise Specified)
- ☐ Childhood Disintegrative Disorder
- ☐ Other (please indicate) _____

5. Who/Which institution has put the diagnosis of your child?

6. How was the diagnosis put to your child? (methods, tests etc.)

7. What are the most significant problems your child faces with in daily life? (home, school, outdoor etc.)

8. What are the materials or objects that your child uses the most in daily life?

9. Do you observe any problems your child has while using these materials or objects? If yes, what are these problems?

10. Does your child has any object, toy etc. that he/she carries all the time? If there is any, what are these objects?

11. Do you personalize the objects, toys etc. that your child uses at home, school or outside? If yes, how do you personalize them?

12. Does you child has any personal fields of interests and/or talents? If yes, what are these fields of interests and/or talents?

13. Please indicate if you have anything to add related to the subject of the study.

14. Would you give consent for the participation of your child to this design project and its 3 stages (questionnaire, workshop, presentation of the workshop outcomes) as well as the use of the project outcomes with visuals in the outcomes of this study?

- [ ] Yes
- [ ] No

Signature _____

APPENDIX A2: QUESTIONNAIRE FOR TEACHERS

Date: ___/___/_____

This questionnaire aims to identify the problems that children with autism face with in their daily lives to be used in the thesis focused on working with children with Autism Spectrum Disorder in the product design process advised by Assoc. Prof. Dr. Deniz Hasırcı within the Graduate Program of Design Studies at İzmir University of Economics. The data will be used in a design project conducted with the participation of children with autism with the aim of developing design solutions to the identified daily life problems. The questionnaire is the first stage of the study consists of 3 main stages.

Thank you for your participation.

RA. Sevi Merter, sevi.merter@gmail.com, 0 232 4115634 / 0 506 3710241
Assoc. Prof. Dr. Deniz Hasırcı, deniz.hasirci@ieu.edu.tr, 0 232 4117106

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1. STAGE

1. First name / Last name: _____
2. First name / Last name of your student: _____
3. Contact (phone/e-mail): _____
4. What is your student diagnosed with?

- ☐ Autism
- ☐ Asperger Syndrome
- ☐ Rett Syndrome
- ☐ Atypical Autism (Pervasive Developmental Disorder Not Otherwise Specified)
- ☐ Childhood Disintegrative Disorder
- ☐ Other (please indicate) _____

5. Who/Which institution has put the diagnosis of your student?

6. How was the diagnosis put to your student? (methods, tests etc.)

7. What are the most significant problems your student faces with at the school?

8. What are the materials or objects that your student uses the most at the school?

9. Do you observe any problems your student has while using these materials or objects? If yes, what are these problems?

10. Does your student has any object, toy etc. that he/she carries all the time? If there is any, what are these objects?

11. Do you personalize the objects, toys etc. that your student uses at home, school or outside? If yes, how do you personalize them?

12. Does you student has any personal fields of interests and/or talents? If yes, what are these fields of interests and/or talents?

13. Please indicate if you have anything to add related to the subject of the study.

14. Would you give consent for the participation of your student to this design project and its 3 stages (questionnaire, workshop, presentation of the workshop outcomes) as well as the use of the project outcomes with visuals in the outcomes of this study?

☐ Yes

☐ No

Signature _____

APPENDIX B: DESIGN BRIEF

Reconsidering the Trampoline

Exploring Alternative Design Solutions for an Improved Bouncing Activity

Children with autism like jumping on a trampoline. The repetitive up and down movement of trampoline calms them down while providing a whole body workout. Besides being an enjoyable activity with a repetitive movement that interests children with autism, trampoline has many benefits, such as:

- enhancing gross motor skills
- building self-esteem through engaging in an activity independently
- improving vestibular (balance) and proprioceptive (body awareness) systems
- relaxing and regulating the body systems
- increasing spatial awareness
- increasing cognitive development (learning skills, memory, etc.)
- helping children sense and maintain balance
- practicing the whole body and making children feel their joints and muscles
- improving coordination skills, etc.

This project will be carried out in collaboration with Guzelbahce Special Education, Application, and Vocational Training Center. You are asked to reconsider how trampolines should be and what other purposes it can serve for. Instead of the conventional designs of trampolines, this project seeks alternative design solutions for an improved bouncing activity that is both beneficial and enjoyable for children with autism. Throughout the process of the project, the focus will be on developing diverse design solutions and exploring the potential uses of trampoline in order to:

- help children improve their fine and gross motor skills
- help children improve their vestibular and proprioceptive systems
- contribute to children's physical and cognitive development
- provide safer physical experiences
- provide children additional sensory input
- provide additional support for children with autism, who are physically disabled
- improve the trampoline activity with alternative ways of usage, etc.

APPENDIX C: OBSERVATION FORM: This form is to be used by the designers.

OBSERVATION FORM

OBSERVATION INFO	
Name of the Subject	
Name of the Observer	
Name of the Gym Teacher	
Class Days and Hours	

INSTRUCTIONS	
1	Observe the activities.
2	Take photographs and videos during the activities.
3	Put a mark in the boxes every time the subject exhibits the behavior or the condition is seen.
4	Note down your comments. (reasons of behavior, explanations, your thoughts, inspirations, etc.)

SPORT ACTIVITIES					
		DAY 1	**DAY 2**	**DAY 3**	**COMMENTS**
Duration of the Observation					
CLASS STRUCTURE					
1	The class is structured and includes planned activities in certain periods of time.				
2	The lesson requires additional support of parents.				
3	The lessons are tailored to each child specifically.				
4	The lesson seems suitable for the child's special needs, conditions and/or interests.				
ENGAGEMENT AND INTEREST					
5	The child is highly interested in all sport activities.				
6	The child is encouraged to engage in sport activities by using his/her specific personal interests.				
7	The child is encouraged to engage in sport activities by using verbal directions.				
8	The child accepts engaging in sport activities easily.				
9	The child seems enjoying the lesson.				
10	The child seems fascinated during the lesson in general.				
11	The child appears nervous during the lesson in general.				
12	The child appears frustrated during the lesson in general.				
13	The child changes mood during the lesson.				
14	The child seems calmed down after the lesson.				
15	The child seems overstimulated after the lesson.				
INTERACTION AND COMMUNICATION					
16	The child interacts with his/her teacher during the sport activities.				
17	The child interacts with peers during the sport activities.				
18	The child communicates verbally during the sport activities.				
19	The child communicates non-verbally during the sport activities.				
20	The child does not communicate verbally and/or non-verbally during the sport activities.				

21	The child follows directions given by his/her teacher.				
22	The child follows directions only when repeated.				
SUPPORT AND INTERVENTION					
23	The child seeks physical support from the teacher during all sport activities.				
24	The child needs to be reminded how to complete the tasks at the beginning.				
25	The child needs to be verbally directed to start and complete the tasks during all sport activities.				
CONCENTRATION					
26	The child is able to concentrate on sport activities.				
27	The child is distracted during the sport activities. (If so, please indicate the cause)				
PHYSICAL DEVELOPMENT					
28	The child uses fine motor skills (hands, fingers, toes, wrists, etc.) during the sport activities.				
29	The child uses gross motor skills (arms, legs, feet, etc.) during the sport activities.				
30	The child has control over his/her body during the sport activities.				

THE TRAMPOLINE ACTIVITY					
		DAY 1	**DAY 2**	**DAY 3**	**COMMENTS**
Duration of the Observation					
REASONS OF USING THE TRAMPOLINE					
1	The child gets on the trampoline as a reward.				
2	The child uses the trampoline as a therapy/physical education.				
ENGAGEMENT AND INTEREST					
3	The child is highly interested in using the trampoline.				
4	The child is encouraged to engage in using the trampoline by using his/her specific personal interests.				
5	The child is encouraged to engage in using the trampoline by using verbal directions.				
6	The child accepts engaging in using the trampoline easily.				
7	The senses of the child are stimulated. (If so, please indicate which senses are stimulated.)				
8	The child seems enjoying the trampoline.				
9	The child seems fascinated by the trampoline.				
10	The child appears nervous during the use of trampoline.				
11	The child appears frustrated during the use of trampoline.				

12	The child changes mood while using the trampoline.				
13	The child seems calmed down after using the trampoline.				
14	The child seems overstimulated after using the trampoline.				
INTERACTION AND COMMUNICATION					
15	The child interacts with his/her teacher while using the trampoline.				
16	The child interacts with peers while using the trampoline.				
17	The child communicates verbally while using the trampoline.				
18	The child communicates non-verbally while using the trampoline.				
19	The child does not communicate verbally and/or non-verbally while using the trampoline.				
20	The child follows directions given by his/her teacher.				
21	The child follows directions only when repeated.				
SUPPORT AND INTERVENTION					
22	The child seeks physical support from the teacher while using the trampoline.				
23	The child needs to be reminded how to use the trampoline at the beginning.				

24	The child needs to be verbally directed to start to use the trampoline.				
25	The child needs to be verbally directed to stay on the activity while using the trampoline.				
26	The child needs to be verbally directed to stop to use the trampoline.				
CONCENTRATION					
27	The child is able to concentrate on the use of trampoline.				
28	The child is distracted during the trampoline. (If so, please indicate the cause)				
ACTIVITIES ON THE TRAMPOLINE					
29	The child uses the trampoline alone.				
30	The child uses the trampoline with peers.				
31	The child jumps on the trampoline.				
32	The child dances on the trampoline.				
33	The child plays with balls on the trampoline.				
34	The child lies on the trampoline.				
35	The child holds an object while using the trampoline.				

36	The child shows unexpected behaviors/use of the trampoline.				
PHYSICAL DEVELOPMENT					
37	The child uses fine motor skills (hands, fingers, toes, wrists, etc.) while using the trampoline.				
38	The child uses gross motor skills (arms, legs, feet, etc.) while using the trampoline.				
39	The child has control over his/her body while using the trampoline.				
SAFETY ISSUES					
41	The child faces with risks during the use of the trampoline.				
41	The child is injured while using the trampoline.				
42	The child is provided with an adequate measure of safety on the trampoline.				
43	What are the risks that are caused by the way the child uses the trampoline?	• • • •			
44	What are the safety problems of the trampoline? (Please draw a quick sketch and indicate the problems)				

PERSONAL INSIGHTS		
* Please try to reflect on your observations and generate ideas on the questions below. You may want to add different questions you find important as well.		
1	What are your overall insights about your observations?	
2	What are the strengths and weaknesses of the child?	
3	What could be the additional activities for a whole body workout?	
4	What could be the additional sensorial properties for the trampoline?	
5	What could be the additional and/or alternative uses of the trampoline?	
6	How could the risks of the trampoline be eliminated?	
7	How could the trampoline be used more safely?	
8	What are the most notable things that are/could be related with the sport activities and the physical development of the child you observe in other places?	

APPENDIX D: PRODUCT ASSESSMENT SHEET: This form is to be used by the designers.

PRODUCT ASSESSMENT SHEET

Name of the Designer Being Evaluated	
Name of the Participant Child	
Name of the Design Product	

INSTRUCTIONS	
1	Review the items in the assessment sheet before examining the design product.
2	Listen to the designer's presentation carefully.
3	Evaluate the design product according to the criteria in the items.
4	Put a mark in the boxes for rating from 1 to 5. * 1 = poor 2 = below average 3 = average 4 = above average 5 = excellent
5	Write down your comments, if you have any.

PRODUCT ASSESSMENT						
		1	**2**	**3**	**4**	**5**
1	**CLARITY OF THE DESIGN PROBLEM** The problem definition is precise and corresponds to the scope of the design brief.					
2	**FOCUS OF THE DESIGN PROBLEM** The definition of the design problem is focused on a specific problem area rather than a relatively broader area.					
3	**CLARITY OF THE DESIGN IDEA** The design ideas are presented clearly and straightforward.					
4	**PARTICIPANTS' INVOLVEMENT** Participants' involvement in the process is apparent and reflected on the design solution.					
5	**ORIGINALITY OF THE DESIGN IDEA** The designer is not reproducing the existing ideas but rather generating new ideas and experiences for children with autism based on the gathered information and knowledge during the process.					
6	**ELABORATION** The design solution is detailed and well planned by the designer.					
7	**APPROPRIATENESS TO THE DESIGN PROBLEM** The design solution responds to the problem identified by the designer.					
8	**UTILITY** The design solution is logical, useful and beneficial for the children with autism that have cognitive, behavioral, physical, sensorial, and psychological characteristics specified by the designer.					
9	**ADAPTABILITY** The design solution is improvable for and adaptable to the children with autism that have different cognitive, behavioral, physical, sensorial, and psychological characteristics specified by the designer.					
10	**AESTHETIC QUALITY** The elements of the design product are used and combined aesthetically.					
11	**CREATIVITY** The design idea is beyond the expected and conventional product ideas.					

Please note down your comments, if you any:

APPENDIX E: SELF-ASSESSMENT SHEET: This form is to be used by the designers.

SELF-ASSESSMENT SHEET

Name of the Designer	
Name of the Participant Child	
Name of the Design Product	

IDENTIFICATION OF THE DESIGN PROBLEM	
Problem Definition Please identify the design problem based on the information you gathered	
Motivation Please describe the reasons that motivated you to select this particular problem	

EVALUATION OF THE DESIGN PROCESS

* Put a mark in the boxes for rating from 1 to 5.
1 = poor 2 = below average 3 = average 4 = above average 5 = excellent

		1	2	3	4	5
1	What is the level of involvement of the participants in your design process?					
	Children with autism					
	Parents					
	Class Teachers					
	Gym Teachers					
	Other (please indicate) _____					
2	Which one, do you think, contributed to your design solution the most?					
	Observing the child during his/her sport activities					
	Observing the child during his/her class activities					
	Observing the child during his/her daily activities					
	Interacting with the child					
	Communicating with the child					
	Observing the child's interaction with his/her teachers					
	Observing the child's interaction with his/her parents					
	Observing the child's interaction with his/her peers					
	Observing the child's interaction with his/her surrounding					
	Communicating with the child's parents					
	Communicating with the child's teachers					
	Discussing with the other designers					
	Other (please indicate) _____					
3	What was the level of interaction between you and the child?					
4	What was the level of verbal communication between you and the child?					
5	What was the level of non-verbal communication between you and the child?					

* Please answer the questions below clearly.	
6	What could be done (differently and/or additionally) in order to involve the participants more in your design process?
7	After the completion of this study, how do you feel about working with children with autism in a design process?
8	What is your overall evaluation of this study?
9	Would you consider taking part in a further study with children with autism?

☐ Yes ☐ No