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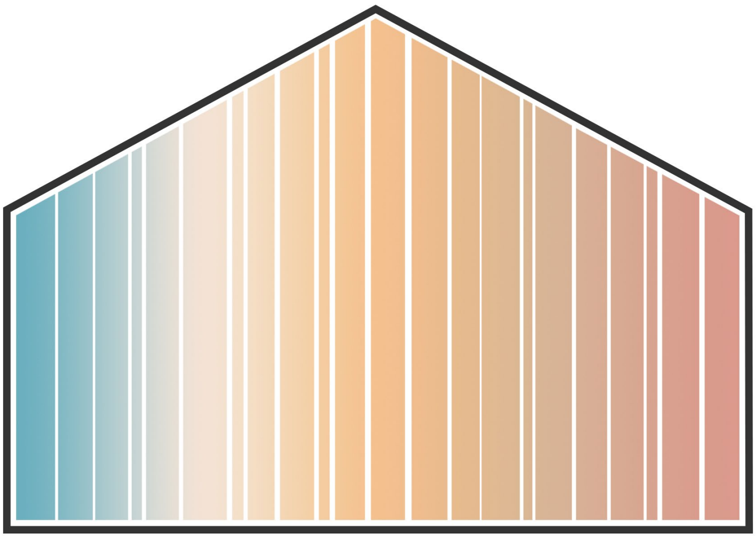
DAY CENTRE FOR PRESCHOOL AGE CHILDREN WITH AUTISM

PLANNING AND DESIGN STRATEGY FOR AUTISM FRIENDLY INTERVENTIONS



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INTRODUCTION

Keywords

Architecture; Autism Spectrum Disorder; Accessibility; Therapeutic spaces.

General premise

Autism Spectrum Disorders (ASD), commonly known as Autism, introduced by the latest Diagnostic and Statistical Manual of Mental Disorders (DSM-V), refer to a group of complex neurodevelopmental conditions. Individuals with autism are characterized by difficulties in social interaction and communication, and by the presence of restricted and repetitive patterns of behaviour, interests, and activities (APA, 2013). The term *spectrum* stands for the broad range of ways autism can manifest itself because the symptoms and their severity vary widely across the two deficit areas. Furthermore, a large number of comorbidities accompanying autism make the experience of everyone on this spectrum unique. For instance, people with autism may range from 'gifted' to severely challenged, talkative to completely non-verbal, and from independent to needing constant personal support.

At the moment, to the best of my knowledge, there are no studies that report an overview of the international situation of the autistic community. However, numerous survey attempts – mainly at the local level – provide a preliminary estimation on the prevalence of autism., The periodic biennial study conducted by The Center for Disease Control and Prevention in 11 States of the US in 2014 reported a prevalence of 1 in 59 children (Baio et al, 2018). On the other hand, the National Survey of Children's Health in the US, through a state-representative survey in 2016, estimated that 1 in 40 children fell on the autism spectrum (Kogan et al, 2018). While these studies report a seemingly increasing trend regarding autism' cases, they are not airtight due to a series of limitations in methods application and case definition (Fombonne, 2018).

The first signs of autism can be detected starting from the 18th month of life, but usually, a complete diagnosis is available only between the second and the third year of life. Autism is a lifelong condition, i.e., it will accompany a person for the rest of his/her life. It is not a disease, thus there is no cure, however, people with autism can benefit from a series of interventions. A wide array of therapeutic interventions and support actions can have profound impact on the quality of life of individuals on the autism spectrum.

Problem area

From the discovery of possible autistic traits, a difficult and endless journey for the entire family begins. The diagnosis of autism represents a crucial moment for the child, but even more so for their parents. It is a process that draws back pre and post-trauma experiences. It is an onerous situation since the early stages, as the diagnoses of autism are usually reported to be protracted due to waiting lists and 'ping-pong' – standing for the referrals among the different specialists. Confusion, pressure, disorientation, anxiety, and sometimes, hope escort this period. Then, if the assessment is positive, shock takes over. Some of the families do not want to accept the situation and struggle to contemplate the immensity of the task that lies ahead of them. It is a hard time for the parents and the siblings of the affected individual. Parents try their best to help their children, but the former usually know almost nothing about autism and the next steps they need to take.

Although autism is not reversible, children with autism can grow and flourish with adequate support and training. They face a series of limitations in their daily life –in different degrees- but at the same time, they also demonstrate resilience and great potential for growth. Therefore, they can aspire to live with dignity and in healthy conditions and have the opportunity to build their life project. As autism is considered a way of being, therapeutic interventions and support are meant to help individuals on the spectrum to better cope in our world, which as a matter of fact is attuned for 'neurotypicals'[1]. Children with autism need to try to adapt to a challenging environment for them. For that to work, perennial effort is necessary, starting from learning everyday skills to make

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[1] A style of neurocognitive functioning that falls within the dominant societal standards of "normal" (Walker).

life easier for them and their families. This process requires the combined effort of everyone around the individual with autism. To address their developmental challenges, a series of treatments, including behavioural, linguistic, physical, and occupational therapies, can help ameliorate the symptoms. Nonetheless, for these therapies to work, it is important that all the caregivers work together. That means that parents, teachers, therapists, and siblings need to be trained and prepared emotionally and mentally, so they can provide all the necessary support during the day to the child with autism. The early years are fundamental in this process, because during that time, the child's brain develops exponentially. Therefore, an early diagnosis of autism and access to adequate therapeutic interventions imply better chances for an easier life for both children with autism and their loved ones.

The early years, mainly those of preschool age, are very important for all children. The education in these years is not mandatory, however, the experience during this period should support their healthy development. It needs to be filled with indoors and outdoors activities that help to learn and stimulate creativity through play, exploration, and interaction with peers. These activities can be provided by various institutions such as nursery schools or childcare centres. Unfortunately, sometimes, a child with autism may not be able to attend mainstream childcare institutions as his/her neurotypical peers. In the worst case, those with more severe symptoms are less able to stay with other children and may find the environment very uncomfortable and challenging. They may need specific care and tailored interventions. On the other side, children with less severe symptoms could be integrated in the mainstream activities with some rehabilitative therapies.

The wide range of therapeutic interventions that address the autistic issues are actually offered in a variety of settings, e.g., hospitals, schools, day centres, etc., in different forms and through different professional figures. Nonetheless, precise care policies that indicate what needs to be done and how seem wanting. Given the chronic nature of autism, the response is asymmetrical for care services organised around singular events and not as part of a coherent and cohesive scheme. Coordination and cooperation among institutions and professionals, the essential traits of care effort's success, are deficient.

In addition to a lacking strategy by these childcare options for children with autism, the positive outcome of therapeutic activities might be even more inhibited by the environment where these activities take place. The said therapeutic interventions purport to ameliorate the symptoms and to teach useful life skills to individuals grappling with autism to help them adapt to the surrounding physical and social environment. Nevertheless, this is just one side of the coin. The environment can be as important as the quality of treatments, if the former can accommodate the particular needs of children with autism. The proper therapeutic environment – other than making a person with autism feel on his/her ease – can enhance the efficiency of the intervention.

Research question

As autism prevalence rate in new-borns is shooting over 2% and care networks are consistently missing to provide the right support to children with autism and their families, this study aims to explore potential promising avenues that can help individuals affected by autism to overcome their everyday challenges. The favourite setting for therapeutic interventions for preschool age children with autism can be the Day Centres. Referring to the Italian Ministry of Health, Day Centres should be polyvalent structures that offer support, rehabilitation, aggregation, and socialisation to a group of users. This image and, to the best of my knowledge, the lack of systematic research on the topic prompted the question that this study purports to answer, "How should a Day Centre for children with autism be like?" In particular, this research focuses on the features of Day Centres with respect to the accessibility for the children with autism and the relevant design. The first objective is to understand the role that this setting can have in providing support to the affected families over the covered territory. At the same time, it also aims to examine how to create welcoming and health promoting environments for children with autism.

Research outcome

The outcome of this research is the delineation of a strategy for the realisation of Autism Friendly Day Centres for preschool aged children. The approach for the description of these facilities is developed in two levels that lead to a better comprehension of possible interventions for autism. As a result, the proposed strategy engenders two research products: the first concerning the programming phase and the second regarding the designing phase. With respect to the first level, this paper describes the planning and the management strategy of care interventions programmed for children with autism. This tool identifies a series of highly important topics related to the well-being of children on the spectrum and relevant for the design process of these interventions. The next level refers to the strategy to follow in order to design autism-friendly environments that respond to the needs of people with autism, which in turn could serve as a positive amplifier for therapeutic interventions.

Structure of the research

In order to reach the established objectives, this research is developed in three stages:

1| Background study

The first part of the research presents the background of the problem area. In order to provide a more complete overview of the topic, it examines the current level of knowledge on different related issues. In other words, during the first stage, this research reviews the multidisciplinary scientific literature concerning autism. The most significant findings from different studies are evaluated together and integrated to create a solid footing for the next stage. Briefly, the explored aspects in this section are: the features of autism spectrum disorder according to the latest researches; the network of care and services for people diagnosed with autism in different contexts; the core problems and needs of individuals on the spectrum; and the impact of architecture on their wellbeing and the existing designs for autism experiences.

2| Investigation

The second phase involves a field analysis, i.e., the on-site examination of the problem area. The focus is on environments where therapeutic and support interventions are provided for preschool aged children with autism. This study examines four different countries set in different contexts regarding autism: Albania (my birthplace), Italy (the country where I have conducted my university studies and the doctoral programme), the United Kingdom and the United States (countries where autism research is particularly developed). In these four countries, I have engaged in on-site visits to four case studies and analysis to understand how the same problem is affronted in different contexts. In addition to assessing independently the quality of the relevant surroundings, I have complemented my analysis with the feedbacks of one or two staff members who accompanied me during the visits. Furthermore, to better understand the reality that families having children with autism face every day, I have conducted interviews with four parents. These parents are well-known in their countries as public figures, who have also contributed in raising autism awareness. Last, this study also uses in-depth interviews with selected autism experts – one for each country – to elaborate and solve the critical issues and doubts emerged during the research.

3| Proposal elaboration

The last phase sets forth my proposal. It involves the processing of data that were gathered in the previous steps and the drafting of programming and designing strategies of Day Centres for children with autism. The method used is the description of the structure of the Day Centres in a narrative way following the overall research approach, which is based on the qualitative interpretation of facts, evidence, experiences, and hypotheses. The reason for this choice stems from the complex, spectral, and, sometimes, even conflictual nature of autism. Thus, the products of this research use the concept of the spectrum and balance to describe the wide range of possible configurations that a Day Centre may assume in different contexts. It attempts to identify the variables, and their spectral range, which are significant factors of the wellbeing of those on the spectrum and of the project equation. At the same time, it promotes the finding of an equilibrium between the various choices, so to balance the adaption of children with autism to the environment with the adaption of the environment to their specific needs.

Significance of the study

This research aims to offer useful tools for the comprehension of, and guide the interventions into the, therapeutic contexts for children with autism. The thesis products intend to fuel a critical interpretation of the programming and designing facilities capable of providing adequate support to children on the spectrum and their families. Its main addressees should be architects who handle the design tasks of the Day Centres. The key findings show them what they need to know for the briefing phase – issues relevant to autism that impact the design process and in what degree – and the general approach to design autism-friendly environments according to the needs of those with autism. In addition to designers, the output of this study is addressed to public officers, institutions and foundations, public or private organisations, which are active in field of autism. They can be useful aids for the preparation of assistance policies and measures for people with autism and intervention plans through the correct identification of the areas where to locate the interventions and configurational features, definition of management methods, and designation bids and the consequent evaluation of the presented projects.

PART I

AUTISM BACKGROUND

The first part of the research presents the background of the problem area. In order to provide a more complete overview of the topic, it examines the current level of knowledge on different related issues. In other words, during the first stage, this research reviews the multidisciplinary scientific literature concerning autism. The most significant findings from different studies are evaluated together and integrated to create a solid footing for the next stage. Briefly, the explored aspects in this section are: the features of autism spectrum disorder according to the latest researches; the network of care and services for people diagnosed with autism in different contexts; the core problems and needs of individuals on the spectrum; and the impact of architecture on their wellbeing and the existing designs for autism experiences.

CHAPTER I
AUTISM SPECTRUM DISORDER

This chapter gives an overview of the most important features of autism. It commences with a brief explanation of what is meant by 'autism spectrum disorder' and retraces some historic moments in its definition course. It goes on to outline the prevalence of the disorder and some important data as reported in the latest surveys. The next section describes the symptoms, the common characteristics of the spectrum, as well the classification model as suggested by the official diagnostic systems. In this chapter, are also described the tracks of the aetiology of autism according to the most recent researches. The final part briefly summarises the current level of knowledge concerning the prognosis of individuals with autism.

I.1 Overview of the history of autism

Autism Spectrum Disorder (ASD) in general terms, is used to identify a group of complex disorders of brain development characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and restricted, repetitive patterns of behaviours or interests (APA, 2013). The term 'autism' derives from Greek, which stays for 'self', and was initially used by the Austrian-American child psychiatrist Leo Kanner in 1943 to designate children who were excessively self-involved (HCN, 2009). It is defined as 'spectrum' because the severity of symptoms varies widely and each individual with autism is considered unique. There is even a popular saying among the autistic community: «If you've met one person with autism, you've met one person with autism.» What it is today known as autism has been object of great debates over the years and, consequently, has resulted in a series of changes in approaches to the diagnosis (Volkmar et al, 2013).

The first scientific article to describe autism was "Autistic disturbances of affective contact" which reported Kanner's documented observations (Kanner, 1943). Kanner described a group of 11 children (eight males and three females), aged from 2 years and 4 months to 11 years, with striking behavioural characteristics referred as 'insistence on sameness' and an extreme inability to relate to others that appeared to be present throughout infancy (Kanner, 1943). Kanner also observed unusual language development, no eye contact, repetitive behaviours along with sensory sensitivities.

In 1944, Hans Asperger – an Austrian paediatrician – described a group of children with contact disorders with the term 'autistic psychopathy' (Asperger, 1944). These children had difficulties with non-verbal communication and with social skills showing little or no interest in interacting with others, but with a superior language development compared to those described by Kanner. Even though the core symptoms were much the same to Kanner's study, Asperger's work didn't spread through the English-speaking scientific community as it was published in German and during the Second World War (Masi et al, 2017). It became widely known only in 1981 when Lorna Wing - an English psychiatrist – studied the clinical features of the syndrome of Asperger and proposed to rename the term 'autistic psychopathy' as 'Asperger syndrome' (Wing, 1981). She highlighted the similarities with the Kanner's autism and included both in a wider group of conditions which have in common impairment of the development of social interaction, communication and imagination.

In 1980, autism appeared for the first time in the classification of mental disorders, which is done through two official diagnostic systems: Diagnostic and Statistical Manual (DSM) produced by the American Psychiatric Associations; and International Classification of Diseases (ICD) produced by the World Health Organization (WHO). Autism entered in the DSM of Mental Disorders, third edition (DSM-III) in 1980, and it was included in a class of conditions called Pervasive Development Disorder (PDD) (APA, 1980). The criteria for the diagnosis required an onset of the syndrome prior to the age of 30 months, failure of responsiveness to others, gross deficits in language development, and awkward responses to environmental stimuli. Soon, it was revealed that the age criteria were restrictive, as individuals could show symptoms of deficits not enough early in life to receive the diagnosis (Masi et al, 2017). Therefore, in 1987, DSM-III-Revisioned broadened the criteria for the recognition of the pervasive nature of the disorder not limiting to infants, introducing a subthreshold category described as Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).

In 1994 there were released the DSM-IV (fourth edition) and ICD-10 (tenth edition). The syndromes described above were incorporated in both diagnostic systems under the name of Pervasive Developmental Disorders. In this group, there were included five disorders, two of DSM-III-R (childhood autism and PDD-NOS) and three other new ones (childhood disintegrative disorder, Asperger's disorder, and Rett's disorder). DSM-IV and ICD-10, even though with slight differences on issues of comorbidity and impairment requirements, did come to convergent definitions (Volkmar et al, 2013). The diagnostic systems defined three core symptoms for this group of disorders, such as limitations in social interactions (especially in terms of social reciprocity); qualitative limitations in terms of communication (both verbal and non-verbal); and rigid and stereotypical behaviour (APA, 1994)(WHO, 2010). In most cases, development is abnormal from infancy and, with only a few exceptions, the conditions start to manifest during the first five years of life.

The release of DSM-V (fifth edition) in 2013, brought a series of changes in the diagnostic criteria, broadening the definition of the syndrome, but reducing the specificity of the symptoms (Masi et al, 2017). Childhood disintegrative disorder was eliminated as a category and Rett's syndrome was removed from the group of disorders, given its single-gene aetiology (Volkmar et al, 2013). Diagnoses of childhood autism, Asperger's syndrome and PDD-NOS were removed as diagnostic classifications and collapsed into two diagnoses: 1- Autism Spectrum Disorder – the new name of the class of disorder; 2- and Social Communication Disorder (SCD). The latest was introduced to describe cases of difficulties in the social use of verbal and nonverbal communication, without impairments relating to restricted and repetitive behaviour (APA, 2013).

In regard to the core symptoms of the ASD, they were reduced to two instead of three. It was decided to combine communication and social difficulties – very closely related to each other - into a single category and to have a second one similar to the Kanner's 'insistence on sameness/restricted interests with the addition of a sensory sensitivity symptom (APA, 2013). DSM-V diagnosis approach reduced the potential criteria combinations to identify individuals who fall in the autism spectrum disorder, having reduced the core symptoms categories and having increased the number of symptoms needing to be met, leading frequently to cases losing the diagnosis given according to DSM-IV (Volkmar et al, 2013). Furthermore, DSM-V introduced the classification of ASD severity in base of the required levels of support to assist with the impairments in social communication and restricted and repetitive patterns of behaviour (APA, 2013).

Very recently, the diagnosis trajectory has reached another milestone. On June 2018, it has been published the 11th Revision of the ICD. It seems that it goes pretty much alongside its American equivalent. ICD-11, as DSM-V, has changed the denomination from PDD to ASD, which is included in the Neurodevelopmental Disorders class, which at its turn is part of the Mental, Behaviour or Neurodevelopmental Disorders chapter (WHO, 2018). Concerning the definition of the syndrome, there is an alignment with DSM-V, characterizing autism by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive and inflexible patterns of behaviours and interests. It also identifies only two core symptoms. The onset period of the disorders occurs during the developmental period, typically in early childhood, but some symptoms may not manifest until later when social demands exceed limited capacities. Deficits can be sufficiently severe to cause impairment in personal, family, social, educational, occupational or other important areas of functioning. They are usually pervasive features of the individual's functioning observable in all settings, although they may vary according to social, education, or another context. Individuals along the spectrum exhibit a full range of intellectual functioning and language abilities. Based on this range, ICD has introduced a new possibility of classification of cases with autism (WHO, 2018).

In conclusion, even though since the first document on autism in 1943 and its appearance in diagnostic systems in 1980, research on the disorder has noticeably expanded, its definition reflects a continuity. As regarding the diagnostic approach, the same thing can't be confirmed, as there has been a sequence of broadening and narrowing concept leading to significant changes in diagnostic. The presence of two diagnostic systems, often not fully in convergence, seems not to help the scientific community communicate more effectively about clinical problems and to ensure comparability of samples.

I.2 Prevalence of autism

The prevalence of a disorder is generally defined as the number of cases in the population per thousand or in terms of frequency at a specific time or during a defined period. At the best of my knowledge, there are no studies or surveys that report the reliable situation of the international autistic community. However, according to some researches, to get a sense of the autism epidemiology, the rate of around 1 in 100 people can be considered currently as the best estimate of prevalence (Elsabbagh et al, 2012); (Fombonne et al, 2011); (CDC 2014). Furthermore, Autism Speaks (2013) the largest autism advocacy organization in the US - estimates that ASD affects over 2 million individuals in the US and tens of millions worldwide.

One of the most recent studies on the autism prevalence at a national scale reports that about 1 in every 40 American kids have autism (Searing, 2018). The study led by Kogan et al. (2018) was based on the 2016 National Survey of Children's Health, a nationally representative survey of 50212 children, ages 0 to 17 years old. They estimated that the prevalence of parent-reported ASD diagnosis in 2016 to be 2.5 per 100 children, which is much higher than the previous estimation conducted by the US Center for Disease Control and Prevention (CDC). It was based on an analysis of medical and educational records of children aged 8 years from 11 monitoring sites across the United States in 2014. The overall prevalence of cases with autism along the spectrum was 16.8 per 1000 children, or 1 in 59 (Baio et al, 2018).

The survey of CDC (Baio et al, 2018) and the study of Kogan et al. (2018) confirm the influence of sex in the autism prevalence estimates, where males were nearly 3.5 times more likely than females to be identified with autism. CDC (Baio et al, 2018) reveals also that race/ethnicity varied the prevalence estimates, whose were higher for non-Hispanic white children compared with non-Hispanic black children, and both groups were more likely to be affected by autism compared with Hispanic children. Another important data coming out this autism monitoring survey is the age of diagnosis, which is found to be after the age of four, though autism can be reliably diagnosed between the eighteenth and thirtieth month of age (Baio et al, 2018).

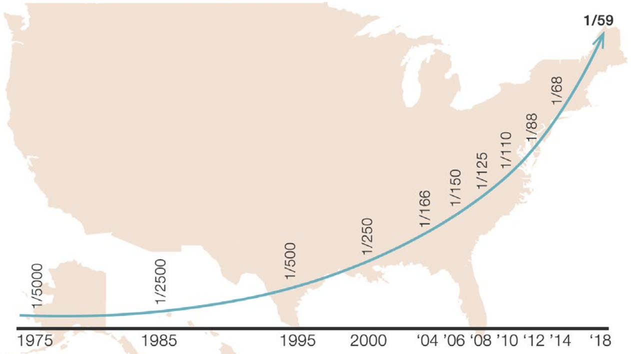

Fig 1 Prevalence of autism, reworked version of Autism Speaks

The prevalence of autism has increased within the last 40 years (HCN, 2009) (Baio et al, 2018) (Kogan et al, 2018). As reported in the graph below, extracted from the website of Autism Speaks, it seems that cases with autism are growing at an exponential rate. Comparing the last two estimates of CDC (2014), there is a 15% increase in prevalence in the US: from 1 in 68 children to 1 in 59. This prevalence increment, according to the overview in the last decades presented by Autism Speaks as shown in Fig.1, is terrifying as estimates report that in the United States, the prevalence in 1975 was 1 in 5000 children. Similar situations can be encountered in reports from Asia, where the prevalence in 1980 was 1 in 5000 children (Sun et al, 2010).

However, it must be admitted that tracking the prevalence of autism cases in the spectrum is a very difficult challenge and with low-reliability results. The aforementioned increasing rates, probably, do not represent the real epidemiology trend of autism because in the meantime there have been a series of changes in concepts, definitions, diagnostic approaches, service availability and awareness on autism among the public and professionals (Fombonne, 2009). This uncertainty is verified also in prevalence estimates in narrower time and spatial context. Just looking at the details of the most accurate statistics done by CDC (Baio et al, 2018), it comes out that prevalence estimates vary widely between monitoring sites, ranging from 1 in 76 to 1 in 34 children, with significantly higher numbers at sites with better access to school records. This suggests that even the new US numbers – 1 in 40 children – reflect the uncertainty of autism's true prevalence.

I.3 Symptoms and classification

Diagnosis of autism is based on observation of aberrant behaviours (Masi et al, 2017) with regard to the criteria – described by the two official diagnostic systems – focused on impairments in social communication and interaction, and restricted and repetitive interests and activities. Even though the two manuals ICD-11 (WHO, 2018) and DSM-V (APA, 2013) highlight these two core symptoms characterizing autism, the specific symptoms and their severity vary widely among individuals making them unique. This reflects that there is an entire spectrum of disorders, that could be reframed as 'the autisms'. At one extreme, there are individuals with severe intellectual disabilities, deficits in socio-affective relationships, difficulties in motor skills; whereas at the other end of the range, there are individuals who are highly intelligent but socially awkward (HCN, 2009).

People on the spectrum can manifest themselves in a broad variety of ways and often the symptoms change throughout childhood and adolescence (Autism Speaks, 2013). However, some of the most common characteristics referred by Autism Speaks (2013) and illustrated in Fig.2 - that can be considered challenges or strengths depending on their severity – are:

- difficulty understanding language and social cues;
- excessive or minimal speech;
- concrete thinker, often with difficulty with abstract concepts;
- difficulty relating to others;
- social awkwardness;
- intense interests or concentration;
- repetitive behaviours such as pacing, rocking or hand flapping;
- sensitivity to light, sound, smell or other sensory issues;
- anxiety or abnormal fears;
- complex and in some cases challenging behaviours;
- difficulty managing transitions or changes in routine;
- strong visual skills;
- excellent memory for facts and statistics;
- difficulty in generalising acquired skills;
- musical, mathematical, technological, artistic ability or interest.

The heterogeneity of presentation of autism is fuelled by the psychiatric and medical comorbidities[1] as reported at a significant proportion of individuals along the spectrum (Masi et al, 2017). Some of the most commonly identified psychiatric comorbidities are social anxiety disorder, oppositional defiant disorder, attention-deficit/hyperactivity disorder, and intellectual disability. To give an instance, in the CDC (2014) survey in the U.S. on the prevalence estimates, 31% of children with autism spectrum disorder were classified in the range of intellectual disability - Intelligence Quotient (IQ) <70.

In regard to the medical conditions, comorbidities include immune system abnormalities, gastrointestinal disorder, sleep disorders and epilepsy (Mannion et al, 2016). For example, epilepsy is indicated in 11%-39% of individuals with autism and sleep disturbance in 50%-80% of them (Masi et al, 2017).

The classification of individuals with autism is based on the severity of symptoms. For this topic, the two diagnostic manuals, DSM-V and ICD-11, haven't found a common ground and, as a result, they use different severity specifies. DSM-V (APA, 2013) classifies the severity of autism in base of the required levels of support to assist with the impairments. It describes three levels of severity: 1- requiring very substantial support; 2- requiring substantial support; 3- and requiring support (APA, 2013). Whereas, the ICD-11 (WHO, 2018) describes the severity of autism in base of the range of intellectual and language abilities. It identifies 6 categories according to the combination of cases with or without disorder of intellectual development and cases of mild impairments, substantial impairments and absence of functional language.

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[1] Comorbidity is defined as the occurrence of two or more psychiatric and/or somatic disorders in the same individual.

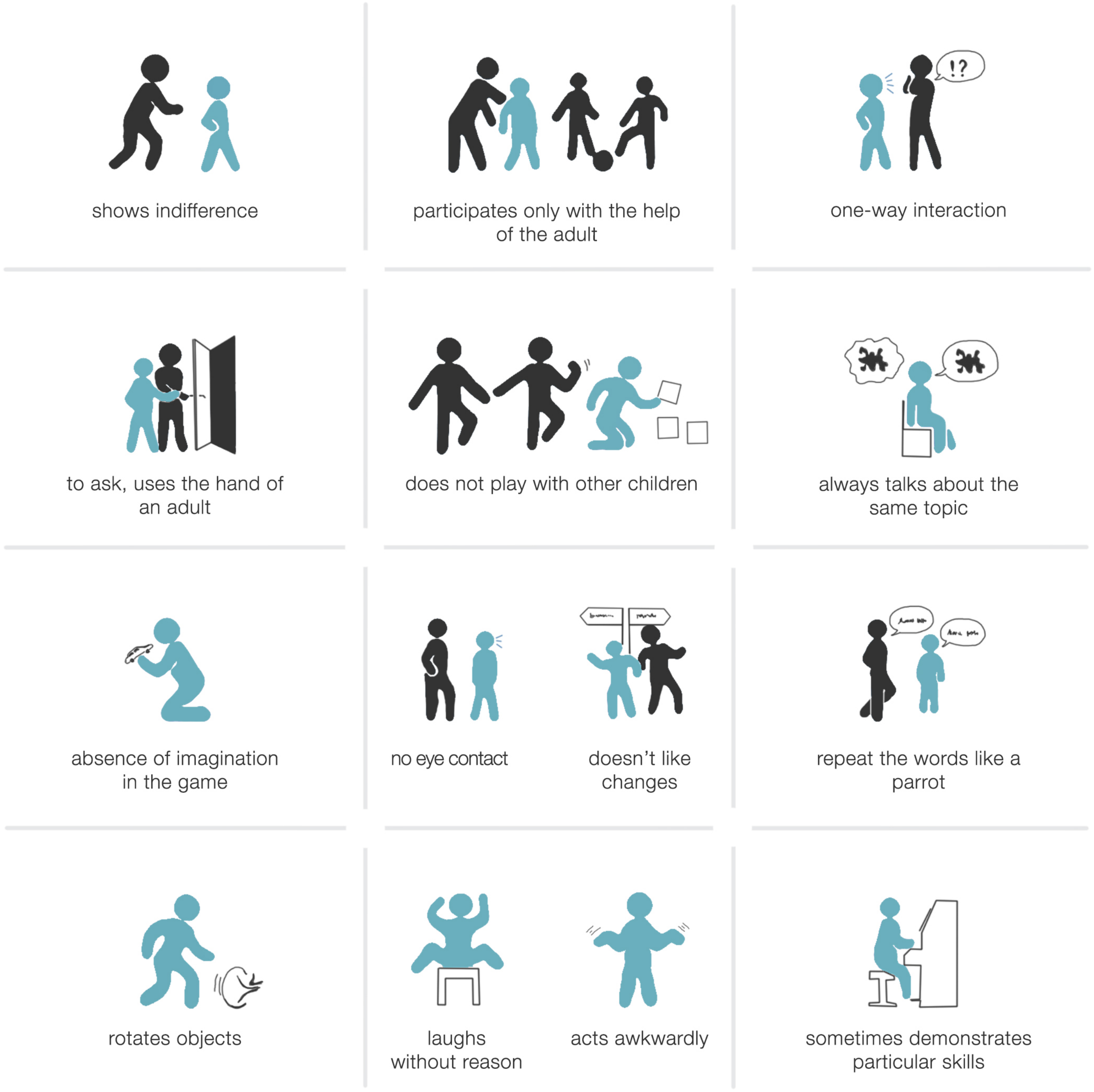

Fig 2 Prevalent symptoms of autism

I.4 Aetiology

Thus far, there is no cause of autism accepted by the scientific community, even though there have been conducted many researches which have led to the discovery of interesting cues. Researchers suggest that the aetiology of autism could be described as a combination of genetic and nongenetic, or environmental, influences (Newschaffer et al, 2007). The genetic and nongenetic influences appear to give birth to autism by affecting some crucial aspects of early brain development; affecting how brain nerve cells or regions of the brain communicate with each other. These influences are not found to be the exact cause but appear to increase the possibilities that a child will enter in the spectrum. For example, not all people with some gene changes associated with autism, will develop the disorder. The same is true about the environmental impact, where only a few of them exposed to an environmental risk factor will develop autism.

The genetic influence is related to changes in certain genes, that consist in genetic deletions and/or duplications. These variants can be inherited from parents – if a parent carries one or more gene changes and they may pass to a child (even though the parent is not affected by autism) – or other times they can appear de novo (Masi et al, 2017). The de novo genes arise spontaneously in an early embryo or during the combination of the sperm and the egg. Researches from the scientific community have identified nearly 1000 genes vulnerable to autism development, but despite that, the genetic aetiology of at least 70% of cases with autism remains unknown (Masi et al, 2017).

The nongenetic factors implicated in autism risk - otherwise known as environmental - may increase or reduce the predisposition through all the natal phases, pre-, neo- and post-natal (Gardener et al, 2011). About the prenatal phase, the most common risk factors for autism are the pregnancies spaced less than one year apart and the advanced parents' age. Many studies have produced evidence that, compared with younger parents, fathers aged over 40 and mothers aged over 35 years are at increased risk of having a child with autism (HCN, 2009). In regard to the neo- and post-natal phases, the pregnancy and birth complications like extreme prematurity or low birth weight, are believed to be increasing risk factors (Gardener et al, 2011).

Fig 3 Child with autism (http://aklat.net/cdn/fles/1a/5b86a560da.png)

In addition to these considerations from the scientific community, there are rumours about other real causes of autism. For a long time, but still nowadays, many people believe that vaccines are one of the major causes of autism. This link derives probably due to the time alignment of autism diagnosis and child's vaccinations. However, extensive researches have been done in this area and there is no evidence of a connection between exposure to antibody-stimulated from vaccines during the first 2 years of life and the risk of autism (DeStefano et al, 2013).

I.5 Prognosis

It is hard to foresee what will be the course of an individual with autism and there is some debate on the prognosis of cases with autism. Autism is a neurodevelopmental disorder, which means that something develops differently from ‘neurotypical’. Despite that, people on the spectrum have the capacity to develop just like everyone else, but they do it in their own way (HCN, 2009). The first debate relates to the way autism is considered. Some researchers like Baron-Cohen et al (2009a) prefer to consider it a condition instead of a disorder, a way of being of people on the spectrum. They have their own identity with weaknesses and many strengths that need to be appreciated and empowered. However, they both believe that autism is not a disease and, as a consequence, it is quite irrational talking about cures for it, even though there is always someone that tries to fill parents with a false belief that a person could exit the spectrum.

Considering that autism is a spectrum and that each person with autism is unique - due to aetiology, to severity of presentation of the disorder and to comorbidities -, the prognosis of each one will vary as well. Autism can be thought as a lifelong condition or disorder, but the good news is that those on the spectrum can grow and flourish if they have the right support to address their difficulties (Kogan et al, 2018). There is a wide range of treatments that can be very helpful and can have a direct impact in improving the quality of each individual’s life. The various interventions aim at the development of various compromised skills by ameliorating this way the symptoms of the disorder (SNLG, 2015). One crucial aspect of the interventions, rather than its specificity tailored to the needs of individual with autism, is the age of the person. The earlier the interventions begin, the higher are the chances for a better prognosis (HCN, 2009). As a corollary, every delay in diagnosis represents a missed opportunity in combating the symptoms.

Treatments are designed to optimise the activities of everyday life and a high-quality intervention can improve learning, social skills and daily function into the school-age years, and likely across the lifespan (Eldevik et al, 2009). Studies have shown a marked increased percentage of children who have acquired speech - after having not previously spoken -, or who can attend school in a typical classroom and go to live semi-independently in community settings (SNLG, 2015). Certainly, despite the early intervention, most probably individuals with autism will never exit the spectrum. The acquired skills are, however, modelled on an autistic identity (SNLG, 2015).

Nevertheless, according to some experts, a few assumptions on the prognosis can be made based on the intellectual capacities of the individual with autism (HCN, 2009). The report from the Health Council of the Netherlands (2009) suggests that « Children with a normal IQ and normal language development have the best prognosis, while those with a low IQ and impaired language development have the worst prognosis. In the case of children with a normal to high non-verbal IQ but with impaired language development, it is difficult to give a prognosis.» Here, it can also be added that pervasive and chronic features of the autistic symptoms will determine serious limitations in the autonomy and the social life of the person on the spectrum (SNLG, 2015). Studies have shown that only a small portion, 5% to 17% of such individuals, lead a satisfactory social life performing well in school and at work (HCN, 2009). Most of the rest instead, remain dependent on continuous support ranging from full-time assistance, covering all house-related tasks – including dressing, bathing, eating, meal preparation, and cleaning - to simply a few hours a week (Brand, 2010). However, even those with a good prognosis will continue to need encouragement and moral support in their struggle for an independent life, as reported also in the classification made by DSM (APA, 2013) (see § I.3).

CHAPTER II
TAKING CARE OF PEOPLE WITH AUTISM

This chapter deals with the care system for people diagnosed with autism. It starts by giving a general overview of their human rights and what has been done to their fulfilment. It then goes to explain the importance of care in the life of individuals on the spectrum. It also tries to show how the care infrastructure is articulated and highlights some of its issues. The next section deals with the current level of knowledge about available therapeutic interventions for people with autism and in support of their families. Finally, it ends by describing the major care settings where these interventions may take place.

II.1 Autism in the regulatory framework

The fundamental rights universally belong to all human beings. The respect of these rights forms the basis and is a parameter of legal equality and constitutes the substantial dimension of democracy. The rights of people with autism were explicitly presented at the 4th Congress of Autism Europe and adopted by the European Parliament in 1996. The charter of rights of individuals on the spectrum was based on the previous declarations on the Rights of Mentally Retarded Persons of United Nations (UN) – Office of High Commissioner for Human Rights (OHCHR) (1971) and the Rights of the Handicapped Persons (UN - OHCHR, 1975). In this charter were included the following rights for people with autism:

- to live independent and full lives to the limit of their potential;
- to an accessible, unbiased and accurate clinical diagnosis and assessment;
- to accessible and appropriate education;
- (and their representatives) to be involved in all decisions affecting their future; the wishes of the individual must be, as far as possible, ascertained and respected;
- to accessible and suitable housing;
- to the equipment, assistance and support to live a fully productive life with dignity and independence;
- to an income or wage sufficient to provide adequate food, clothing, accommodation and other necessities of life;
- to participate, as far as possible, in the development and management of services provided for their well-being;
- to appropriate counseling and care for their physical, mental and spiritual health; this includes the provision of appropriate treatment and medication administered in the best interest of the individual with all protective measures taken;
- to meaningful employment and vocational training without discrimination or stereotype; training and employment should have regard to the ability and choice of the individual;
- to accessible transport and freedom of movement;
- to participate in and benefit from culture, entertainment, recreation and sport;
- of equal access to and use of all facilities, services and activities in the community;
- to sexual and other relationships, including marriage, without exploitation of coercion;
- (and their representatives) to legal representation and assistance and to the full protection of all legal rights;
- to freedom from fear or threat of unwarranted incarceration in psychiatric hospitals or any other restrictive institution;
- to freedom from abusive physical treatment or neglect;
- to freedom from pharmacological abuse or misuse;
- (or their representatives) to all information contained in their personal, medical, psychological, psychiatric and educational records (Autism Europe, 1992).

At an international level, one of the most important steps was the adoption of the Convention on the Rights of Persons with Disabilities (CRPD) approved by the UN General Assembly on 13 December 2006. The initiative was driven by the awareness by the High Commissioner for Human Rights through these words: «There is no doubt that the existing human rights' system was meant to promote the rights of persons with disabilities. There is also no doubt that the existing standards and mechanisms have, in fact, failed to provide adequate protection in the specific case of persons with disabilities. It is clearly time for UN to remedy this shortcoming.» (Giani, 2010).

The purpose of the CRPD, according to Article 1, was «to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.» (UN, 2008). It is the first human rights' instrument which acknowledges that all disabled persons are right holders and that impairments must not be used as a justification for denial or restrictions of human rights (Degener, 2016).

Another feature of the disability policy introduced by the CRPD was the new image of people with disabilities. The CRPD sought to promote the disability model proposed by the WHO through the International Classification of Functioning, Disability and Health, known more commonly as ICF. In the 1970s, the concept of disability experienced a shift from the medical model of disability to the social one. While the first reduced disability to a medical phenomenon of impairment, the latest approach recognized that disability is a social construct which is created when impairment interacts with societal barriers. In 2001, in the ICF was proposed a fusion of the two models coming up with the "biopsychosocial model". This model defined disability as the result of a complex and dynamic relationship between a person's state of health and the individual's contextual factors – which can be of personal and/or environmental nature[1] – (WHO, 2001). The CRPD, referring to the ICF, described persons with disabilities as «those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.» (UN, 2008).

In terms of discrimination, the CRPD included also the denial of 'reasonable accommodation', a new term introduced for the «necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.» (UN, 2008). It also recalled the principle of 'Universal Design', formulated by the arch. Ronald L. Mace in 1985, «to design products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaption or specialized design.» (UN, 2008).

The UN Convention has had a profound and global impact on disability reaching more than 90% universal ratification – exactly 177 State Parties ratifications. Most State Parties have reviewed and revised domestic disability law and have established National Monitoring Mechanisms as prescribed by the Convention (Degener, 2016). Nevertheless, "Human rights of people with autism not being met, leading expert tells United Nations" (2017), as the Director of the Autism Research Centre at the University of Cambridge -Prof Baron-Cohen- confirms. Even with the UN Convention to support people with disabilities for over 10 years now, yet people with autism still do not enjoy human rights to the same extent as everyone else. «A right is considered as such if it is assisted by forms of guarantee that ensure its effectiveness.» (Giani, 2010). Actually, it can be noticed that the respect of the rights of people with autism – even though must be inviolable – usually faces two obstacles: the first related to the limited economic resources; and the second related to the weak organizational power of the public administration (Giani, 2010). Besides, the advocacy of human rights devoid of real perceptiveness because of the programmatic nature of the organisations, which is translated in an extremely slow process of developing concrete policies in the definition and the provision of adequate services and support.

For instance, Italy has ratified the CRPD and its Optional Protocol with the law n.18 of March 3rd, 2009. With the same regulatory provision, it was established the National Observatory on the condition of persons with disabilities. To the Observatory, it was given the task to ensure the implementation of the Convention. The first measure for autism came with the elaboration of the indications from the Heath Institute (ISS, 2012) on how to promote and improve the care system. The presence of autism for the first time at a juridical level, instead, came with the approval of the law n. 344/2015 from the Senate of Italian Republic (2015). In particular, this law envisaged interventions aimed at ensuring health protection, the improvement of living conditions and the inclusion in the social life of people with autism. It also identified the need to have an adequate path of assistance and to update the current *Essential Assistance Levels*. The update should include the performance of early-and-specialised health diagnosis; recommended treatments; measures for social and educational integration; and treatment services; in order to provide assistance throughout the territory through a coordinated network of intervention (law n. 344/2015). This law on autism decrees the Higher Institute of Health to take care of Guidelines update and coordination of interventions and services (law n. 344/2015). The work for the elaboration of these new Guidelines by a panel of experts started only in September 2018. That means that people with autism and their caregivers will still have to wait for a long time before getting an intelligent network of services and support.

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[1] Personal factors include the individual's background and other characteristics unconnected to their state of health: gender, ethnic origin, age, physical condition, lifestyle, habits, education level, capacity to adapt, social background, training, profession, past and current experiences, general behaviour models, character traits. Personal factors can influence a person's participation in society and can have a negative or positive impact on a disabled person's living conditions. These, however, are not yet classified by the ICF.

Environmental factors are related to the physical and social environment in which the person lives; they are classified in two levels: individual and social. The individual level, namely the personal environment of the individual (for example home, workplace and school), includes the physical and material features of the environment in which the individual performs their activities and in which they enter into direct contact with others (for example relatives, acquaintances and strangers). The social level, which is to say the formal and informal structures, services and interactions with the community or with society having an impact on people include organisations and services linked to the work environment, community activities, institutional services, communication and transport services, formal and informal networks, laws and regulations, behaviours and ideologies (WHO, 2001).

II.2 Care chain

Autism is a lifelong disorder or condition – a way of being, as some prefer to consider it. Jim Sinclair (1993) described it as «… pervasive; it colours every experience, every sensation, perception, thought, emotion, and encounter every aspect of existence.» Thus, autism roughly shapes the life experience, making individuals on the spectrum look like 'strangers' on earth (Sacks, 1995). They have their weaknesses, but at the same time many strengths that need to be appreciated and empowered (Baron-Cohen et al, 2009a). The problem is that the social and physical context are egoistically attuned mostly to neurotypicals' behaviours. Therefore, being different precipitates in exclusion – to not use the word rejection – or simply in a limitation of possibilities to be part of the community in dignity. Unfortunately, individuals with autism due to the pervasive features of the disorder face a series of difficulties in everyday life (NICE, 2013).

However, the society has not been completely insensitive to the cry for help and respect of people with autism and their families. In the past years, a lot of work has been done on treatments and counselling to support those on the spectrum. Treatment – in general – can be interpreted as achieving a cure or as a way to combat the symptoms. And as a matter of fact, the scientific community has worked on both directions. There is a group – everyday becoming smaller – that still believes that autism can be considered a disease and people affected by autism can exit the spectrum; unfortunately offering nothing else than false hope (HCN, 2009). The good news is that regarding the interventions to alleviate the effects of the disorder, there is a wide evidence on a range of treatments that have a positive impact in the quality of life of people with autism (SNLG, 2015). Meanwhile, counselling was also object of attention because it is a very important aspect in offering support to those on the spectrum and their caregivers.

The fundamental aspect of every form of care is that it should be based on the individual aspirations of who will benefit from them (DRC, 2002). Everyone has his own aspirations in life, but trying to group and highlight the basic ones, there can be identified: being healthy; living peacefully; and having a 'life project'. Every person can fit themselves in these life aspirations. They may have different weights or may change over time, but these are the ones that contribute to the overall happiness and wellbeing of humankind. People with autism do not make an exemption on this case, but they need assistance to achieve that. They need support at home life, in education, at work, during leisure time, to establish friendships and to maintain relationships (HCN, 2009).

Taking care of individuals on the autistic spectrum means adjusting the physical and social environment to make them feel safe, confident and more capable, and help them cope in the activities of everyday life. Given the chronic nature of autism, they will probably require care throughout all their life. Therefore, it is an open-ended process articulated in all stages of life; maybe in varying intensity, but yet continuous. Considering the complexity of the disorder, its high prevalence and the strong impact it has on individuals with autism and their families, it is crucial to provide an appropriate and efficient care system. The long-term goal of the care system is to favour the adaptation of the person with autism to his environment, in order to guarantee a satisfactory quality of life for them and the whole family (Rubiolo, 2018).

The care system that supports people with autism is highly complex due to a series of aspects. The first regards the fact it should consider all ages, from childhood to elderly. The second aspect is related to the spectral feature of the disorder. No two peer individuals with autism are alike, resulting in different symptoms to treat and, therefore, having to tailor the type of assistance to the situation in which each individual is at that particular moment. The third is about the numerous actors involved in the support of an individual with autism and the variety of their backgrounds. The last is somehow related to the previous but regards the setting where the care intervention takes place. All these aspects, and perhaps others, contribute to the fact that in order to ensure the right response to the requirements of a person on the spectrum, a highly coordinated care infrastructure is needed. So, it is not sufficient to ensure only segments of care, such as the proper treatment or the proper setting, the best therapist or educator. What people with autism need is a regular and effective care chain that guarantees the coordination and the cooperation among those involved and the different domains (SNLG, 2015).

The care infrastructure is the product of the care policy. The last – depending on the local and national policies – is site-specific. Therefore, exactly which professionals and institutions will be involved, which treatments and support are considered valuable for each age, it is different in each country and often different even among regions of the same country. As a result, referring to this study, it was considered as case limiting to describe a care system of a certain territory, because it would be too specific and probably in a few years not anymore in force due to the dynamics on the matter. What can be done, it is to think of a generic scheme that reassumes the concept of the care system demanded by people diagnosed with autism. The care chain can be imagined as compounded by two elements: services and settings. By services, it is intended the immaterial part of the care chain represented by therapeutic interventions, which is compounded by treatments and counselling. Settings, instead, represent the physical environments where the interventions take place. In the next paragraphs, it will follow a description of the care system as viewed by each one: the services and the settings.

II.3 Treatments and counselling

There is no way yet to prevent the disorder from developing and there is no way to cure it. The good news is that it is possible to prevent the symptoms worsening and ameliorate them. There is a broad range of interventions - through treatments and counselling - that may help individuals on the spectrum in the daily function across the lifespan. The report of the Health Council of the Netherlands (2009) considers treatment and counselling as a prosthesis of people with autism which makes their life easier. Usually, the family gets to know about the autistic condition of their child from a neuropsychiatrist or a psychologist after the referral of the paediatrician who takes care of that child. Once the diagnosis has been made, an intervention plan needs to be prepared to identify the right treatment for the affected person (Masi et al, 2017). It is an important step because the heterogeneity of autism traits that may be present in different individuals has implications on the treatment efficacy. That's why, each person's treatment plan should be specific and personalised to the severity of limitations, level of development, ability to cope with social interactions and life stage (HCN, 2009).

TREATMENTS

Treatments try to work on compromised skills. The series of interventions aim to: improve the social skills; enrich the communication; and favour a greater flexibility of actions and interests (Rubiolo, 2018). The variety of treatments has undergone through several examinations in evaluating their therapeutic benefits. Only part of them have produced evidence-based proofs in influencing the lives of people on the spectrum. Despite that, the scientific community doesn't share the same reliability on these treatments, showing, therefore, a certain preference toward some of them. The causes of this disagreement probably derive from their short experience in their application and the lack of consolidated proofs of their efficiency. However, each country - based on the viewpoint of selected researchers – has elaborated a plan of interventions, guidelines or simply a report on the most suggested treatments to carry on in assisting people with autism. In this research, there were reviewed four documents of different countries in order to give an overview of what are considered the most effective treatments for autism. Part of this study were: "Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders" of Scottish Intercollegiate Guidelines Network (SIGN, 2016); "Autism Spectrum Disorders: A lifetime of differences" of the Health Council of the Netherlands (HCN, 2009); "Autism spectrum disorder in under 19s: support and management" of the National Institute for Health and Care Excellence in the England (NICE, 2013); "Treatments of autism spectrum disorders in children and adults" of the National System of Guidelines of the Health Institute in Italy (SNLG, 2015). The first subdivision of interventions the experts suggest is into: pharmacological and non-pharmacological interventions.

NON-PHARMACOLOGICAL INTERVENTIONS

There are slight differences in describing each category in the different reports and their further classification. However, in this paragraph, instead of showing all of them which would be at some point repetitive or showing one of them which could be too selective, the description of the most suggested treatments is based on their approach to the problem. There is not a clear line of demarcation of the various approaches as they may overlap at some degree. However, there can be identified three approaches according to the problem they address:

1| Behavioural approach

Intensive behavioural interventions are considered the best option in terms of effectiveness in reducing the behavioural symptoms associated with autism, especially if undertaken in the early stages of life (SIGN, 2016). Trained teams – which sometimes include also parents – teach children several skills. Usually, the training course is given in one-to-one settings and the content of the course is tailored to address the specific issues of the child. These interventions programmes emphasize play-based interactions (HCN, 2009). The commencement of such therapies takes place usually at the age of three, but also adults can benefit from them. Three most noted therapy programmes that fall in this approach are:

Fig 4 ABA Therapy session (Albanian Children Foundation)

Applied Behaviour Analysis (ABA) – it is one of the most valid treatments. Studies have shown its efficacity in improving the intellectual abilities, language and adaptive behaviours in individuals with autism (SNLG, 2015). Its main features are personalisation, progressivity, and continuity. ABA works on certain behaviours that need to be modified. It manages to change a behaviour by intervening on the causes and consequences of that behaviour. This kind of intervention aims at the adaption of the person to the environment and not the opposite (Rubiolo, 2018). This approach pushes toward the development of capabilities.

Treatment and Education of Autistic and Communication Handicap Children (TEACCH) – This behavioural therapy programme is meant to be applied in the whole net of services for autism and all age ranges. However, it is used especially in learning environments offering highly structured spaces within which children or young people can develop individual skills (HCN, 2009). TEACCH doesn't aim at achieving 'normality' but reaching autonomy to participate in social life through empowering the strengths of those with autism (Rubiolo, 2018). Studies report that this kind of therapeutic and educational intervention has led to better motor abilities, cognitive performance and social interaction of children with autism (SNLG, 2015).

Cognitive Behaviour Therapy (CBT) – It is a skill-building therapy, best suited for those with a normal IQ and certain language development. It is recommended to be used for the treatment of comorbidity with anxiety disorders and to improve rabies management skills (NICE, 2013).

2| Interaction approach

This therapeutic intervention approach is focused on the social sphere of people with autism. The strategy of this approach is based on play – whether with parents, caregivers and teachers or peers – in order to increase joint attention and favour engagement and reciprocal interaction of the person with autism (NICE, 2013). The environment where social interaction takes place, in this case, is very important (Rubiolo, 2018). One of the therapy programmes adopting this approach is:

DENVER – It is a comprehensive intervention programme for children. The programme focuses on social learning and social-cognitive development to encourage communication exchange and imitation. This treatment tends to put the child in coordinated and interactive social relations for several hours. In that way, it is attempted to establish a relationship and bridge the difficulties resulting from the inability to socialise. Play is a very important part of the programme, which aims to make the child experience pleasant in interacting with adults and his/her peers (SNLG, 2015). A crucial requirement is the intensity of the intervention which should be practised also by parents at home. Studies show an improvement in adaptive, cognitive and social skills (SIGN, 2016).

3| Communication approach

The aim of this approach is to overcome the deficits in communication in people with autism through alternative ways that increase or cover for the verbal language. The messages for asking and for replying are simplified and can make use of the technology or not. There could be used as a multi-sensory stimulus to facilitate the process. Some therapeutic programmes using this approach are:

Picture Exchange Communication System (PECS) – It is a step by step learning programme which aims to develop functional communication, and communication as social interaction (SIGN, 2016). PECS uses visual suggestions and it is based on an exchange; at the request of the child through the use of the communication cards the adult responds giving reinforcement in exchange.

Social Story Telling – Considering the unique ways of learning of people with autism, this intervention serves to teach social communication skills in real contexts. Through this treatment, individuals with autism learn how to improve social skills; rules of everyday life; how to describe daily routines and to explain abstract concepts (SNLG, 2015). There are used short and simple story descriptions according to the needs of each individual.

> «I'm often tired and overwhelmed.
> I fight to get my child all the services he needs.
> I often feel alone.
> I sometimes need a good cry.
> My child has challenges that you will never know or understand.
> I study and research to learn all that I can to help my child.
> I have to deal with therapists and doctors daily.
> I love my child with all of my heart and soul.
> I am the mother of a child with autism».

PHARMACOLOGICAL INTERVENTIONS

Pharmacological treatments have a modest part to play in the treatment of autism (HCN, 2009). They are to be used in support to the non-pharmaceutical treatments and under strict medical control. There are plenty of drugs and medications that pretend to have an effect on autism, but most of them have not proved evidence of treating autism. There are only two pharmaceuticals that are approved by the US Food and Drug Administration, risperidone and aripiprazole. They could be used for the treatment of symptoms associated with autism (Masi et al, 2017). Both are approved antipsychotic for the treatment of irritability, including aggression, deliberate self-injury, and tantrums. However, significant side-effects are often associated with their use, like weight gain or drowsiness (Masi et al, 2017). In addition, there have been rumours that diets or food supplements could be used for the management of core features of autism, but the opposite has been proved (NICE, 2013).

COUNSELLING

Counselling, unlike treatments, it is not working directly on ameliorating the symptoms of autism. It aims to provide support and help individuals on the spectrum and their caregivers to structure and organise everyday life. Considering that autism affects all spheres of life, counselling needs to go over all that. It regards those on the spectrum but also those around them. It must reach all those involved in the care of people with autism, such as parents or educators, but at the same time, it is recommended to reach also those who interact with them, such as siblings or peers. Support coming from counselling can be of various types, from moral support, informative or instructive, physical assistance, or economic aid. It extends across many different sectors including housing, education, health, social care, employment, etc. Furthermore, given the chronic nature of autism, the effects of counselling extend to all age ranges.

To illustrate some of the implications of counselling, parents will be taken as an example. Parents are usually the main caregiver and, therefore, the reference point and the interface figure for the care chain. Regarding treatments, as they need to be personalised and intensive, parents have a key role in therapeutic interventions. They know better than anyone their child and they can help the psychologist, or the neuropsychiatrist identify the strengths and weaknesses. They can also help in the treatment process by continuing the therapeutic programme at home. They have to get some 'parent training' classes to learn the way how to do that out of the presence of therapists. This way, their child will get longer and a continuous treatment which has been proved to be highly worthy (SNLG, 2015).

Having a child with autism often puts parents under a great deal of stress. Rearing a child on the spectrum requires them to devote much more time than they would spend with their siblings or parents of 'neurotypical' children. Parents have to accompany their child and assist them quite in every step. This leads to a lack of time for themselves. Thus, parents rearing a child with autism often need to reduce work hours, or indeed one of them may have to quit their job. Having almost no free time for leisure activities, and sometimes, due to the severity of the autism features of their child, there may be a lack of understanding from their social circle. Consequently, they may feel isolated from the rest of society. All these factors, and many others, have resulted not rarely in depression, loneliness feeling of parents putting at risk sometimes even their marriage (HCN, 2009). For this reason, the provision of both emotional support and formal assistance has a beneficial effect on the parents' wellbeing. They need practical assistance, such as someone to stay with their child to let them have a break or in emergency cases; financial aid to help them cover the high costs of various therapies for their child, but also to integrate the incomes being unable to work full time; and a dose of moral support to appreciate their work on raising a child with autism (HCN, 2009).

As the child grows, the support provided by parents does not noticeably decline. Individuals on the spectrum will continue to need assistance – to different levels in base of the severity of symptoms. One of the dramatic moments for those with autism is the transition from one context to another as they grow old. For instance, moving from home to school, then from primary to secondary school, and then from home to independent settings. This is related to their low ability to adapt to new situations. For parents, the biggest preoccupation is the moment when they will not be able anymore to take care of their autistic child. The transition from home to other housing option will be one of the most difficult challenges to carry out, so they will need the help of social care.

II.4 Care settings

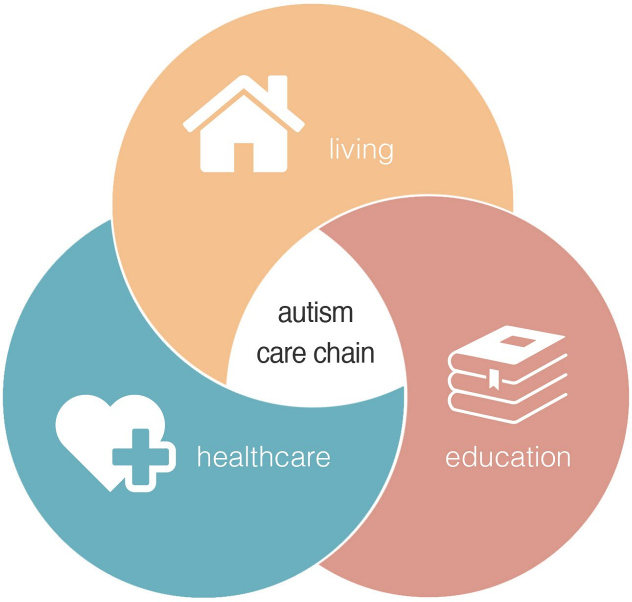

Fig 5 Diagram of care chain for autism

There can be identified three major contexts:

LIVING CONTEXT

Home has a particular significance for everyone. It is described as the most important anchor in the environment for an individual (Coolen, 2006). It offers a deep-rooted sense of identity, intimacy and protection (Lauria et al, 2019) making everyone feel at ease. For people with autism, home often represents the context where most everyday activities take place. In particular, for those with highly challenging symptoms, it means everything because they do not leave the house most days. Therefore, the home environment represents a delicate element in the life of individuals diagnosed with autism. How they experience everyday life is a key ingredient in making them live happily and fulfilled lives (Gaudion, 2013).

Being such important, a great deal of care for people with autism is given in the living context. The care provided is related to the support in daily activities. Autism is characterized by difficulties in everyday functioning, which tend to limit the person's ability to be autonomous and live independently. Individuals on the spectrum, therefore, need support in managing daily tasks. Primary activities such as clothing, bathing, eating, toothbrushing could all be extremely difficult for those on the autistic spectrum, but they are an important part of the everyday life. Also, complementary activities like cleaning, doing laundry, cooking, washing dishes or using domestic appliances may pose big challenges for them. Performing these tasks demands a certain level of body coordination, motivation, planning and organisational skills, etc. which should not be taken for granted (Gaudion, 2013). These skills need to be developed in time and through the assistance of caregivers. Meanwhile, they learn to do on their own, care allows individuals on the spectrum to 'compensate' an impairment by delegating to the caregiver the task execution (Ratzka, 1989).

As a result, caring at home has multiple valences: it assists in doing daily tasks but also teaches how to do them, hoping that one day the person diagnosed can manage to perform on his own. At the same time, by participating in everyday activities, there is a greater possibility to engage in social interaction, increasing the overall benefits for a better quality of life. It seems that people with autism want to be alone, but actually, they suffer from loneliness. «Many descriptions of autism and Asperger's describe people like me as "not wanting contact with others" or "preferring to play alone" ... but I'd like to be very clear about my own feelings: I did not ever want to be alone. I played by myself because I was a failure at playing with others. I was alone as a result of my own limitations and being alone was one of the bitterest disappointments of my young life.» (Robinson, 2007).

The time and support time needed at home depends on the age and severity of symptoms in every individual. It may range from a few hours a week and consists in a base level of supervision and support in checking that everything is proceeding in the right way, up to full-time cover, assistance with personal care and all house-related tasks (Brand, 2010). In a survey conducted by Autism Speaks (2013) and SIS International Research on the National Housing and Residential Supports, it was reported the

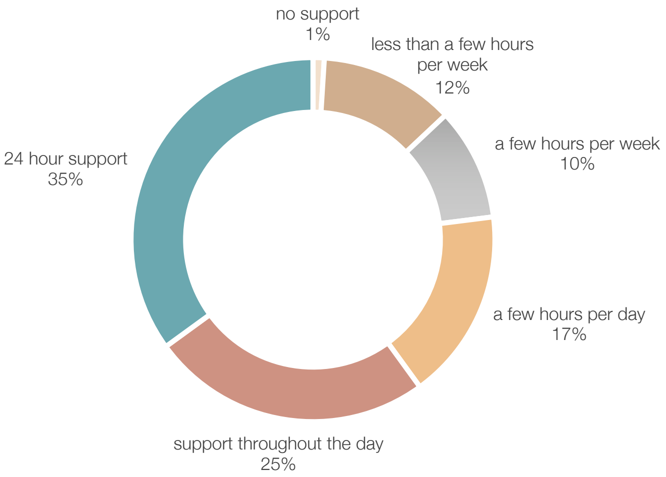

Fig 6 Level of support needed by people with autism (Brand, 2010)

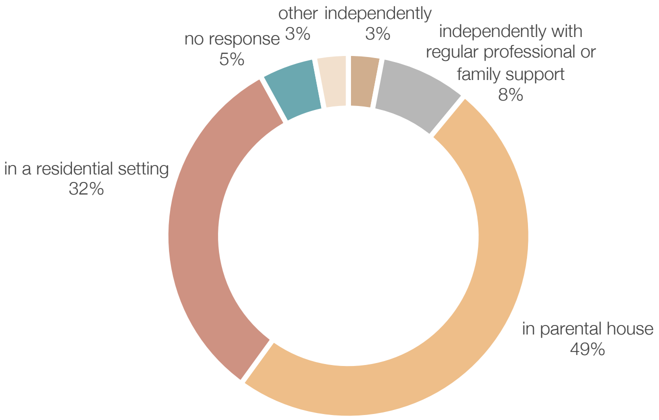

Fig 7 Common type of dwelling for adults (Brand, 2010)

current level of support needed according to the caregivers. The online surveys were completed by over 10,000 people, including nearly 400 individuals with autism. Only 1% responded that needed no support and a further 12% who needed less than a few hours per week. Whereas, nearly 35% of respondent reported needing '24/7 support'.

The most widespread form of care in home environment is that provided by parents or other familiars living with the person diagnosed with autism. Usually, they, not only look after, but also make enormous physical, emotional and economic sacrifices (Laurìa et al, 2019). In nearly one-third of cases, support from family it is not enough and there is necessary to request help from outside, which may be a paid personal assistant or a social care worker (HCN, 2009). According to the level and type of care needed, it can be a service provided occasionally, or at specific times of day, or continuously throughout the day. The caregiver looks after the person with autism in the daily activities such as personal hygiene, help in meals, cleaning, accompanying to outdoor activities, etc. This kind of assistance helps parents or family members manage their time and routine and allows them to have a break. When they will be unable to take care of their child, or when they will no longer live, then the external assistance becomes fundamental.

While young or teenagers, more than 90% of individuals on the spectrum live with their parents and therefore, are cared for at home (HCN, 2009). The alternative of parents' house is often a residential school. As they become adult, families' concern regarding the continuation of their care grows. Parents gradually tend to be less able to take care of them and the majority of people with autism are unable to face a completely independent living. Families need to be assured that their loved ones are comfortable and safe. As there is no ideal single prototype that fits the vast spectrum of individuals with autism, there is a range of dwelling opportunities. The good news is that there has been a shifting on the approach on how to address the day-to-day living environments of people on the autism spectrum from institutional care residences to domestic-sized buildings in the community (Brand, 2010; Ahrentzen et al, 2010). The aim is to provide as much as normal home-like environments.

So far, there have been developed different models of accommodation for individuals on the spectrum. They could be differentiated according to four key characteristics:

1| Locality
suburban area | selected urban areas | rural areas | farmsteads

2| Building type
family home | planned community | town house | apartment | multi-family attached house | assisted living facility

3| Resident occupancy
with family | alone | with self-selected friends | with provider-selected roommates

4| Care support
temporary supervision | daily care | constant care | fulltime personal assistance

HEALTHCARE CONTEXT

The first contact of a child to healthcare context is the maternity hospital. After that, a paediatrician will supervise him/her across childhood to take care of his/her healthy growth. Autism it is not diagnosed until approximately the 18th month of life, indeed it is averagely diagnosed between the second and third year of life. However, that would not make a difference, because the paediatrician will continue to be the person to refer to for primary check-ups and interventions. During the child follow up, if the doctor notices the first signs of autism or under the concern of child's parents, he will ask them to see a psychologist or a child neuropsychiatrist. Those doctors usually work in the hospital at the neuropsychiatry department, but they also can be found in either private diagnostic centres or at their private offices. They can help to obtain the diagnosis, evaluate the severity of the symptoms through examinations and specialised visits, and give advice on treatments programmes and where to get them.

Fig 8 Therapy session (Albanian Children Foundation)

The therapeutic interventions mainly proposed and offered in the healthcare context are generally these ones:

Physiotherapy - physiotherapeutic intervention can help children to improve their motor skills;

Psychomotor therapy – which aims to: favour eye contact and referential look; increase attention time; facilitate an appropriate use of objects; stimulate communication; enrich the vocabulary; and discourage certain behaviours;

Speech therapy - deals with the management of communication disorders, swallowing, voice and language. It helps individuals with autism: communicate both verbally and nonverbally; articulate words well; develop conversational skills; initiate communication, etc. (Rubiolo, 2018).

Other than the diagnosis and therapeutic interventions, it has been shown that individuals on the spectrum show up at the healthcare facilities much frequently than neurotypicals do (Croen et al, 2006; Lunsky et al, 2015). Just to give an idea of the incidence of the phenomenon, there can be called the studies in North California in 2003 from Croen et al (2006) and the study in Ontario in Canada in 2010 from Lunsky et al (2015). It has been recorded a nearly three times higher rate of medical visits of people with autism and approximately the same rate for recoveries in the hospital (Croen et al, 2006; Lunsky et al, 2015).

This higher frequency cannot be justified directly from autism by itself. Indirectly though, it can be related to comorbidities alongside autism which include immune system abnormalities, gastrointestinal disorder, sleep disorders and epilepsy (Mannion et al, 2016). For example, epilepsy is indicated in 11%-39% of individuals with autism and it is the reason for nearly 9% of Emergency Room cases (Masi et al, 2017). Meantime, another aspect that links the higher presence of people on the spectrum in the healthcare settings is their vulnerability to injuries. They are highly exposed to injuries in the everyday life due to limitations on motor abilities and some forms of mental crisis, such as self-injurious behaviour and aggression (Lunsky et al, 2015).

In conclusion, the healthcare context is particularly important for people with autism, either for the therapeutic interventions or either for ordinary visits or managing emergency cases. The experience in healthcare facilities by itself it is not joyful, because health issues – even if not painful – cause fear and stress to the patient and their families (Del Nord, 2006). However, if a person is at ease and feels comfortable, the stay is less stressing and painful, and the recovery seems to be faster (Del Nord, 2006). The experience of a person on the spectrum could be extremely fragile due to their particular sensory sensitivities, comorbidities, the assumption of complex pharmacological therapies, difficulties in communication, the absence of autonomy and the consequent need of constant care and attention. This presents a real challenge for the care policy and the design approach.

EDUCATIONAL CONTEXT

The formative years in the educational context are crucial for building the future. It is worthy to precise that formation it is not all about learning, literally meaning. School – at all levels – is not just the academic learning space; indeed, it is far more than that. It is the environment where lots of new experiences take place. Children get to know their peers and teachers, work and play together, develop social relationships, improve communication skills, learn to know better themselves, learn to fail and raise up again, create an environment in which to grow, and learn how to follow their dreams. Each child is different; has his/her own strengths and weaknesses, preferences and dislikes, desires and fears, and the most important has a dream to pursue. The dream grows along with the child and takes form in becoming his/her life project. As part of the community, as these children grow and their dreams start materialising in some forms, they contribute to develop the society. For individuals on the spectrum, the formative years, are also one of the richest moments full of experiences that leave traces in their memory and that help to engrave the future. Even they participate in the society through their personal manner and their own life projects.

As regarding the educational context for children with autism, the biggest dilemma in whether they should follow mainstream schools or they should go to a school specifically designed for pupils on the spectrum (Beaver, 2011). This debate has gone on for years and scholars still have not come to a common point. Some believe that it depends on where the child is on the autism spectrum. Whilst there are many pupils that will perform well in a mainstream environment, many other require a more specific and personalized setting (Scott, 2009). Others believe that educational spaces are best to foster inclusiveness in the society. Therefore, mainstream schools help to vanish the disability concept and to embrace all pupils together. Children with autism will have a richer environment of interactions and relationships to engage, and other neurotypical pupils will learn to accept diversity as part of the society.

The last – the inclusive approach – seems perfect for the integration of those on the spectrum. The problem is that pupils with autism are often bullied by their peers and the physical environment is usually underestimated. Children diagnosed with autism can find the school environments very stressful, instead of a place of safety and tranquillity. As a result, the experience at educational context can turn to be not auspicious.

It is hard to say which model we should opt for. Obviously, each country has its own educational system, but countries also differ in the way how they have approached to the aforementioned problem concretely. For instance, two contrasting models will be shortly described, the Italian and the Dutch one. In the Netherlands, referring to the report of the Heath Council of the Netherlands (2009), a child with autism has three options. Normally he/she would have to attend a mainstream school. Inside these institutions, there are employed a number of counsellors, who are normal teachers with special background. They are responsible for coordinating individual educational needs programmes and supporting the teacher of the child who needs extra attention. If the child experiences learning difficulties, he has the right to ask for additional support offered within the context of mainstream education. He will be transferred to a school with smaller class sizes and additional human resources. If that is still insufficient, a special needs education may be requested. The last is intended for children with disabilities and it is divided into four clusters:

1| schools for visually handicapped children with or without multiple disabilities;

2| schools for deaf and hearing-impaired children and for children with severe speech difficulties, possibly in combination with another handicap;

3| schools for pupils with intellectual and/or physical limitations and pupils with chronic illnesses;

4| schools for severely maladjusted children, chronically ill children without a physical disability and schools attached to pedological institutes.

In Italy, the situation is much simpler. Considering the integration of children with learning disabilities in the community as one of the most important things to go on for, there is only one option: the mainstream school. A child diagnosed with autism has to attend mainstream learning environments with his/her neurotypical peers. A support teacher will be assigned to him/her to offer assistance in the educational programme which will be tailored according to their needs.

In other countries, the situation can be similar or in between to those described above, such as specialized schools dedicated only to pupils with autism completely detached from mainstream schools or attached to them as a stand-alone extension (Beaver, 2011). So far, there has not been proved which is the best model or the ideal one. However, it should be an environment in which the child feels comfortable and one that can actively aid in his education. To this aspect, there has not been a widespread attention until recently.

Once educational support ends – whether it is at the age of 16, 18 or 21 in different countries – young adults are usually placed in systems set up for supervision, and not for growth and development (Gaudion, 2013). It is sad saying that knowing that there are many adults on the autism spectrum capable of employment. Only a few of those with autism could work on a mainstream job. Others will struggle to find a job and will find it hard to keep it. Relatively new living facilities or day care centres are trying to combine training for life skills with basic tasks that could permit adults with autism work in several sectors, such as supermarkets or gardening.

CHAPTER III
UNDERSTANDING AUTISM

In this chapter, an in-depth description of autism takes place trying to give some insights on the symptoms associated with autism and to highlight the demands of people on the spectrum. It starts by focusing on the possible explanations of the causes of the common symptoms among individuals with autism through examining the various hypothetical mechanisms of autism. Finally, it sets out a framework of what there can be considered the needs of individuals with autism.

III.1 Theories of autism mechanisms

Autism is characterized by limitations in social interactions and communication, and by stereotypical patterns of behaviour, interests and activities (APA, 2013) (WHO, 2018). However, the two core features and some of the symptoms aforementioned are simply the outer display of autism. In order to support people with autism or to plan interventions for them, it is important to understand the internal mechanisms of autism.

Autism is a complex neurodevelopmental disorder and affects every domain of human experience: from sensation and perception to motor behaviour, emotion, communication and cognition. So, its neurobiology is probably as complex, the challenge therefore, is to understand how these different domains might be related. It is believed that the biological basis of autism can be found in differences in central nervous system structures (Coulter, 2009), which means that the autistic brain works differently compared to neurotypicals. A group of researchers on autism, Baron-Cohen et al (2009b), even suggest using the term 'condition' instead of 'disorder', as they don't consider autism a disability but a condition with cognitive strengths.

For the first time, the diagnostic criteria of DSM-V (APA, 2013) included the sensory issues as core diagnostic feature – even though they were noticed quite since in the beginnings of autism definition. It enlightened, even more, the presence of two levels of autism traits: the low-level of perceptual behaviours; and the high-level of social-cognitive processing; which turned into a central puzzle for the autism research (Robertson et al, 2017). The dilemma that arises is whether the sensory symptoms are primary, or they simply reflect secondary outcomes of alterations in the higher-order domain. Neurobiologist – studying how these disparate symptoms might be related in autism – are largely divided into two camps, giving the key primacy to one of the symptoms levels.

COGNITIVE STYLES

'TOP-DOWN' EXPLANATION

The 'top-down' group thinks that the symptoms appear due to alteration in general-domain mechanisms affecting both levels of information processing in the brain (Robertson et al, 2017). So far, there have been elaborated three cognitive styles that try to give insights into the 'top-down' mechanisms of autism: 1- weak central coherence; 2- under-development of theory of mind; 3- and executive dysfunction (Evans, 2013).

1| Weak Central Coherence (WCC) posits that autistic neurobiology is characterized by a centralized perturbation of neural processes that aggregate information into coherent perceptions or cognitions (Happê et al, 2006). People with WCC have great difficulty combining single elements into a meaningful whole which makes them see the world as fragmented, something that neurotypicals do automatically (Schrameijer, c). Often, people with autism are characterized as 'seeing the trees, but not the forest': a strong tendency to focus on details at the expense of the global composition (Robertson et al, 2017).

This phenomenon connects and explains other traits of autism such as the difficulty in recognizing objects/situations and the inability to generalisation. Generalisation is the capacity to generate the basic principle and then to adapt and apply what is learned in a new situation. A 'neurotypical' after seeing an object, will compare it with similar objects of his previous experience, and if it doesn't match, will inspect some of its details and create a prototype of it, to use it in the next exploration of similar objects (Schrameijer, c). Conversely, people with WCC will inspect all details of an object and if it doesn't fully match to previous ones, will be stored in the memory as new. It is very hard for them to see similarity between objects or situations – even with few changes – and that makes people on the spectrum experience a new situation which in fact is only a variant of one they already know.

Temple Grandin (2006), one of the most famous people with autism, reports how she can't think of a 'generalized church' when

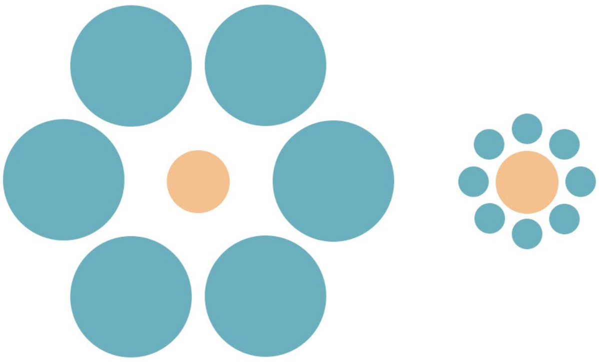

Fig 9 Illusion test

asked to describe how a church look like, as all the churches that she has seen and that are stored in her memory (like photographs) come to her mind.

This attention to detail compromises the ability to transform experiences into more abstract. The more one is attuned to details, the harder generalization becomes since the last requires a focus on similarities (Brown et al, 2012). In the everyday life, that may result in challenging situation for people with autism, as this description offered by Donna Williams (1996): «Jenny refuses to look at people although she can see an entire person, she can only visually process the meaning of one bit of them at the time and only forms a mental impression from the bits of what she has seen rather than forming coherent mental images. Seeing in bits also means that Jenny defines people and places and things by these bits, and she can suddenly find once familiar things to be strikingly unfamiliar if slight components have changed, such as when someone moves the furniture or doesn't wear the same coat as usual.»

This inability to experience the whole without full attention to the constituent parts, however, depending on task demands can be seen as a quality, rather than a deficit. They are less susceptible to optical illusions and have a good performance where attention to local information is important or advantageous, i.e. recognizing an object from a single part; showing often particular talents (Evans, 2013). In the Ebbinghaus illusion, where most neurotypicals see the second central circle as being larger than the first. The second being surrounded by smaller circles stimulates an illusion, which is impossible to fool people with autism. This universal feature of the autistic brain has been described by the leading British autism-expert Simon Baron-Cohen (2009a) as an excellent attention to detail. It seems also to be connected to the higher-level aspect of cognition, the systemizing ability, which is very strong in people with autism. It has been suggested that this aspect of cognition – the systemizing – can be considered even as different cognitive style, as it goes further in detail explaining autistic features compared to the WCC (Happé, 1996).

Systemizing is the drive to analyse or construct systems, which means identifying the rules that govern the system, in order to predict how it will behave. For example: if we multiply 3 by itself, then we get 9; or if we turn the switch down position, then the light comes on. Individuals on the spectrum show particular talent in highly systematised domains like numbers (e.g. spotting if a number is a prime number), calendrical calculation (e.g. telling which day of the week a given date will fall), drawing (e.g. perfecting an artistic technique), music (e.g. analysing the sequence of notes in a melody), memory (e.g. recalling lists of information) (Baron-Cohen et al, 2009a). This capacity in systemizing better explains why details strongly matter for people with autism.

The prominent systemizing ability in autism explains also the autistic traits in presenting: limited interests; repetitive behaviours; and showing a resistance to change (Baron-Cohen et al, 2009a). Systemizing requires keeping track of changes and understanding what causes them. Repetitive behaviours help them get closer to the system, analyse better the problem for many times to recognize the pattern, while the limited interests and the need for sameness are due to the necessity to render the surrounding world predictable.

2| Underdevelopment of Theory of mind – Theory of mind – a human cognition characteristic – is defined as the ability to impute mental states to oneself and others (Evans, 2013). People on the spectrum find it difficult to reflect on their own and others' thoughts and emotions, showing delays in the development of this capacity (Baron-Cohen et al, 1985). It also influences the social interactions across the lifespan due to the consequences in the cognitive empathy, the ability to understand and respond appropriately to others' mental states and emotions, which is different from the affective empathy and must not be confused (Robertson et al, 2017).

Another trait of autism that could be explained through this limited capacity is the weak imagination of people on the spectrum. Baron-Cohen et al (1985), through the Sally-Anne false belief test, suggested that individuals with autism have difficulties with symbolic play and are not good in false belief tasks. That's why they often cannot understand intentionally non-literal words or phrases. People with autism have difficulty also to inference about what other people believe to be the case in a given situa-

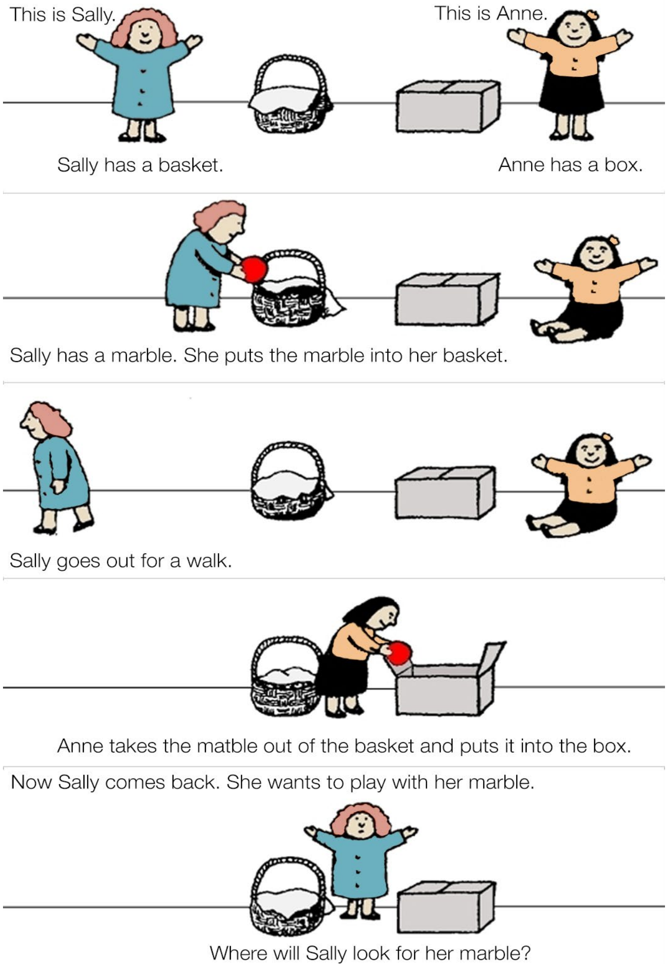

Fig 11 Imagination test

tion, preventing them to predict what they will do or how they will behave (Schrameijer, c).

3| Executive dysfunction - Executive function is a cognitive process that regards attention, short-term memory, planning and cognitive shifting (Schrameijer, c). It can be found in the prefrontal cortex of the human brain and it enables a regular and effective functioning in the everyday life. Executive function requires the ability to capture relevant information, store them in the working memory and enable a flexible planning ahead (Evans, 2013). It includes also the capacity to shift or switch one's thinking and attention between different tasks, known as cognitive shifting. People with autism appear having some executive dysfunction through showing a lack in cognitive flexibility of attention and planning; and short-term memory difficulties which make them get lost or lose their belongings leading to perseveration which explains the repetitive behaviours and narrow interests (Baron-Cohen et al, 2009a). A task that highlights this capacity is the game Tower of Hanoi. The objective is to transfer the entire tower A to the peg B, moving only one disk at a time and never moving a larger one onto a smaller one.

Fig 10 Tower of Hanoi

Each of these three cognitive styles alone cannot explain autism, as they singularly can give insights only on some of the features of the autistic conditions but are unable to enlighten the remaining. For some of the autistic traits, the three theories, give even different explanations, like the repetitive behaviours. It could be more convincing thinking of autism as the result of the combination of the three cognitive processes: weak central coherence for explaining the global-local processing and the special talents or peaks in performance; limits in the theory of mind to explain impairments in social interaction and communication; and the executive dysfunction to explain the narrow interests and activities. At that point even, the broad variety of exhibition of autism would make more sense (Schrameijer, c). The three cognitive styles may be affected in varying grades giving birth to different autisms, e.g. one person may not develop social attachments while another is presented as competent but has awkward behaviours.

SENSORY SYMPTOMS

'DOWN-TOP' EXPLANATION

The second group shares the idea that the atypical sensory processing in early years causes the development of a non-typical social cognition and the appearance of social-cognitive symptoms (Robertson et al, 2017). Atypical sensory experience is estimated to occur in more than 90% of autistic individuals and can affect all senses (Robertson et al, 2017). It is believed that for people on the spectrum something runs differently in the perception processing (Schrameijer, c).

The perception is a dynamic and complex process through which external stimuli – coming from the surrounding environment – and internal stimuli – coming from the inside body – are receipt by our senses through a sensory channel such as vision or taste and interpreted in our brain. A signal in order to be interpreted, must be first selected from brain (Laurìa, 2003). Apart from the five senses commonly known – sight, hearing, smell, taste and touch (pressure, pain, temperature) – human beings have two others exteroceptive senses: the vestibular system; and the proprioceptive system. The vestibular system is the capacity to perceive and interpret the position and movement of the head, through which one can orient oneself in space and time. The proprioceptive system mainly perceives and interprets the condition of the muscles in one's own body. Furthermore, there are a series of interoceptive sense responsible for the sensations of the internal organs.

In order to percept a signal, stimuli must flow from receptors (the sense organs which are specific for each sense) where the information is registered and reaches the brain thalamus. At this brain centre takes place the modulation phase where perceptual stimuli are distinguished and filtered based on the comparison between signals, to determine which is meaningful to focus on and which is not. Then subsequently, it is transferred to several centres in the cortex to be identified and become conscious through evaluations according to reference systems formed with the consolidation of experience (Evans, 2013) (Laurìa, 2003). At that point, it can also trigger an action.

The complexity of the sensory processing is due to the several mechanisms that the brain employs to make sure the received signal is optimized. Some of these mechanisms are: suppression of less important stimuli in order to emerge the useful ones; convergence of different stimuli to make sufficient information to activate a reaction; integration of stimuli from different senses to make more complete brain-maps (Schrameijer, c). Therefore, perception – being such a complicated system – becomes vulnerable to imperfections. The distortion of the perception process can occur at the lower-order function of the process (reception and the modulation of the signals) or at the higher-order functions (cognitive interpretation).

It has been observed that people with autism show deviations of the sensory processing compared to neurotypicals in both levels (Roberston et al, 2017). The characteristics of the higher-order functions were described above through the three cognitive styles, while here will be shown a series of sensory difficulties of the lower-order that individuals on the spectrum experience. These experiences are not unique, as many of us feel similar sometimes, but their intensity and continuity make these experiences normal for autistic people (Bogdashina, 2003). Olga Bogdashina, one of the major contributor to this area, in her book about sensory perception in autism (2003) reports the most common sensory experiences and some of them are: fragmented perception (perception in bits, stimulus overselectivity); delayed perception; disturbance by certain stimuli (sensory intolerance); fascination with certain stimuli (sensory fascination); sensory overload; system shutdowns; peripherical perception (avoidance of direct perception); hypersensitivity and/or hyposensitivity and the fluctuation between them.

The two most remarked sensory perceptions among autistic people are the hyper- and hyposensitivity, otherwise known as modulation disturbances. They may affect all senses, sometimes even in contemporary, but that does not mean that all senses are hyper-or hyposensitive. Additionally, it has been found that both hypersensitivity and hyposensitivity can co-occur in individuals with autism (Ying-Hua et al, 2012). The hypersensitivity is a heightened perception with exaggerated, rapid onset and/or prolonged reactions to sensory stimulation. In case of hearing hypersensitivity, it can result in the person hearing everything at once and loudly causing great distress, which makes him cover his ears or become very agitated (Schrameijer, c). Other examples of oversensitivity regarding other senses could be: the autistic person seen as very picky eater, due to taste over sensitivity; easily vomiting due to smell; complaining from the tight clothes or rough surfaces; or feeling uncomfortable from the type of lighting used indoor due to the visual acuity of flickering.

The hyposensitivity is the unawareness or slow response to sensory input. In this case, the neurological thresholds are too high and in order to get response, more stimuli are needed (Schrameijer, c). The problems with hearing may impact the understanding of the words and conversation causing the person not to respond to requests. If touch is under sensitive, they don't feel pain or the temperature and appear to touch everything. Researches have shown that hyposensitivity is slightly more common in autism compared to hypersensitivity (Ben-Sasson et al, 2009).

An important fact about sensory symptoms to be considered is that they can be traced since the sixth month of age in infants that later would be diagnosed with autism (Estes et al, 2015). It means that they can be traced much earlier than the average diagnosis age (18-24 months). They precede even the key developmental milestones in social cognition (14-18 months), as confirmed by a series of neuroimaging evidence for alterations in the primary sensory cortex during perceptual processing (Robertson et al, 2017). As a result, sensory differences can be considered potentially markers of autism, and thus of social-communication deficits and repetitive behaviours (Estes et al, 2015). This suggests thinking that the sensory symptoms – them lower-order

Fig 12 Altered perception of the outer world (www.shutterstock.com)

functions – could lead to a hypothesis of explaining autism mechanisms. In fact, this idea has been explored since the 1960s from Rimland (1964) who suggested to consider the sensory-perceptual abnormalities as one of the core features of autism. And later, in the 1970s, Delacato (1974), after long observations, research and experiments, suggested that autism is a neurological, rather than a psychological disorder and that autistic children suffer from sensory distortions. He formulated a theory of sensory dysfunction to explain the autism traits. Although unusual sensory experiences have been observed in autistic people for many years and are confirmed by autistic individuals themselves, until recently, they have been ignored by many other researchers (Bogdashina, 2003).

Delacato (1974) described children with autism as having perceptual problems. Therefore, the outside world gets distorted on the complex way from receptors to the brain. Everything we know about the world and ourselves comes through our senses. All our knowledge, therefore, is the product of what we have seen, heard, smelt, etc. The autistic child, as other fellows of his/her age, is continuously exploring, because he/she is curious and wants to acquire numerous sensations, but his/her sensorial system creates many difficulties. As a result, the autistic child explores only what he/she can control; he/she does not venture into new territories because he/she is afraid of them. One of the main functions of the brain is to create an appearance of order in the chaos of the sensations that surround us. Because of the ambiguous input given to his/her brain by an unreliable sensory system, the autistic child cannot establish this order; he/she can only store ambiguous sensory data. Therefore, he/she tries to control the inputs, letting only those he/she controls by him/her-self enter, and rejects others as chaos. His/her awkward behaviour is his/her attempt to normalize the distorted sensory pathways (Delacato, 1974).

This theory, for years, has been construed as a secondary aspect of autism, but with the introduction of sensory symptoms in the diagnostic manual, some researchers got back again considering how difficulties in sensory processing could relate to the other domain of behaviour that characterize autism (Evans et al, 2013). After all, it makes sense that in a feedforward manner, if the information inputs are lesioned, even the higher-order functions will be subject of. Social communication is carried out through dynamic sensory information exchange. Children with autism often show difficulty discerning the relative presentation order of two closely occurring tones and show delayed evoked neural responses to auditory tones compared with typically developing children (Robertson et al, 2017). This is deteriorated in multisensory integration in autism, as two senses can have different time elaborations due to modulations disturbances, leading to confusion, instead of consolidation of the information. Deficits in multisensory binding are particularly observed with audio-visual speech paradigms, in the integration of vocal and facial cues, stunting the typical development of language and communication. Thus, if a child has difficulties in integrating sensory information, may find social information confusing and struggle to build social relationships, therefore choosing to leave away.

Some of the awkward behaviours of people with autism also seem to be related to the distorted perception. In high threshold situations (hyposensitive), people with autism are either seeking for sensations like: touching everything, getting close to lights or hearing loud music; or either self-selecting to remain away missing a lot of what happens around. In low threshold conditions (hypersensitive), individuals on the spectrum try to avoid overwhelming sensations: closing their eyes or ears with hands, not being touched, exhibiting rule-bound behaviour to let only familiar stimuli in; or are easily distracted and hyper-active.

Another trait of autism that could be related to sensory issues is the motor awkwardness, which almost all people on the spectrum have (Schrameijer, c). Otherwise known as the impaired motor functions cover a broad range of behaviour from walking or running, to reaching or grasping with hands. It seems evident that the information coming from our senses involving at least vision, proprioception and balance are fundamental to such tasks. Thus, in people with autism vestibular (among which balance) problems imply a lessened orientation of the body in space and proprioceptive problems disturb adequate feedback from the muscles (Schrameijer, c). A beautiful description of how it can feel to be physically clumsy is in a letter Gordy (Itkowitz, 2016) wrote to a police officer who was involved in an awareness programme about autism. «... I felt very strongly about writing you today, to give a little extra insight on the disconnected links that were supposed to make my brain and body work together in harmony. (…) My brain, which is much like yours, knows what it wants and how to make that clear. My body, which is much like a drunken, almost six-foot toddler, resists.»

CONCLUSION

Neurobiological theories of autism must account for atypical processing in both social and sensory domains. Both accounts have some valid arguments but are incomplete as they cannot fully explain autism experiences. Given the evidence from neuroimaging for alterations in the primary sensory cortex during perceptual processing, higher-order differences alone are unable to account all autism traits. For example, the higher-order mechanism presumes that the sensory signalling is unaffected in the autistic brain, whilst people on the spectrum show a perception acuity higher that neurotypicals like noticing the flickering of the light or high frequencies. On the other side, the perception in autism cannot be explained simply by hyper/hyposensitivity alone, as people with autism show faster detection of single detail but struggle with global motion perception, which means that the temporal processing is more slowly over time and noisier. Furthermore, sensory symptoms may explain certain aspects of language development, but are unable to explain cognitive empathy disruption. That makes the argument remain still unclear, where there can be found also extremist viewpoints of researchers such as: giving up on the hypothesis that symptoms of autism in different domains spring from common neurobiological and genetic origins. However, as long these theories help somehow to build a picture of the complexity of autism, it might be premature giving up all.

III.2 Description of people with autism's needs

The design of efficient interventions dedicated to people with autism requires the adoption of a need-based approach. It demands two important sequential steps: the awareness of the needs of the individuals on the spectrum; and the alertness of programmers/designers to correctly implement as solutions the responses to the said needs. Both steps are highly complex, but the first one is particularly significant as it serves as the input of the second. Therefore, the failure to get the proper answers in the first stage can tarnish the entire process. For this reason, this paragraph provides a detailed description of the needs of people with autism.

Before delving into the gist of the analysis, a series of remarks are in order. First of all, the complexity of understanding the needs of those with autism stands for the spectral variety of the autistic condition's displays, a wide variety of symptoms and levels of severity. This implies that the needs of every individual on the spectrum are personal. This is not a unique trait of autism, as even among the neurotypical the needs of every person are different. To find out the specific needs of a person requires to get close to that person and analyse his/her limits and strengths. As a result, designing interventions tailored to his/her needs can be challenging, but at least, the objectives are clear. This creates a natural quandary when having to design for a group of persons, which often are not known individually. In that case understanding what the aggregate needs of the group could be, becomes extremely challenging given the presence of intra-group differences. The ef-

Fig 13 During the presentation at the Department of Psychology of the Kingston University

AUTISM TRAITS	**WELLBEING of individuals with autism**		
	be SAFE	**be AUTONOMOUS**	**feel MOTIVATED**
altered sensory perception	non threatening sensory stimuli	clear and harmonious sensory stimuli	sensory interests seeking
awkward behaviours and motions	low harming risks	usability	encouraging challenges
focus on details and systemizing obsession	simplicity	order	flexible order
inability to generalise/ resistance to change	stability	comprehensibility	controlled change
weak imagination to foresee	familiarity	predictability	fantasy stimulation
difficulties to engage in social relationship	strangers avoiding	social relationships	control over social interaction
compromised ability to understand and reply	simplified danger notification	communication tools	alternative means of expression
weak short-term memory to perform operations	supervision	orientation & wayfinding	visual support
reduced attention span and planning flexibility	spatial shifting	no distractions	shift time

Tab 1 Framework on the needs of individuals on the autistic spectrum

forts should be directed towards the finding of common ground, able to cover the specifics of everyone. That's where the performance of this phase is brought into sharp relief.

The second remark relates to the method used to explore the needs of people with autism. In this case, the issue is about the particular needs of those on the spectrum, and not those common to all human beings. Over the years, different approaches have been adopted by different authors through the assessment of autobiographies of people diagnosed with autism and their past experiences or caregivers' prospective. The risk here is the opposite, i.e., being too much case-sensitive and less inclusive. Therefore, in order to have a better overview of those that can be considered the needs of the people with autism, the mechanisms of autism (see § 3.1) have to be taken into account. They explicate the roots of the common symptoms among people affected by autism. Henceforth, describing these mechanisms can be a solid base to start the analysis from.

The last remark is about the required approach to identify and then solve the issues that inhibit the lives of people with autism. A common approach is that of 'neutralising', implying that in front of a problem, we concern ourselves solely with its solution. This approach is not erroneous, rather it is limited. It offers a solution to the problem at hand, but it does not try to look further. The simple idea behind this assertion is that while it is valuable to induce a disabled person to feel less so, it is far better to make him/her feel also enabled (Henry, 2011d). That suggests a shift toward an affirmative approach on the issue, considering the wellbeing of individuals with autism under a much wider perspective. Wellbeing is a crucial aspect of one's health and being, supported by the definition of health that the WHO provides as "a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity." This analysis equates the proper wellbeing of a person on the spectrum with an individual who is safe and autonomous and feels motivated.

Taking into account these remarks, a common qualitative framework describing the needs of individuals with autism – that contribute to their overall wellbeing – is built referring to a list of possible autistic traits as does Tab.1. Each row represents an autistic trait and is broken down in three columns, which stand for the proper responses that allow people with autism to be respectively safe and autonomous and feel motivated with respect to the initial adverse stimulus. The framework is followed by a more thorough explanation of each identified need. This work was proposed to and reviewed by Dr Elisa Back, a Professor of Psychology, and her research team composed of PhD candidates on autism at the Department of Psychology of the Kingston University, in London, during a research stage at this university between February and April 2019.

1| SAFETY needs

Safety should be our first priority when dealing with people with autism. Considering the limitations and impairments dictated by autism, individuals on the spectrum can be more vulnerable and susceptible to injuries and/or situations that could compromise their wellbeing. To safeguard their physical and emotional integrity, individuals with autism need:

non-threatening sensory stimuli

because of their sensory deviation, some perception incumbrances, such as hyposensitivity, may make them unaware of potential risks, for example to appliances and fixtures.

«… my son would touch everything to better know them and I'm afraid of his unconsciousness of heat or sharpness.»

low harming risks

possible accidents during spatial motion as they might have an altered vestibular and proprioception sensitivity and during moments of anxiety, fear, or stress which may be accompanied by some form of aggression and triggered challenging behaviours.

simplicity

because individuals on the spectrum are considered to see the tree and not the forest, helping them to not miss important information.

stability

because they need to find the same arrangement/situation/conditions, as they might not be able to recognize changes and might think the modified arrangement is a completely different one.

«The autistic child simply cannot function if there are too many daily changes.»

familiarity

because of their difficulty to adapt to new situations.

«We made a refurbishment of our apartment to have a more spacious room for G. by exchanging his room with the kitchen. So, now when he wants to go to his room, he says "I am going to the kitchen", even though there have passed almost ten years since then.»

strangers avoiding

because individuals with autism can be particularly sensitive about the size of their personal space and unknown people might be seen as a threat to their comfort zone.

«Sometimes I heard and understood, while other times, sounds and speech reached my brain like the unbearable noise of an onrushing freight train. Noise and confusion at large gatherings of people overwhelmed my senses.»

simplified danger notification

danger alerts might not be perceived if not clear, or these alerts might have different effects on individuals with autism, where instead of informing these individuals about risk, the former might cause the latter to feel stress, fear, or panic.

supervision

because they are unaware of potentially dangerous situations and tend to wander off.

«All of us need a private place to hide.»

spatial shifting

because giving to the individuals with autism the right space, they feel their comfort zone is not infringed, consequently, they feel less oppressed and can be more successful to process information.

«In the setting of a "too-limited" space, stimuli are closer to the person with autism. The social information per cubic yard is too high in that case. This leads to overstimulation and raises stress levels.»

2| AUTONOMY needs

Autonomy is a multidimensional process that plays a fundamental role in the life of every human being and contributes to his identity formation. Personal autonomy is generally interpreted as the ability to carry out certain activities, also referred to as a personal capacity for self-management (Laurìa et al, 2019). The sphere of personal autonomy hinges on the ability to fulfil personal needs such as cleaning, feeding, dressing, entertaining oneself, etc. (D'Alonzo, 2003). Considering the limitations of people with autism to complete certain activities, in order to foster their performance, they need:

clear and harmonious sensory stimuli
because they may demonstrate under or overdeveloped sensitivities, adverse reactions might be instigated from the presence/ absence or composition of certain stimulations such as visual details, noises, aromas, etc. They can become easily overwhelmed or agitated due to these sensory abnormalities.

«The school bell sounded like eleven alarm bells all sounding at once.»

usability
in order to facilitate their daily experiences or activities due to possible physical limitations.

order
because things in a certain order have a calming effect.

«The autistic child is unable to bring order in his world.»

comprehensibility
to be able to seamlessly comprehend the surrounding world.

predictability
because of their inability to imagine unobvious things, they need to be put in easily predictable situations, for that gives them a sense of certainty raising the self-confidence and making them feel calmer.

social relationships
in order to have opportunities to engage in social interactions and, somehow, to try to overcome their difficulties.

«People describe us as "not wanting interaction with others," but I have never wanted to be alone. I stay alone because of my limitations in communicating…. »

communication tools
because having support tools for communication can enhance confidence. .

«He might be screaming because he wants something, but I just do not know.»

orientation & wayfinding
because of their weak sense in identifying their location in the surroundings and finding their way back, others can buttress children with autism by letting them 'know where they are in terms of time, place, and social situation.'

«… after visiting a new apartment, she does not succeed in pointing out the right door to the exit.»

no distractions
due to their attention deficit, carrying out more than one activity simultaneously may be impossible.

«Sometimes, even the fleck of dust can attract his attention and make him loose in his world.»

3| MOTIVATION needs

Motivation is considered as one of the most important factors determining people's actions and goals. It inspires people to move forward by seeking the fulfilment of their desires, i.e., a need for satisfaction. The motivation of a person can stem from the individual him/herself (intrinsic motivation) or may be triggered by the social and physical ecosystem (extrinsic motivation). Motivation is strongly related to the sense of independence, which, in turn, hinges on the concept of decision-making's control and the possibility of choice to seek to accomplish wants (Lauria et al, 2019). These competences influence a person's ability to manage his own life. Therefore, in order to make people on the spectrum to carry out and to push with persistence the completion of their desires, they need to be motivated through:

sensory interests seeking

because they can easily feel overwhelmed, stressed, or fearful out of ordinary activities and experiences due to their sensory abnormalities, calibrating the stimulation helps them decrease anxiety and reduce agitation.

«Autistic children need their secret places to recharge themselves.»

encouraging challenges

because occupational or leisurely activities are powerful tools to attract attention, children with autism can reduce their stress levels by exercising physically and mentally.

flexible order

so their obsession for orderly situations is fulfilled by giving them the pleasure to follow them.

controlled change

because they insist on sameness unless a change derives from their actions. Thus, they must be in control of changes.

fantasy stimulation

so, they can work out on imaginative situations and play.

control over social relationships

because having the possibility to adjust the desired level of social engagement or privacy can result in increased levels of social interaction.

alternative means of expression

because finding spontaneous non-verbal forms of communicating and expressing their feelings and thoughts increases the possibility to interact with others, improves the quality of assistance provided by caregivers, and enhances the self-esteem of children with autism.

«I feel so much alone because not being able to speak is a big limit.»

visual support

because visual prompts containing different kinds of information may help them keep track of what is expected from them.

shift time

because they might need additional time to comfortably switch from one activity or task to another.

CHAPTER IV
DESIGNING FOR AUTISM

This chapter deals with the relationship between architecture and autism. It starts by describing why it is important to talk about autism in architecture by briefly showing its impact and the environmental features influencing the wellbeing of people on the spectrum. In this chapter, in base of the experiences of different architects who have worked in autism-friendly environments, there have been identified the macro design approaches for autism. A comparison among them follows by highlighting the advantages and disadvantages of each. In the next section, it is described an overview of the core literature on design guidelines and recommendations. The chapter concludes with a vision of what could – or should – be the future of autism-friendly design research.

IV.1 Genesis of Autism-Friendly Design

During the reconstruction of the Commons Chamber of the British parliament in 1943, Winston Churchill came out saying that «we shape our buildings and afterwards our buildings shape us.» Such a phrase prompts for a reflection on the tight bond that exists between human being and architecture. The environment is not a neutral space; it is not just the container of activities, but an operating factor of human life (Laurìa et al, 2019). The interesting feature of this relationship is the dynamism: the environment shapes behaviours, expectations and aspirations of those who inhabit it, and in turn the inhabitants transform it to adapt to their changing needs (Laurìa, 2017a). This symbiosis highlights the impact of design in the lives of end-users.

In the last decades, in particular, a close collaboration has involved architecture and neuroscience in order to better understand the relationship of human beings with the environment. Neuroscientists believe that the human behaviours and emotions are structured in the brain but are strongly influenced by the attributes of the environment, rather than by the cognitive sphere. Evidence coming from neuroarchitecture support the initiative to improve people's wellbeing through more accurate designed environments. Therefore, architects may be considered as charged with social responsibility, because through shaping spaces, they create conditions affecting the quality of life of the users. Each of us feels every day the impact of the environment that surrounds us and influences our behaviour: a noisy restaurant that makes us speak loudly to be listened by other, a dimly lightened room, or a building with a labyrinth layout where it is easy to get lost, make us feel uncomfortable and increase anxiety, stress and fear.

Fig 14 Scene captured from the movie Awakening (1990)

Fig 15 Scene captured from the movie Awakening (1990)

This becomes particularly important when it comes to people with specific needs. Often, even very small measures or precautions can make a big difference. Just to prove the point it would be enough referring to the movie Awakenings (1990). There is a scene where the lady suffering from catatonia – a brain lesions due to unidentified virus – while walking at the hall of the hospital, would suddenly stop. Neither Dr Sayer's attempt to help could make her step further. She refused to go beyond a limit, which seemed to correspond to the changing of the appearance of the floor. To verify this hypothesis, Dr Sayer drew a series of tiles to continue the pattern and the next day he saw the reaction of the lady. For the first time, the lady continued with her slow step toward the window, showing that the change in flooring pattern had given a sense of insecurity until then. Therefore, «the environment not only defines to what extent an impairment is disabling, but also the degree to which a certain solution for increasing accessibility is enabling.» (Laurìa et al, 2019).

Placing human outputs first can drive architecture toward better user experience and a positive impact on wellbeing, also preventing the high costs of poor physical and mental health. This is found to be true even for people with autism. Apart from the expectations of early intervention through treatments and counselling, environment adaptions can highly improve the quality of life (Schrameijer, a). The benefits of suitable environments could be comparable to those of treatments. Just consider, that even good training is less effective when it takes place in non-adequate spaces (Schrameijer, a). For instance, how can a child with autism concentrate during a training session in a room plenty of light reflecting on the table coming from large windows with a view through the chaos of the city, and with a continuous rumour coming from the ventilator of the heating plant unnoticeable for most of us.

People with autism can learn to somehow adapt to the everyday environment, just as every neurotypical do. The problem is that the adaption threshold for people on the spectrum is lower, thus making them feel uncomfortable more easily. Consider how just the accumulation of placards or neon signs can become e barrier to the wayfinding and, in turn, originate frustration and strange behaviour (weird movements, verbal utterances…). To a casual observer it may seem simply a misbehaviour, while, actually, it is the imbalance between the environment and the individual's ability to adapt to it, what has triggered that (Sánchez et al, 2011). To overcome this limit, it is necessary to make the environment adapt to them. This has made architects – mostly those in charge of designing buildings for people with autism – reflect and take into account the specific needs of individuals on the spectrum. The widespread of the awareness that the way these buildings were built and furnished could make a great deal of difference to their well-being, gave birth to the Autism-Friendly Design research.

Initially, in the late 1990s, there were spontaneous researches ad-hoc done by architects for the briefing of their projects for people with autism. They were mainly architects having family members with autism such as Christopher Beaver or Simon Humphreys. Later, around 2006, as cited in 'Architecture for Autism' website of the Dutch researcher Flip Schrameijer (d), it became a more structured and richer research engaging other disciplines – like psychology – for an extended analysis of various needs and mechanisms of autism. The Autism-Friendly Design research has tried in these years to explore the relationship between individuals on the spectrum and the environment. It has gone through monitoring the behaviour of people with autism in different contexts and analysing their reaction (Schrameijer, d) . The aim of these researches has been to give a contribution on the design and specification of buildings dedicated to people with autism.

Some of the psychological and social processes that researches on environmental psychology consider and investigate are: perception of environmental quality; memory and orientation through cognitive maps; personal space and privacy; socio-spatial schemes; affection to a place; communicative spaces, etc. (Giofrè, 2010). The spatial – physical and social – dimensions of the human experiences are in fact very peculiar because they are produced by the binding of information coming from various sensory channels; thus, it is a very complex process. In case of autism, the most difficult part is dealing with a spectral of autistic conditions and their atypical reaction.

This complexity is transferred even in the next steps. First, this difficulty is reflected in the challenge of architectural design to reconcile different and sometimes conflicting needs. Autism, being a spectrum, induces a wide range of interactions with the environments posing different demands on the building design. Secondly, having not the certainty of a scientific matter, the quality of the designed environment – as conceived by the architects – may not match the quality perceived by the end-user. The bigger this delta of the environmental quality is, the farthest the reaching of the environmental wellbeing is.

IV.2 Environment attributes impacting autism

What can the environment do for people with autism? In general terms, it can be said that it contributes to the overall wellbeing of individuals on the spectrum. An environment that takes into account likes and dislike, strengths and limits, makes a person feel better and help to cope more easily and willingly in that space. It must be noticed that it is a personal experience based on the individual perception of that physical environment (Baumers et al, 2010a). Marta Dischinger (2006) notes how different people see and experience the same environment, for example how they identify different features as landmarks, based on their personal interests, attention and perceptual capacities. Therefore, the perception, the understanding and as a result the appropriation each person makes of the surrounding environment is different. Speaking about autism, perception might be even more different compared to other people. As mentioned before, autism, as a pervasive disorder, is considered to roughly shape the world

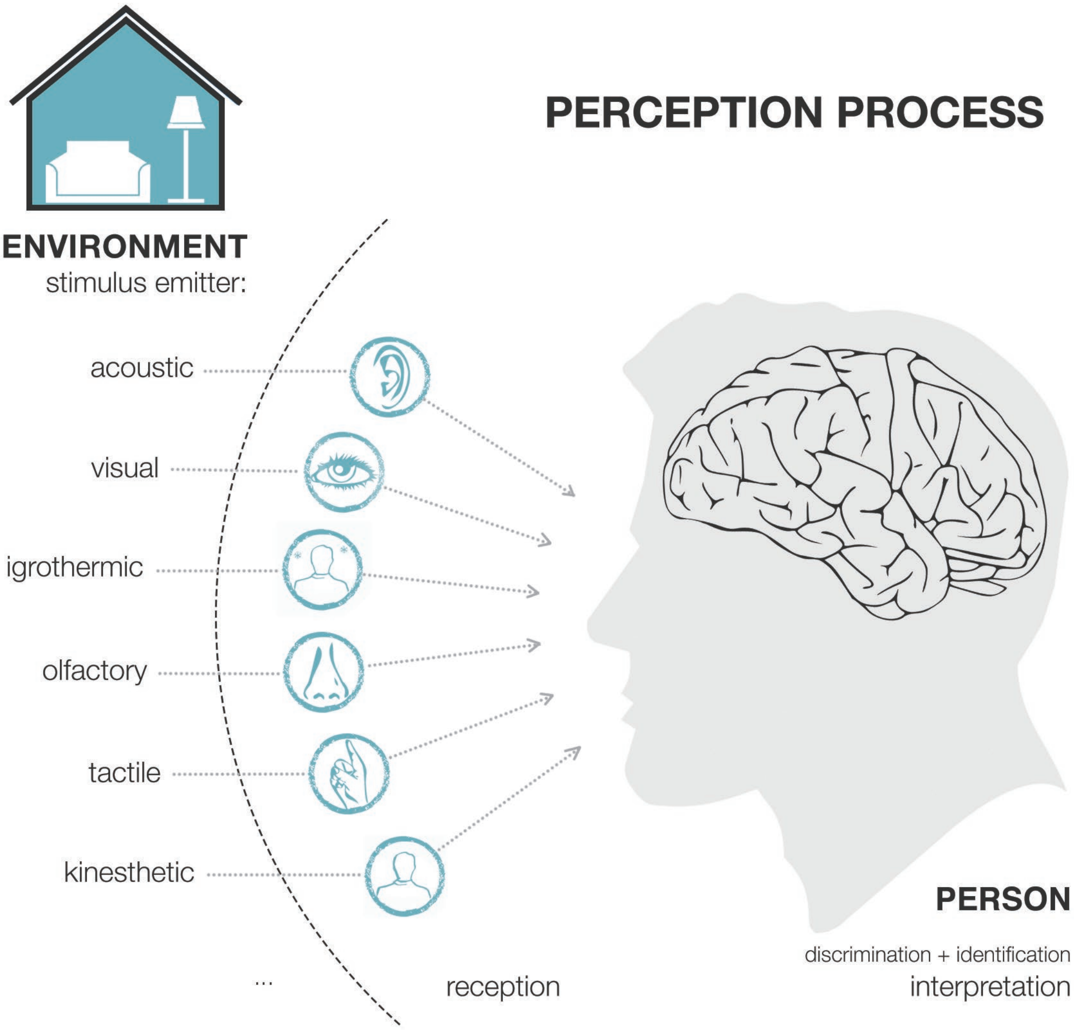

Fig 16 Perception process (reworked version from Lauria, 2003)

of perception experiences. Authors of different autobiographies refer to this peculiarity of their perception of the reality. Liane H. Willey (1999) relates «I was only beginning to see how peculiar my world was, not wrong or embarrassing or unessential, just peculiar and different.»

This seems to complicate things in trying to find out the environmental attributes that impact the wellbeing of individuals on the spectrum. However, it is not a mission impossible. People diagnosed with autism, like everyone else, explore the surrounding environment and engage in relationships through their senses. All the knowledge comes from what an individual has seen, heard, smelt, touched etc. as shown in Fig. 16. In people with autism, the process of perception is distorted at some point (see paragraph I.3.1). That is what causes the different way of perceiving the world by individuals on the spectrum. The various available therapies try to work on that part. However, the input comes from the environment and the output takes place there. That means that the environment impacts the overall process by stimulating and by welcoming the reaction. Therefore, the key elements are the environmental stimuli it emits and the users' activities it can accommodate. In order to promote and enhance the physical and mental health of individuals with autism, the effort for autism-friendly spaces should be working on the quality of environmental features and spatial conformation.

The built environment is a system of elements and relationships. It is composed by the spatial subsystem and by the technological subsystem. The spatial subsystem is referred to physical architectural space, but in fact, it regards immaterial concepts that describe that area. The technological subsystem, instead, is referred to the technical elements that delimit and make up the space, therefore it regards physical entities. Environmental attributes from both subsystems have an impact on the wellbeing of individuals with autism. Below, in Tab. 2, there are listed some of the most important features according to their subsystem.

SPATIAL SYSTEM	TECHNICAL SYSTEM
location	finishes
access	windows and doors
functional layout	fittings
circulation H|V	lighting
orientation	acoustics
proxemics	climate control
wayfinding	colour
flexibility	furniture
sight	equipment
privacy	signage

Tab 2 Framework of environmental attributes influencing autism.

IV.3 Design approaches

It is interesting to see how architects, over time, have dealt with designing environments for people with autism. Unlike other forms of the end-user's condition, there hasn't been a unifying adopted strategy to face the demands of autism on the environment. For example, for people on a wheelchair, the problem to address is known and the design focus is on the technical and creative solution. Of course, solutions differ in quality, creativity and integrity with the overall architectural intervention, but the issues that design must deal with are circumscribed. In the case of autism, the lack of a common approach can be related to the uncertainties of identifying people with autism's needs and what it is the best for them.

Difficulties can be found in a series of questions like: the way autism should be considered, whether it is a disorder to be treated or just a different way of being that needs respect; the understanding of autistic profile needs, considering the spectral presentation of autism; the fulfilment of conflicting needs in shared areas; the design's focus shift in addressing a group of symptoms considered more crucial rather than another one. All these issues, and maybe others, have been subject of discussion among architects. It may seem bizarre why architects should face these arguments, but they influence the theoretical project activity, otherwise known as meta-design[1]. The debate among architects about these topics has grown also because there is little design experience in this area and insufficient evidence of design efficiency (Henry, 2011a).

Some of the architects who have designed buildings for people with autism are: 3XN, James Vance & Associates Architects, Fletcher Thompson, GA Architects, Simon Humphreys, Haverstock Associates, Penoyre & Prasad, and Magda Mostafa (Henry, 2011a). A researcher on design for autism, Christopher Henry (2015), has tried to identify the design strategies used by these architects and group them in two approaches: the 'neurotypical' approach and the 'sensory sensitive' one. Their vision is opposing under many aspects strongly affecting the way spaces are designed. The differences between the two approaches will follow and in order to support the explanation, a school for children with autism will be taken as an example.

The first aspect where the approaches differ is the way they consider people with autism. The 'neurotypical' approach posits that individuals on the spectrum should be treated just like everyone else, as 'normal' people and that is the reason why the approach is named 'neurotypical' (Henry, 2011c). Those who advocate this approach, somehow, negate the existence of deficits and are very optimists for the future of people with autism. The architects

Fig 17 Developmental Learning Center, New Jersey USA Architects (photo © Rob Faulkner)

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[1] It is the transition process between the project briefing (data collection) and the concrete design, which defines the design strategy.

Fig 18 Netley School Autistic Resource Base, London (photo © Dennis Gilbert)

believe in the integration in the community of those with autism and this is reflected in the project characteristics. People with autism should share the same environments with neurotypicals. If a dedicated facility is needed, the building should simulate the real-world environments to favour the walkout process. If a school for children with autism is requested, it should be developed according to the features of mainstream schools, so the transition to outside environments becomes easier (Henry, 2011c). The “Celebrate for Children” school for children with autism in Stanhope New Jersey was designed bringing back up features of mainstream schools (Wallis, 2006).

On the other side, the ‘sensory sensitive’ approach recognizes the deficits of people with autism and puts its efforts in ameliorating them. In other words, it can be said that the ‘neuro-typical’ pushes individuals with autism to the limits, while the ‘sensory sensitive’ tries to create a protective shell. Those who advocate for the ‘sensory sensitive’ approach believe that people with autism should not be forced to live in ‘typical standards’ (Henry, 2011c). This seems the right observation but having too many special facilities for individuals on the spectrum, the risk to margin them is greater.

The second aspect that deepens the contrast between the two approaches is the main problem they try to address. The ‘neurotypical’ approach focuses on the difficulties that individuals with autism have with generalization skills (Henry, 2011c). They struggle to transfer a skill learned in one environment to another (see § III.1). For example, learning bathroom skills in a residential bathroom may not transfer to a public bathroom setting. To overcome this difficulty, some architects have chosen to create environments that are samplings of the real world. The “Developmental Learning Center” for children in New Jersey – designed by USA Architects – is a replica of a supposed typical American main street. It has a bank, a restaurant, a market and even some apartments. The central corridor is decorated with coloured panels, photos, pictures and crafts by the students, similar to mainstream schools. The architects claim that these kinds of environments represent the everyday life outside the campus (Henry, 2011c). That will help children with autism have a less intimidating transition from school to the real world (Marion, 2006).

The idea of creating simulated environments is not seen as an effective intervention by those who advocate for ‘sensory sensitive’ approach (Henry, 2011c). To master a skill, it is not enough to have a specific replica of the real world, because one must be able to use a skill in a variety of environments. In other terms, being able to generalize doesn't mean being able to function only in a substandard situation. So, in the case of the Developmental Learning Center, learning how to act in the store or at the bank inside the campus, doesn't guarantee that the children will transfer those skill in other banks and grocery stores. A series of different stores or banks could be needed to help them understand the differences and be ready to use a similar setting outside the school. This proposal makes the 'neurotypical' approach little rational due to the high costs[2].

Furthermore, the proponents of 'sensory sensitive' approach believe that, in order to generalize a skill, first you must learn it. Thus, people with autism need environments that help them acquire skills. Mainstream environments are often over stimulating and tend to be more distracting than productive. Architects sustaining the 'sensory sensitive' approach address this problem through designing subdued environments (McAllister et al, 2012a) (Humphreys, 2011). An example of this concept is the "Langagerskölen" school in Århus, Denmark, designed by 3XN. In this school, there are very few spaces with windows that look outwards (classrooms are not among these), because they believe that openings to the outside and strong natural light can be counterproductive (Henry, 2011a). Clerestories or opaque glass walls are used to bring natural light into classrooms and corridors illuminating the space without distracting students.

Another aspect that separates the two approaches is the way they deal with the sensory issues of people with autism (see § III.1). Architects advocating 'sensory sensitive' are very sensible to the difficulties of the sensory processing of individuals on the spectrum. Therefore, they try to subdue environmental stimulation and create predictable and organized spaces (Henry, 2011c). They sustain that calm colours must be used, noise levels should be reduced at minimum, ceiling heights preferably must be kept low and spatial volume small, and it must be paid particular attention to lighting (Henry, 2011a). Trying to generalize, the focus is on the hypersensitivity extreme end of the sensory distortion in autism. The strategy chosen is the low threshold of various stimuli, in order to not reach overloaded sensory experiences.

The advocates of the 'neurotypical' approach strongly disagree with this aspect and favour the opposite environmental attributes, like high ceilings or large volumes. Initially, they used to argue with the fact that sensory distortions in people with autism were not prevalent in autism. This was until 2013 when the DSM-V was published. Sensory issues were included in the diagnosis (APA, 2013) after it was found that more than 90% of individuals on the spectrum show difficulties in sensory processing. However, they still don't share the same idea, as recent reviews of sensory therapies have not found evidence to support the efficiency of such therapies (Henry, 2015). As a result, their application would not lead to successful architectural intervention. They would simply limit the development of abilities in individuals with autism and would make them prisoners of specific environments (Henry, 2011c).

Both approaches have arguments to be considered advantageous, but also weaknesses. Their biggest limit is the inability to prove their hypotheses. It is difficult to measure the effects and to control all the compounding factors. Most of the architects' decisions are based on anecdotal evidence or observational studies that lack the methodological rigour needed to be considered reliable (Henry, 2011b). Having no experimental studies to compare the two approaches, it is hard to say which one is appropriate. Anyway, the goal should be to make individuals on the spectrum feel comfortable and make them able to attend and train for skills outside the designed environments to become more integrated with the larger world whenever they will be ready.

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[2] A good alternative good be teaching through video modelling. Individuals with autism will learn through displayed images and videos on how to act in different types of settings. Studies have shown that it is a more effective teaching skill generalization than learning single prototypes of settings. For example, individuals with autism were not able to generalize purchasing skills to three different community stores after learning the skills in a single store. However, they were able to do that after watching videos of the skills performed in all three stores.

IV.4 Guidelines for autism-friendly spaces

Despite the significant epidemiology of autism and the various architectural interventions dedicated to those affected mainly in the last two decades, autism is minimally included in the accessibility codes and design norms. To overcome this gap, researchers and architects who were assigned to design for autism, have tried to develop a preliminary framework of architectural design guidelines for autism. Some of the authors were driven from the design experience, others from the experience of close parents with autism, some through interviews with caregivers, and a few through experimental surveys. The frameworks elaborated from different authors are not all referred to a specific age range. Some of the studies describe specific settings like education or living arrangements, while others are more generic. Some of the authors are limited to posit general strategies to design, whereas others go into detail often defining even preferred materials or architectural solutions. The complexity of autism disorder, as for the design approaches discussed above, has sometimes led to contradictory design instructions among different authors.

In this paragraph, a review of the consulted scientific literature of design goals will follow. This includes published non-statutory official guidance, selected books, research reports, scientific journal articles, conference proceedings or presentations, and one web platform. They will be presented by the author following the alphabetic order.

Prof Sherry AHRENTZEN and Prof Kimberly STEELE – respectively, a researcher in policy making and strategic initiatives and a professor at the School of Architecture, are both members of Arizona State University. They did a research that examined housing for adults with autism, by presenting a comprehensive review of housing features for individuals on the spectrum in the United States. They analysed a number of residential settings, including different types of buildings – independent detached and attached houses, clusters of attached homes with common spaces, single-room occupancy units...–; different situations of dwelling – with or without family, with selected friends or agency chosen room-mates –; mixed or exclusionary residential complexes; and different types of care and support situations (Ahrentzen et al, 2010). Their effort was to formulate evidence-based design goals and guidelines to direct future housing design and development (Ahrentzen et al, 2010). Initially, there were identified 101 projects to consider as case studies of exemplary residential developments. Only 17 of them were visited on-site and interviews with staff were conducted to gather information. The design goals include the necessity to: ensure safety and security; maximize familiarity, stability and clarity; minimize sensory overload; allow opportunities for controlling social interactions and privacy; provide adequate choice and independence; foster health and wellness; enhance one's dignity; ensure durability; achieve affordability; ensure accessibility and support in the surrounding neighbourhood (Steel et al, 2016). The report elaborated aimed to help housing providers, architects, developers, planners, public officials in understanding the demand of adults with autism in the housing settings.

Arch Junik BALISHA – is a young architect and PhD candidate in architecture. His research experience on autism-friendly design – prior to the present study – was conducted with an interdisciplinary focus group including various experts on autism. The goal was to set up a design strategy for the realisation of a Centre for adults with autism. After analysing the needs of individuals with autism, exploring several case studies, visiting and evaluating two recently built facilities for people on the spectrum, Balisha elaborated a design strategy and a kit of 60 indications for the design of autism-friendly environments. The key principles that guided the process were: integration of the intervention with the context; work on skills and self-esteem; enhance wellbeing; maximize usability; guarantee users' safety; and provide a sustainable economic management (Balisha, 2017).

PhD Stijn BAUMERS and Prof Ann HEYLIGHEN – are two researchers at the Department of Architecture of the University of Leuven. They have studied the interaction of people with autism and the built environment through a qualitative research with a user-centric approach (Baumers et al, 2010b). They investigated the physical environment from an autistic user perspective through the interpretation of autobiographies of people with autism. By analysing their experience descriptions, they tried to get closer to the way people with autism think and act in relation to the space (Baumers et al, 2010b). Seeing the world through their eyes challenges the way we – neurotypicals – think about the built environment. This research was deepened a few years later by Baumers and Heylighen in collaboration with Kinnaer (2014). They made an effort to report how people with autism (like to) live and how this could relate to concepts of autism-friendly architecture. Even this research adopted a qualitative and interpretative approach, through interviews with 11 adults on the spectrum and visits to their houses. Interviews were semi-structured and introduced a selection of concepts in the form of thematic dilemmas adults with autism face when searching for a place to live. The picked themes were neighbourhood; housing type; layout; and interior (Kinnaer et al, 2014). The stories of these 11 adults on the spectrum revealed different viewpoints on the various themes. These experiences suggested that autism-friendly concepts could not be static, but a balance and a harmony among them must be sought (Kinnaer et al, 2014) (Kinnaer et al, 2016). The contribution of this study was to give a more profound insight of what autism-friendly living environments mean to people with autism.

BB 102_UK Government Building Bulletin – "Designing for disabled children and children with special educational needs" is a guidance for mainstream and special schools. This bulletin is a collection of helpful information for everyone involved in designing qualitative and efficient schools, in particularly for architects, designers and education advisors. It has not a statutory value, but it is presented as a guidance on planning and designing accommodation for new and existing schools in England. With regard to the school environment, the bulletin lists the design issues for children with autistic spectrum disorder as: «Simple layout: calm, ordered, low stimulus spaces, no confusing large spaces; indirect lighting, no glare, subdued colours; good acoustics, avoiding sudden/ background noise; robust materials, tamper-proof elements and concealed services; possibly H&S risk assessments; safe indoor and outdoor places for withdrawal and to calm down.» (BB 102, 2018).

Arch Christopher BEAVER – is a British architect who has been working on the design of buildings for people with autism since 1996. He is the founding partner of the GA Architects; design and development consultancy studio in London. He presents a practice-driven approach through his working experience with providers and educators on the design of autism-friendly buildings (Beaver, 2011). His professional background is enriched from feedback studies of post occupancy evaluations of his projects. His work is focused on residential and educational building with no reference of age, because he believes there is no difference in designing for children or adults (Beaver, 2011). He gives insights for new build, but also for possibilities of refurbishment of existing buildings. The framework of design instructions elaborated in the years and presented in conferences goes through all levels of design: from giving indications about the way finding, clear geography, good lighting and ventilation, good acoustics, particular attention to the circulation space; to the finest detail like doors, colour palette, toilet appliances, finishes and materials (Beaver, 2011).

Engr Andrew BRAND – is a designer and engineer. He is the founding member of a start-up company Squease, developing smart clothing for teenager with autism, which makes the wearer feel protected and at ease when on move. He conducted a research in collaboration with the Helen Hamlyn Centre for Design commissioned by the Kingwood Trust, a charity in support to people with autism. The research project was about the residential buildings for adults with autism exploring their impact on the wellbeing and how they could be more autism-friendly (Brand, 2010). The focus was shifted from the residential institutions to community-based models of housing. In order to understand the housing needs of adults on the spectrum, his research started by looking at how people are currently supported in homes. Seven homes for autistic adults were visited and residents were interviewed in situ (Brand, 2010). There were organized also workshops with individuals on the spectrum to get feedbacks on selected issues. The outcome of the research was the elaboration of four main design themes to help architects and designers in their projects of residential buildings. The four design themes aim to: «enhance the motivation, confidence and self-esteem by encouraging exploration of their environment and providing spaces for developing interests and skills; reduce the triggers of agitation and anxiety and provide comprehensible, coherent spaces that meet the sensory needs of individuals; keep residents and staff safe in a robust environment that is tolerant of unintended use; and give staff the tools to deliver people-centred care and support.» (Brand, 2010). From these themes, design recommendations were generated for the location, orientation, structure, layout and interior design of residential buildings created specifically for adults with autism. The design guideline targets were planners, housing providers, architects and designers.

PhD Katie GAUDION - is a Senior Research Associate at the Royal College of Art's Helen Hamlyn Centre for Design. Her specialist interest lies in exploring ways to involve children and adults with neurodevelopmental conditions into the design process. Among other researches on autism-friendly design, a particular research project was that on outdoor environments for adults with autism. The research was conducted in collaboration with Chris McGinley and focuses its attention on how design can create beneficial green spaces for adults on the spectrum (Gaudion et al, 2012). The various methods used to understand the needs of adults with autism included: examining the timetabled activities in three residences for adults on the spectrum; spending time with them; conducting workshops with them and the support staff; shadowing a horticulturist who works with adults with autism; and identifying best practice by interviewing experts on site (Gaudion et al, 2012). The study explored the way how to translate the individual interests into opportunities for social, emotional, academic and vocational growth within the garden. The researchers built upon four design themes in relation to outdoor space and developed a series of considerations for each: growth (leisure, occupation, exercise, special interests); triggers (sensation, perception, refuge, predictability and control); robustness (safety, durability, ease of maintenance, flexibility); and support (communication and social interaction, personal support, unobtrusive monitoring) (Gaudion et al, 2012). The research resulted in the development of a collection of spaces that respond to common themes and characteristics of autism, while catering for different, individual needs. The research also informed the development of the new garden at Kingwood College resulting in a practical expression of its findings (Gaudion et al, 2012). Her PhD thesis also regarded autism and investigated how people with autism experience their home environment. The PhD identifies and develops design tools involving autistic adults, their support staff and family members (Gaudion, 2015). It explores three home environmental contexts: garden, everyday objects and interiors. Her work is based on a person's strengths which put the emphasis on his/her preferences, interests and capabilities (Gaudion, 2015). This work provides insights of the subjective experience of people who have different ways of exploring and living the environment (Gaudion, 2015).

Arch Simon HUMPHREYS – is an architect. His vision on design for autism is related to his experience with his late autistic brother. He has designed a number of buildings for people with autism and has developed a series of practice-based instructions for designing environments for autism. His approach is founded on a series of simple concepts which he believes could have beneficial effects for people with autism (Humphreys, 2011). The design indications elaborated from Humphrey do not refer to a particular age range or to a specific context. His instructions are more at a strategy level and do not go into specific detail, but they are often illustrated by architectural solutions he has designed in various occasions. Some of the aspects enclosed in his approach are: calm spaces, clear layouts that favour order and simplicity; minimal details and materials; adequate proportions of architectural elements; good levels of natural light and ventilation; attention to the proxemics and containment; observation and staff supervision; good quality acoustics; and cultural account for a stronger bounded intervention to the context (Humphreys, 2011). His framework is limited to simple concept in order to assist designers develop projects for people with autism at a universal scale.

PhD Rachna KHARE and Prof Abir MULLICK – two Indian researchers present their study on how behavioural features of autism can be incorporated in the design process of learning environments. It is an evidence-based research that aimed to determine enabling aspects of educational spaces assisting children with autism. Their research started by selecting environmental design considerations that address educational and behavioural aspects and then by identifying those design parameters connected to autism. The study highlights eighteen 'design parameters' as the most dominating ones and which act as a measurable quantity in the study (Khare et al, 2009). The identified parameters are physical structure; visual structure; visual instructions; community participation; parent participation; inclusion; independence; generous space standards; withdrawal spaces; safety; comprehension; accessibility; assistance; durability and maintenance; limit sensory distraction; sensory integration; flexibility; and monitoring (Khare et al, 2009). Three testing tools are used to evaluate the design parameters and develop a measurement scale. The survey is conducted in educational settings – all age groups from preschool to high school – in the United States and in India. Different type of educational settings – from inclusive to specialized – are included in the survey (Khare et al, 2009). The study involved autism experts and education experts. The survey confirmed that the identified design parameters are favourable for children with and without autism. Therefore, the outcome of this research is expected to help architects and designers to design autism-friendly inclusive educational spaces.

Arch Keith MCALLISTER and Arch Barry MAGUIRE – are lecturer and tutor – respectively – in Architecture at Queen's University of Belfast. McAllister has a particular interest in autism-friendly design as being the father of a son with autism. They have conducted a two-year study on educational spaces, more specifically, key stage 1 (age five to eight) classroom. The research was carried out in conjunction with autism teaching staff on adapted classrooms from existing school accommodation. It highlights the challenges faced by children with autism in a school environment. It also evidences a triad of challenges faced by designers and architects in charge of classroom design, such as: differing severity of autism; differing range of sensory difficulties; and how to best promote and make pupils with autism gain independence in that environment (McAllister et al, 2012a). The method selected this time for the research was by using physical models to facilitate the dialogue with the teachers. The outcome of the research consists in a Design Kit of 16 specific design considerations for autism-friendly classroom applicable to all classrooms in a primary school setting (McAllister et al, 2012b). The design considerations regard: the classroom entrance; cloakroom provision; sight lines; visual timetable; high-level windows; volume height; control; external classroom play area; school playground; quiet room; toilet provision; kitchen; larger areas; storage; computer provision; and workstations (McAllister et al, 2012a).

Prof Magda MOSTAFA – is an architect and an Associate Professor of the Department of Construction and Architectural Engineering, The American University in Cairo, Egypt. She has conducted for years a research on educational spaces for children with autism. The outcome of her research was developing a Design Index called the Autism ASPECTSS. The vision of the index is based on the Sensory Theory of autism explanation (Mostafa, 2008). It hypothesizes that behaviours of people with autism can be altered – positively or negatively – through altering the sensory environment using specific design interventions. This research is an evidence-based project (Mostafa, 2015). The experimental testing was determined through a survey of caregivers and teachers of children with autism. Initially, she elaborated a Sensory Design Matrix, which links the architectural elements with the autistic sensory issues (Mostafa, 2008). The study proposes a strategy which aims to reduce the sensory overload of people with autism and to provide him/her means to mitigate it when it happens (Mostafa, 2015). This strategy is summarized in seven design criteria, the Autism ASPECTSS Design Index: Acoustics, SPatial sequencing, Escape space, Compartmentalization, Transition spaces, Sensory zoning and Safety (Mostafa, 2018). Two of these aspects were tested in two modified classrooms; an acoustically altered speech therapy class, and a compartmentalized general classroom. The indicators used during the survey were attention span, response time and behavioural temperament of the pupils (Mostafa, 2014). The findings of the test were used to define more specific design guidelines. The index could be applied for the assessment of built learning environments to evaluate the building performance and identify critical aspects, as well as for the design of new educational settings (Mostafa, 2015).

Dr Pilar Arnaiz SÁNCHEZ, Prof Francisco Segado VÁSQUEZ and Dr Laureano Albaladejo SERRANO – these Spanish researchers took a different look at autism-friendly environments compared to previous researchers who had worked on that topic. After reviewing the work of their colleagues on design guidelines or design strategies for architectural interventions for autism, they presented a more diagnostic approach to autism. They tried to link the various manifestations of the disorder - limited capacity for imagination; communication challenges; difficulties with social interaction and sensory challenges; behaviour and safety - to the built environment, generating a dialogue of resultant criteria (Sànchez et al, 2011). As a result, they outline several responses how to make the designed environment meet the demands of people with autism (Sànchez et al, 2011).

Dr Flip SCHRAMEIJER – is a Dutch sociologist, mental health specialist, and author of several books on mental health issues. His prominent work on design for autism is related to the foundation of the web platform "Architecture for Autism". This instrument created specifically for designing for autism comes after a collaboration with the Dutch centre for autism, Dr Leo Kannerhuis – the largest treatment and knowledge centre about autism in the Netherlands. He wrote a book in 2013 in Dutch about architecture and autism "Met het oog op autism" (With an Eye on Autism), based on the extensive building and design experiences of the Kannerhuis in conjunction with the results of four years of research conducted by Schrameijer. The website is the re-elaboration of the volume and the result from his continuous research and practical experience. The aim of the website is to systemize the knowledge data, offering both practical recommendations and the considerations behind them. The recommendations are organized according to the context – child home; school; independent living; treatment home; and long-stay home – in five chapters – location; outside area; architectural spaces; interior design; installations and appliances. In addition, there are specified a series of specific ‘themes’ to each chapter to express the general principles and considerations from which the corresponding recommendations follow, such as: light and vision, zoning, sound, colour, etc. To date, there are a total of 194 recommendations of which 133 have been tested: 46 in the context of ‘home for children’, 44 in the school, 43 in independent living solutions. It is an on-going project which aspires to contribute to evidence-based design for autism and help anyone who is interested in the design of environments for people on the spectrum.

Arch Iain SCOTT – is an architect. His research aims to set out the key criteria needed to be taken into account when designing learning environments for children on the autism spectrum. The undertaken study started with an examination of the existing body of knowledge at that time to find out the relevant criteria in designing for autism. These criteria were analysed and illustrated by looking in detail at four new schools through visits and interviews with the architects and end users. The selected schools were: New Struan (Scotland); Netley Primary School ASD Unit (London); Whitton School ASD Unit (Richmond LA); and Mossbrook Special Primary School (Sheffield). The research provided general design guidelines such as: clear and comprehensible layout; variety of spaces; control of the environmental conditions to the user; space flexibility to different teaching methods; balance of security and autonomy; simple and minimal detailing; involving end user in the design process; appropriate use of technology to aid the learning experience; and make use of appropriate technical specification (Scott, 2009). In addition, it provided further key recommendations from the site survey of the application of the design criteria. The framework is addressed to help architects, designers involved in creating effective learning spaces for children.

Dr Teresa WHITEHURST – is a researcher and development officer at Sunfield School – a residential living space and school for children with autism in London. Her research describes the features of the new building designed by the GA Architects for 12 children with autism. The aim of the research was to find out what was the impact of the new intervention upon the children accommodated there. It is based on the users’ feedbacks comparing children’s experience in the new school accommodation with the old one (Whitehurst, 2006). The study was based on interviews with staff and families and a focus group of members from both schools. The research concluded that the positive features of the new-built school impacting children were autonomy in space; choice and privacy; orientation through curved walls; clearer views; long circulation spaces; a general sense of calmness (Whitehurst, 2006). It was noticed also a positive impact on staff referred to: their calmness in assisting and supervising the children; their general well-being; better supported to help children be more autonomous (Whitehurst, 2006). In addition to the positive impacts, the staff reported further issues that could improve the performance of the building and could guide future developments.

IV.5 The future of autism-friendly design

As for the main topics about autism discussed previously, there is a question mark on what is going to be the future of the autism-friendly design research. After less than a decade of research – from 2006 to 2015 – even though there is an increasing trend of the epidemiology, the intensity of exploration has slowed down. From the last paragraph can be noticed something interesting: the design guidelines and recommendations, generally regard specific settings for people with autism and they apply only to facilities dedicated to them. Furthermore, there is a scarce representation of individuals on the spectrum in the building codes (Khare et al, 2009; Mostafa, 2015). This leads to a lack of sensitivity among architects and designers, regardless the overwhelming occurrence of autism and now widely accepted idea that the environment has a great impact on the wellbeing of those with autism.

There are two problems that derive from that, which in turn are interconnected. The first is related to the way we see and consider people with autism. Individuals on the spectrum may experience the world differently, but they live in a social context which counts on certain 'neurotypical' skills (Baumers et al, 2010a). We assume our standards as normative in organising the society and forget that it may result in a deprivation of people with autism's rights to live with dignity. The second issue is related to the approach of special services dedicated to individuals on the spectrum. This system is considered by many authors, such as Ratzka (2007), as contributing to the segregation and discrimination of the disabled people.

To individuals on the spectrum, there are offered a series of services in facilities customized – as much as possible – to their needs such as assisted living or special schools. However, what happens out of these doors and out of their private habitat, it is not a matter of autism-friendly environments anymore. People with autism have to walk in the streets, go to train stations or airports, take the bus, go to a playground, go to the park, go to the hospital, or often in prospect of inclusion are required to go and sit in the same classroom with other students, just pretending to be *normal*. It would seem commendable the will to consider them *normal*, but the reality is far different. To people with autism is given no other option, rather than adapting to our environment.

It seems that something is missing, as Sherlock Holmes[1] would say: «The world is full of obvious things which nobody by any chance ever observes.» (Doyle, 1964). In a world claiming the advocacy of the rights of all citizens, it is not too much asking people with autism to act *normal*, while it is too much asking to the rest of the society to welcome them. The problem of the relationship between disability and normality is that the discrimination cannot be fought by denying the existence of difference or neither by noticeably marking the differentiation, but by modifying our image of the norm (Pontiggia, 2002). It begins with the commitment of each of us to shift in thinking about disables. Consequently, the policies for disability at all levels: from the creation of the laws and institutions at the core of society to regulations concerning labour, education, health, construction; should follow that shift in changing the boundary between ability and disability.

The dilemma that arises is whether we should go for an autism-friendly at all levels, from private to public environments, or whether that is too utopian to ask for. The issue is too complex to answer briefly, but an effort to show the hot spots of the topic will follow.

The first consideration will look at the accessibility norms. Italy will be taken as an example. The last update of the norm on accessibility was the Decree of the President of the Republic n. 503 of July 24th, 1996, «Regulation containing rules for the elimination of architectural barriers in buildings, public spaces and services.» It was an addition of the Ministerial Decree n. 236 of June 14th, 1989, «Technical requisites necessary to guarantee the accessibility, adaptability and visitability of private buildings and subsidized and facilitated public residential buildings, in order to overcome and eliminate the architectural barriers.» The focus is on the obstacles that people with reduced mobility face and to their elimination for comfortable and safe use of

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[1] The fictional detective of the British writer Arthur Conan Doyle in "The Hound of the Baskervilles".

the spaces and equipment. Other than being dated by now, the spontaneous question that pops up is: meanwhile there is wide attention on accessibility topic for the physical disability in every public intervention, why don't we expect the same for individuals with autism? This discussion could have been seen as not worthy in the '80s when autism was estimated to affect around 1 in 5000 children (Sun et al, 2010). But, nowadays, as reported in the latest surveys, the prevalence of autism is estimated 1 in 40 children, which means that nearly 2.5% of new-borns fall on the spectrum (Searing, 2018). This data is strongly comparable to 1.85 % of people who have a physical disability and need a wheelchair (Wheelchair Foundation). What is more worrying about these numbers are the consequences. Individuals with autism very often experience severe mental ill health because of lack of support. As reported in "*Human rights of people with autism not being met, leading expert tells United Nations*" (2017), they can't access the public services or are often asked to leave because of their awkward behaviour. Besides, half of the adults with autism report feeling lonely and a third of them do not leave the house most days.

The second aspect relates to the multiplicity of disorder categories in the diagnostic system. If we believe in autism-friendly design, we should have to consider the friendly-architecture for every other disorder. Just considering that from the last DSM update, the cases with autism known as Pervasive Developmental Disorder were divided into two different disorders: the ASD and the SCD (APA, 2013). That would suggest having ASD-friendly environments and SCD-friendly ones, which is probably too much and seems too utopian to achieve. But maybe it is not that wrong aspiring for that, since there is an extensive and successful evidence-based practice of adapting the environments to the needs of the end-users and it has become generally accepted that customized environments improve the quality of life (Del Nord, 2006).

The third consideration is about the inclusion approach. Inclusion is not all about being together in the same environment. "*Human rights of people with autism not being met, leading expert tells United Nations*" (2017) reports that one in five children with autism has been excluded from mainstream schools deprived of the right of education. Of those remaining, half report having been bullied, which is a risk for depression. That suggests, that letting pupils with autism attend mainstream learning environments isn't enough for their inclusion. To overcome that, we need to change our behaviour toward the welcoming of people with autism and include them in shaping our future together, from design to implementation. Maybe, that is still not enough, but at least, it will permit more pupils with autism to follow mainstream schools and make them feel more comfortable.

The last aspect to take into account in this discussion regards the specificity of autism-friendly requirements. Often accessibility codes are seen by the architects and designers as something they have to cope with, and not as a normal approach to the project "as if people mattered" (Marcus et al, 1988). Consider, how crucial is an elevator for someone with mobility impairments, but at the same time the elevator is useful to many other categories, like an elderly, a pregnant lady, someone with a small child, someone carrying a luggage, someone who has to temporarily use crutches, or simply to someone that is tired after a long day at work. The same can somehow apply to autism-friendly environments. Looking at learning environments, the architect John Jenkins has an interesting viewpoint: "Mainstream children are probably more 'able to cope' with badly designed spaces than an autistic child would be" (as cited in Scott, 2009). That means that environments customized to individuals with autism needs, do not request anything that could not be normal and profitable even for the other pupils. For example, «After deciding about the location of the school, take satisfactory measures towards sound isolation around walls, windows and other facade openings.» (Schrameijer, b) is an indication affecting all pupils. Having soundproof walls and windows helps all students to concentrate and to not get distracted by traffic rumours.

To come to an end, it looks obvious to opt for wider application of autism-friendly indications, but that is easier said than done. What it can be done is to start step by step accepting that diversity is the new 'normal' (Honeybourne, 2018). Meantime, as concerning the architectural project and build environments, Flip Schrameijer (a), the pioneer of *architecture for autism*, has a proposal: «as *ordinary* as possible and as *special* as needed.» At that point, people with autism would feel more comfortable indoor and would fear less to walk outdoor.

PART II
DIRECT INVESTIGATION

The second phase involves a field analysis, i.e., the on-site examination of the problem area. The focus is on environments where therapeutic and support interventions are provided for preschool aged children with autism. This study examines four different countries set in different contexts regarding autism: Albania (my birthplace), Italy (the country where I have conducted my university studies and the doctoral programme), United Kingdom and the United States (countries where autism research is particularly developed). In these four countries, I have engaged in on-site visits to four case studies and analysis to understand how the same problem is affronted in different contexts. In addition to assessing independently the quality of the relevant surroundings, I have complemented my analysis with the feedbacks of one or two staff members who accompanied me during the visits. Furthermore, to better understand the reality that families having children with autism face every day, I have conducted interviews with four parents. These parents are well-known in their countries as public figures, who have also contributed in raising autism awareness. Last, this study also uses in-depth interviews with selected autism experts – one for each country – to elaborate and solve the critical issues and doubts emerged during the research.

CHAPTER V

PROBLEM AREA DEFINITION

This chapter aims to circumscribe the problem area and outline the research methods applied in this study. It starts by describing to whom this research is referred to. Then, it follows by identifying the main investigation focus on the care chain. The next section proceeds by listing the subjects of this research and the study sites. Each section explicates clearly the rationale behind this paper's choices.

V.1 Preschool age children focus

As mentioned, autism is a lifelong condition which means that an individual diagnosed with autism will remain on the spectrum for the rest of his/her life. Whether a person is born autistic or whether autism is developed during the first years of life remains a controversial academic subject. The aetiology of autism, standing for the combination of genetic and non-genetic influences, supports, to a certain extent, the validity of both theses. Empirical evidence do not avail the solution of this quandary either, for some parents report that they knew that something was wrong with their child since early on, whereas others describe a sudden change of their child's behaviour. At the present moment, no single medical examination can accurately and reliably diagnose autism. The latter's identification is carried through behavioural observations, i.e., the identification of the autistic condition is correlated to the exhibition of the spectrum/behavioural traits. Thus, it is hard to define a precise moment for the diagnosis for a spectral condition. This difficulty derives in part from the differences in its display and the ability of children to hide or not its presence. Scholars believe that girls are more able to mask autistic traits, and this could be one of the reasons why the ratio of males affected by autism is reported to be much higher (Dworzynski, 2012). The first signs of autism can sometimes be detected starting from the 18th month of life, although a complete diagnosis can usually be given only between the second and the third year of life. In a few cases, it may take a bit longer to understand the presence of certain symptoms.

The diagnosis is a protracted and difficult process. A schematic representation is shown in the Fig. 19. The first person to notice traits of autism or just something eccentric in the development of a child could be one of the parents or other persons that provide medical care to the child, such as the family doctor (GP), the nursery nurses or health visitors. The diagnosis could follow different paths according to the evinced symptoms. Autism, being defined on a spectrum and accompanied almost always by comorbidities, may not be identified as such until the affected individual consults a specialist for each symptom — only then a pattern between the individual symptoms can be drawn. A complete diagnosis usually requires the presence of a multidisciplinary team composed of several different specialists. This peculiarity of autism can prolong the autism diagnosis procedure in time. As referrals are required to see each of the specialists and, particularly, public health institutions are prone to long waiting lists, the diagnosis process usually suffers from widespread delays. What is more, not all the specialists required for the diagnosis work within the same department, making the overall process feel like a game of table tennis, with concerned parents being bounced from one place to another and not getting definite answers. Therefore, a complete diagnosis may take a very long time — currently, as referred by parents and healthcare staff members in my countries of interests, Italy, the United Kingdom, Albania, and the United States the diagnosis process can take up to two years.

After the diagnosis, if positive, the specialists should draft specific educational and health care plans. These plans describe the needs of the child with autism and the interventions that will be helpful to his/her growth. Every child has different needs, mutable over time. Identifying them and finding the appropriate treatments are complex tasks. Periodical check-ups and updates to evaluate the ongoing performance of the care plan — whether it is working in the right direction to fulfil the necessities and the aspirations of the individual — are necessary. Even though autism is a complex neuro-developmental condition, children on the spectrum can develop as their peers, although in a unique way. This is a crucial moment in the life of a child, because the brain develops exponentially in the early years. Therefore, an early and accurate diagnosis, followed by timely and appropriate interventions, can lead to a highly better prognosis of the autistic condition.

Meanwhile, this could prove a very difficult moment for the family. Particularly, if lacking previous experiences with other children with autism, the parents and siblings can find themselves in an aggravated psychological state. They are concerned about the health of their loved ones and they usually know very little or nothing about autism. While waiting for the dust to settle and to understand their next steps, they can experience anxiety, stress, fear, blame, etc. Often, they have difficulties to face reality and accept that their child is different from his/her peers. Parents that try to hide their child's condition out of fear of potential social repercussions are not uncommon. These families also have to struggle with logistics and bureaucratic hindrances — what should they do, how do they need to behave with their child, where should they get the right therapies for their child, who should they contact, how to get financial assistance, when and who can they ask for support, etc.

Furthermore, families with autistic children face different economic and temporal restraints. While parents, generally, devote a great amount of time to their children, rearing a child with autism engenders more exacting demands for the parents. Children on the spectrum need continuous attention and may even need full-time care. These parents' daily routine could include several time-consuming activities directed to their child, such as taking personal care of the child, arranging for various forms of support, dropping the child off at nursery-schools or childcare centres and picking him/her up at the end of the day, arranging for additional medical and psychological care, requiring assistance from social contacts, accompanying the child when he/she attends various social activities, and maintaining contacts with the official bodies (HCN, 2009). In the end, the family has to carry the burden of care of their loved one. This could limit parents' time for themselves or for the other children, if any. Rearing a child with autism also affects the ability of parents to work for a living, making them switch to part-time jobs, change jobs frequently, turn down a job or give up work completely (Montes et al, 2008). As a result, they may feel the adverse effects of a wanting normal life without leisure activities, career opportunities, and/or social relationships, which aggravate the already dark situation.

For these reasons, I have chosen the moment post diagnosis – being such a delicate moment for the whole family – as the focus of this study. The selected age range carves out the group children in the early years, more specifically, children at preschool age. This paper does not specify a precise range of age values and allows both extremes – the lower and higher – to vary. As mentioned, the age of the child during the initial diagnosis depends on when the child presents autistic traits and someone notices these. On the other hand, the mandatory school age is objective, i.e., set by the laws of that country — it could be 5,6, or even 7 years old in some countries like Albania.

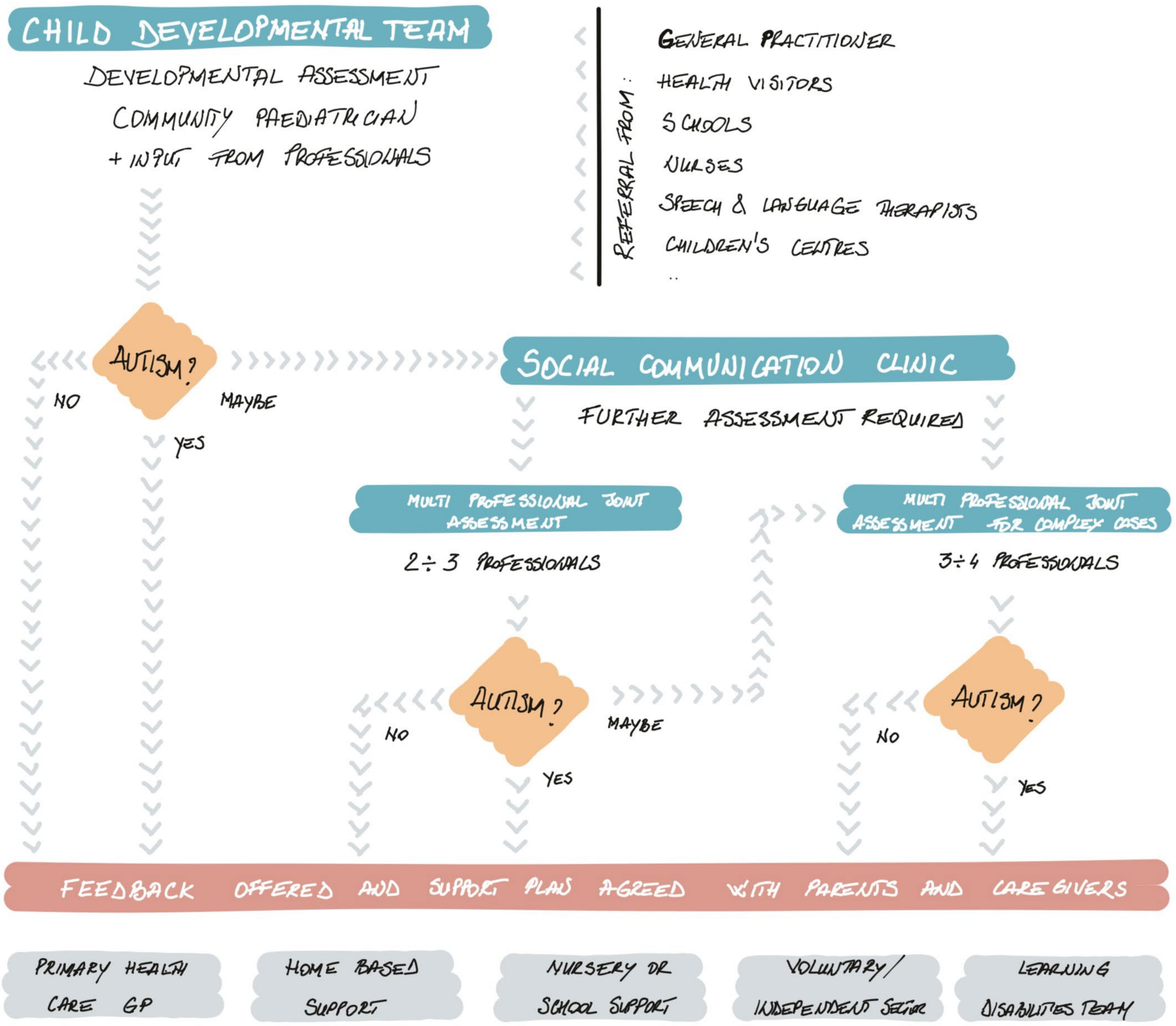

Fig 19 General Autism Diagnosis scheme

V.2 Childcare opportunities

The preschool age represents a very important stage in the development of a child. The experience in the early years should support the child's development while fulfilling his/her care and learning needs could help him/her to get the best start in life. Children also need preparation for future learning, i.e., for primary school. Some of the areas which can contribute to the children's healthy development and learning potential are communication and language, physical development, personal, social and emotional development, literacy, mathematics, world understanding, and expressive arts and design. The preschool period has to cover a wide range of playful learning and exploring activities, both indoors and outdoors, which stimulate creativity and critical thinking.

As education in the early years is not mandatory, these education opportunities can be provided by nursery schools, childcare centres, playgroups, but also by parents or caretakers at home. The nursery school is a pre-primary educational childcare institution. It caters day care nursery for children not older than three years old and preschool services for children from the age of three to that required for attendance in the primary school — depending on the educational system of each country. Nursery schools provide childcare and educational services through a wide range of activities, including arts and crafts, books and stories, indoor and outdoor plays, music and songs. Children learn new skills, get acquainted to new subjects, and socialize with their peers. Nurseries offer full day care with working hours from early morning to evening to suit to the needs of working parents.

Childcare centres are places dedicated to preschool age children and their families. They offer informal support to parents or expectant parents and to children a place to learn and play. The activities provided by childcare centres can vary widely including health services, multi-dimensional support, childcare information, educational services, parent training programs, etc.

Games are very important for the development of a child. They captivate the children's attention because they are fun and give a sense of adventure. Moreover, they brace the learning journey by developing language skills, emotions, creativity, and social skills. Games nurture the imagination and teach essential personal skills such as problem-solving, working with others, and sharing. Therefore, in addition to nursery schools or parents at home, holiday clubs and play schemes arrange games and care during school holidays. These clubs offer gaming opportunities, sports activities, outdoor trips, and quiet places for children to relax.

Lastly, one can provide care and education to children at home as well. If one of the parents, who maybe is not working or can work from home, or grandparents, can look after the child, he/she can also stay at home. His/her family should take care of everything and make sure to offer various play and learn activities. Childminders could also offer opportunities for home education. Childminders are licensed professional day-carers who work in their own houses. They can provide care and education for a few children, usually two or three. They tender personalised care according to the particular needs of each child, as they work with small groups. Childminders are also more flexible with respect to care schedules.

All the said childcare options will try to accommodate all children with special educational needs or disabilities, including children with autism, making reasonable adjustments, if necessary, to ensure that these children have the same play and learning opportunities. Childcare providers try to be as inclusive as possible so they can meet the children's needs. Nonetheless, children with autism, to achieve their full developmental potential, may require even further support through tailored interventions. They need to combine their educative early years with rehabilitative therapies. In particular, those with more severe symptoms on the autistic spectrum may not be able to attend mainstream childcare institutions. The latter may necessitate a more specific care plan that demands a person to work closely and in a custom-made way with the child to follow the child's unique needs and interests.

As of yet, there do not exist pre-emptive or curative methods to prevent or eliminate, once present, autism per se. Nevertheless, averting the symptoms from aggravating is possible. A wide range of interventions introduced previously (see § II.3) is available to improve and treat the symptoms and to make the everyday life of children with autism and their families easier. These therapies address the autistic inadequacies in social communication and relationships and hamper challenging behaviours. The best therapies are combinations of behavioural, speech-language, and occupational therapies and social skills training plans. Through these interventions, children with autism can learn numerous useful life skills, which may enable them to cope more effectively with day-to-day life, to be more independent, to express their thoughts and understand others, and to establish and foster relationships – which, in turn, can help them to control themselves and follow their interests.

On the other side, counselling services may be useful to all those around children with autism, such as parents, siblings, teachers, and therapists, to interact more smoothly with the children and assist them more efficiently. Autism is considered an invisible disability, which means that it is non-instinctive for people to know how to interact and offer help to individuals on the spectrum. Mainstream childcare providers will do their best to meet the needs of all children, but sometimes they do not have the right experience to take care of a child with autism. Furthermore, given the large number of children under their supervision, caretakers working in traditional institutions face a Herculean task in dedicating the right level of attention to children with autism. Even if supported by an assistant, nursery teachers might still encounter difficulties in offering the right treatment to someone with autism. For a child on the spectrum, just being in the same classroom with many peers might be very challenging. Furthermore, some of the therapies require professional figures, such as the logopaedic, the physiotherapist, or the psychologist, and appropriate physical and social environments. The parent training also hinges on the contribution of specialists and the provision of adequate spaces for knowledge sharing and dissemination.

Considering the importance of early access to information and training programs for the parents of the children diagnosed with autism, the efficiency of interventions in the case of early access to the prognosis of the autistic condition, and the effectiveness of interventions if made according to the specific needs of a child on the spectrum, the focus of this research will be on the therapeutic and support interventions targeting preschool age children and their families. The latter is an essential link in the care chain. They can serve as a bridge to the outer world for the children with autism. These interventions work as an integral part of the mainstream activities trying to facilitate the learning process. Furthermore, in more severe cases, it is also the place where they can get full time care to be able to return, as soon as possible, to the mainstream learning environments with their peers, be it a nursery school or primary school. This part of the care infrastructure can also serve a bridge for the parents. In order to overcome the emotional, physical, social, and economic burdens of raising a child with autism, they need the right support to move forward.

Fig 20 Childcare at Autism Centre (Albanian Children Foundation)

V.3 Therapeutic environment

In conclusion, this research will focus on the therapeutic context for children with autism at preschool age. To do so, it will investigate and analyse spatial and environmental aspects of care services in support of children on the spectrum and their careers, under the architectural point of view. The rationale for studying the features and the quality of the therapeutic interventions' environment is because the latter is as important as the treatments themselves in achieving positive results. While the environment does not have the ability to heal, cure, or treat per se, it can enhance or reduce the efficiency of any activity happening in a certain space, i.e., in this case, the efficiency of the therapies.

An interesting research on the significance of the environment with respect to the life's quality of a person with disabilities was carried by Brandt & Pope (1997). They described the environment as an entity supporting the person, a sort of a three-dimensional mat covering a combination of social and physical factors, as shown in Fig.21. The capacity of the environment to support people's lives adequately — expressed by the figurative use of mat as an indicator of flexibility — depends, on the one hand, on its physical accessibility and, on the other, on the efficiency of the available social support network. The amount of mat displacement stands for the amount of disability experienced by the individual, viz., it is a function of the strength of the physical and the social environment supporting the individual and of the magnitude of the potentially disabling condition.

Donna Williams, a famous author and artist diagnosed with autism, provides an interest practical take on the impact of the physical and social aspects of the environment. She recalls many incumbrances that she had to deal with during her time at school and describes her ideal environment for learning as, «… one where the room had very little echo or reflective light, where the lighting was soft and glowing and upward projecting rather than downward projecting lighting. It would be one where the physical arrangements of things in the room was cognitively ordered and didn't alter and where everything in the room remained within routine defined areas. It would be an environment where only what was necessary to learning was on display and there were no unnecessary decorations or potential distractions. It would be one where nobody unexpected would enter without everyone getting a cue and processing time to expect the change.» (Williams, 1996, p. 284).

This insightful interpretation of the relationship between disability and environment brings to light the importance of the spatial

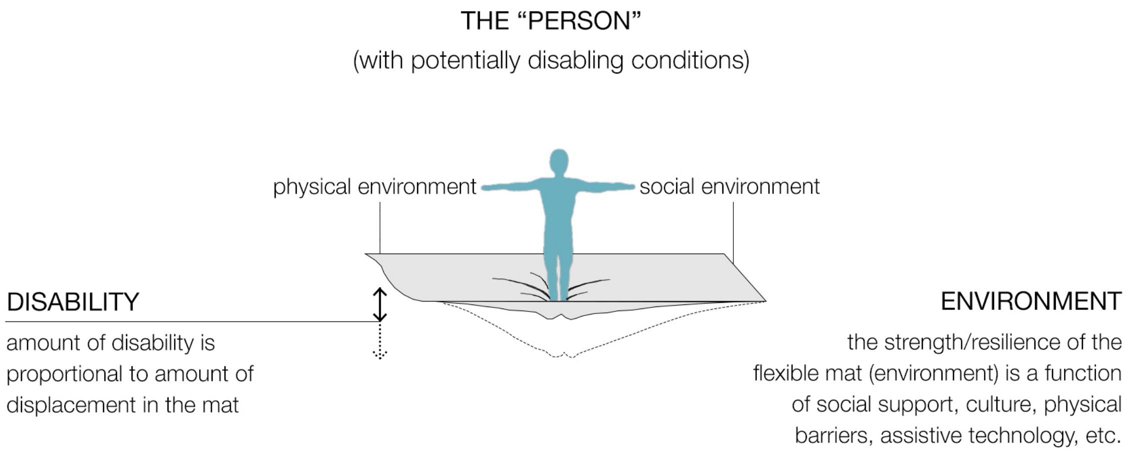

Fig 21 Disability as displacement of the "environmental mat." (reworked version from Brandt & Pope, 1997)

features with respect to the therapeutic context. Therefore, the emphasis of this research delves into the place where a child diagnosed with autism will get his/her treatment and support throughout his/her childhood. It is a difficult task because the articulation of the assistive services is highly complex. The autistic condition, per se, is byzantine to circumscribe given the presence of various phenomenal frameworks in terms of functional and social competences permutated with different comorbidities. Autism develops in a whimsical way and adopting the right response is not easy. Supposedly, there exist numerous treatments, but only a few are considered reliable. These treatments and additional support should be offered by the public health institutions, but practically, they are mostly extended by private subjects. The latter, in addition to being very expensive for most people, can also offer unreliable, never tested, treatments whose leveraging the desperation of the parents of the children on the spectrum.

In other words, this study examines the typologies of the facilities providing therapeutic treatments, focusing on the quality of their environments. To the best of my knowledge, no academic study has dealt with this topic thoroughly, despite that such structures have been projected and already exist. This study does not aim to identify an optimal structural model to be replicated far and wide in the future, but rather to analyse the existing examples and distil the main working principles that could be used as future guidelines. The category of 'type' differs conceptually from that of 'model' because the first offers more flexibility. Using a 'model' encourages an almost exact emulation of a previous structure, whereas, using a 'type' does not lead the architect toward a precise form. The 'type' category suggests a general framework that prefigures possibilities and alternatives (Vessella, 2017).

Examining the architectural typology means looking to concrete examples and attempting to identify functional and organisational variables that are significant common factors in the project equation. While there is not a precise and unique solution, different combinations of variables may satisfy the equation and engender original projects. Argan, in his essay 'On the Typology of Architecture,' provides an additional conceptual element that justifies the validity of the case studies' analyses. He argues that, «The birth of 'type' is therefore dependent on the existence of a series of buildings having between them an obvious formal and functional analogy. In other words, when a 'type' is determined in the practice or theory of architecture, it already has an existence as an answer to a complex of ideological, religious or practical demands which arise in a given historical condition of whatever culture.» (Argan, 1965, p. 76-77). The 'type' can be thought of as something abstract, almost as a concept construed a posteriori and which is the subject of continuous slow evolution. After all, architecture is an open-ended process of building and learning and the past experience, accrued over time, can avail future improvements, willing to trace the emblematic features and the strategic requirements regarding successful facilities' planning and design.

V.4 Delimitation of the geographical context

Even though autism is a chronic condition, care services target single episodes. There does not exist, at least yet, a care model that structures coherently and cohesively the autism services. Moreover, each country has its own care policy, which can be further modified by the administrative localities. Therefore, the way public services are offered to those interested may differ even within the same country. This devolution of autism services may be transmitted to more than one level, i.e., the federal government (if a federal country) delegates the responsibility to the states, states delegate it to the municipalities, which, in turn, delegate it to the localities, and so on. This scheme can become susceptible, regarding the offering of an adequate level of services, when a certain locality, due to restricted economic resources, cannot deliver sufficient personnel or resources to satiate the demand, i.e., fewer than necessary service points will be established. Private or non-profit organizations, foundations, or associations, can, sometimes, fill in for these public health structures.

Accordingly, this study could not have engaged in a study of world-wide care infrastructures supporting children with autism, at least not without assuming significant methodological flows. Therefore, this research has limited, deliberately, its geographical scope to a few case studies around the world. I have chosen to examine care institutions in four countries: Albania, Italy, the United Kingdom, and the United States. These countries were chosen for two, interrelated, reasons. I made this choice considering, first, the objective contribution of each country in promoting the wellbeing of individuals with autism, and, second, considering my personal experiences in these countries. The United Kingdom and the United States have established respectable reputations among the scientific community for their support of autism's research. These countries are also known for being the major promoters and supporters in developing facilities and services for individuals on the autistic spectrum. Nonetheless, my study reveals that the differences between the UK and the US and the rest of the world regarding their position with respect to autism are not as much based-on facts as on the perceptions of many field experts. I chose Italy and Albania, as two countries that I know the best for I have lived for a long time in each of them, but also because of their political and legal eccentricities. The Italian policies on the integration of people with disabilities are unique. Special institutions for disabled people were abolished in the '70s aiming at a wider inclusion and participation of people with disabilities in the community life. These efforts, even though not followed and sustained by adequate instruments to complete the framework and achieve the expected purpose, have been highly appreciated by the domestic population and the European Union community. On the other hand, Albania is a developing country, ingesting a relatively recent democratic transition, undergoing rapid growth and isomorphism, i.e., trying to emulate the best practices and institutions of other countries, particularly the Western ones. For the reasons stated above, this study could not have covered every segment of the care chain and infrastructure even in only these four countries, so it focused on parts of these structures, considered the most relevant and the most accessible.

The four selected countries vary widely not solely regarding the organisation of the care system, the social policies and the rights of people with disabilities, and the managing model of care services, but also economically and culturally. Therefore, I used my personal experiences to cast some light over these realities. Italy was an obvious choice as the research programme is based at the Department of Architecture in Florence, but, also because, I have lived and studied there for almost a decade. Differently, I analysed the other countries during research stages carried out in these realities. This paper has benefited from a collaboration lasting several months with two universities in London, Kingston School of Art and the Department of Psychology of the Kingston University, and 'The Helen Hamlyn Centre for Design' of the Royal College of Art. Both universities are composed of scholars with previous academic experiences and studies on autism-friendly designs, who also permitted me to communicate with a series of useful contacts in various areas. As for the United States, I was engaged in a continuous exchange with the Dr Shpresa Xhakli and her autism network in New Jersey. I visited New Jersey and New York for two weeks, during which time I scheduled numerous intensive meetings. Lastly, I have consolidated a strong partnership with the Foundation Albanian Children, which has been

Fig 22 Meeting with Katie Gaudion at the Helen Hamlyn Centre for Design, London

working for more than a decade on supporting individuals with autism. The collaboration with the foundation has been established since in the beginnings of this research and various Albanian experts on autism, such as the child neuropsychiatrist Dr Ariel Çomo, have followed the unfolding of the study. Furthermore, as Albania is my country of origin, I believe it to be the one whose reality I am better acquainted with.

In conclusion, this research aims to explore the therapeutic intervention system for preschool age children affected by autism in the circumscribed areas in Albania, Italy, the United Kingdom, and the United States. It proposes to trace the architectural typology of facilities providing treatments and support for individuals on the spectrum and their caregivers and analyse the related problems and expectations in order to offer better services. The framework of the investigation phase was consulted with Katie Gaudion – Senior Research Associate at the Royal College of Art's, The Helen Hamlyn Centre for Design – who has a rich experience in researches involving autism-friendly designs.

The investigation is developed through three qualitative tools:

1| Direct analyses and on-site visits to explore how the problem is dealt with in different contexts and how compatible are the environments surrounding children with autism with their needs and the feedbacks of the staff members;

2| Interviews with parents of children with autism, who are well-known in their countries for, among other things, their contribution to raising autism awareness, aiming to understand and internalize these parental experiences when raising a child on the spectrum, including the difficulties they have faced and information networks they have shared with other parents in the same situation;

3| In-depth interviews with autism experts such as child neuropsychiatrists, psychologists, therapists, to understand their points of view and aspirations on the future of therapeutic environments.

CHAPTER VI
CASE STUDIES

In the following sections, it is presented an attempt to analyse some case studies in order to get a sense of what it is really offered to children with autism of preschool age in terms of therapeutic interventions. Initially, it is discussed the research method applied to this part of the investigation; sampling procedure, data collection and analysis methods, as well as the format for systemising them. There were analysed in-depth and reported in the next paragraphs four case studies in four different geographical, social, economic, political and cultural contexts. The chapter concludes with a series of final considerations pointed out through this experience.

VI.1 Objective and survey framework

The first investigative step was to see what is really offered to preschool age children with autism and their parents. It was chosen to analyse one of the most important segments of the care system dedicated to children on the spectrum: the therapeutic context. Therefore, the aim of the study was to understand how actually care and support is provided to children on the spectrum and their caregivers. In other words, it was important to study what services are offered and where are they being carried out. The idea behind was to see how the problem has been faced and if it could be traced a typology of architectural and management that could be used as a reference for future planning and designing of therapeutic centres for autism. The best way to get there is to go through the observation of a series of concrete examples.

In order to get a wider overview and a deeper comprehension of the therapeutic intervention model in different contexts, the examination was undertaken in the four countries mentioned previously (Albania, Italy, the UK and the US) chosen to be part of this research. The selection of the case studies is a task connotated by subjectivity as it not possible to have a full spectrum of cases. In this research, the selection has undergone through a three-step filtering process. In the first step, it was drafted a list of examples that could be part of the investigation. They were the result of the several years of experience of research on autism through the scientific literature and as suggestions from the network of people of different backgrounds interested in autism, there were met over these years. Therefore, the following list of possible significant cases was built based on the background knowledge and suggestions from the established contacts:

- Regional Centre for Autism, Tirana, Albania;
- National Children's Development and Rehabilitation Centre, Tirana, Albania;
- Centre for Autism, Elbasan, Albania;
- Therapeutic Centre of Autism, Lushnje, Albania;
- Day Care Centre for Autism, Milan, Italy;
- Scientific Centre of Neuropsychiatry AITA, Rome, Italy;
- Child Neuropsychiatry University Hospital Tor Vergata, Rome, Italy;
- Saint Agostino Institute, Bari, Italy;
- Centre for Autism and Asperger Syndrome, Cuneo, Italy;
- Kennedy Leigh Family Centre, London, United Kingdom;
- Moor Lane Centre, London, United Kingdom;
- Sunfield Residential Unit, Stourbridge, United Kingdom;
- Caudwell International Children's Centre, Staffordshire, United Kingdom;
- SPA School Bermondsey, London, United Kingdom;
- Child Development Centre (Margaret Wells-Furby), Bracknell, United Kingdom;
- Alpine Learning Group, Paramount, New Jersey, USA;
- The New York Presbyterian Center for Autism and the Developing Brain, White Plains, New York, USA;
- New York Center for Child Development, New York City, New York, USA;
- Spectrum Neuroscience and Treatment Institute, New York City, New York, USA.

Subsequently, the list was reviewed in detail in order to select only those mainly significant to the research. The institutional websites of each facility were consulted with the aim to learn more about them and their relevance to the investigation. A second selection was made choosing two facilities in each country. The list of these facilities along with a short description is reported below:

- Regional Centre for Autism, Tirana, Albania – is a multifunctional centre offering health, education and social services and activities for children with autism aged from three to seven and for their caregivers. The facility, which represents a significant reference as an architectural intervention, was built in 2010 to host the Centre for autism. It is a property of the Albanian Children Foundation, a non-governmental, non-profit and independent organization.
- National Children's Development and Rehabilitation Centre, Tirana, Albania – a centre that offers diagnosis, treatment,

education and problem addressing for the development and rehabilitation of children with special needs from their birth to six years old. It is a public structure financed by the Ministry of Health of Albania.

- Day Care Centre for Autism, Milan, Italy – is a centre for care and study of autism part of the hospital unit of Saint Paul. Its activity is based on the follow-up diagnostic and the rehabilitation of children and young people on the spectrum through therapeutic treatments.
- Scientific Centre of Neuropsychiatry AITA, Rome, Italy – is a private centre created to provide support to children affected by autism and other neuropsychiatric problems and to help families identify the best care pathways. The Centre also offers specialized training on issues related to autism spectrum disorders and in general on neurodevelopmental disorders.
- Caudwell International Children's Centre, Staffordshire, United Kingdom – is an independent centre dedicated to a multidisciplinary assessment of autism, family support services and research into a wide range of autism interventions for children.
- Moor Lane Centre, London, United Kingdom – is an integrated service that brings together professional teams from the health, social care and voluntary sectors providing support and developmental health services to children and young people with disabilities and their families. It is part of the National Health Services.
- Alpine Learning Group, Paramount, New Jersey, USA – offers a full range of diagnostic and ABA-based clinical services, along with established programmes in education, and in-home treatments for individuals with autism aged from three to twenty-one.
- The New York Presbyterian Center for Autism and the Developing Brain, White Plains, New York, USA – is a therapeutic and learning centre which provides psychological, medical and allied professional services in a single setting to address the needs of individuals on the spectrum and other developmental disorders of the brain, at all life stages. It is part of the Hospital's 214-acre Westchester Division campus.

Being unable to analyse in-depth and describe all of them, the final step was to select one of them for each country as the most significant for the research investigation. The selection at this stage was a tricky task because, during the preliminary studies of identifying the study cases, it was noticed an important fact. It is hard to perceive at a first look the presence of an architectural typology. Even in smaller areas of the same city, even though the care system and policies are the same, the type of the interventions dedicated to individuals on the spectrum can vary widely, varying not only as an architectural intervention, but also as services and management features[1].

Trying to simplify things without excluding important cases, the choice was guided by two simple principles: to make the comparison among the different models easier; and to have a reasonable wide range of the characteristics that define the therapeutic centre. However, in order to get a better sense of the case studies, there were organised informal visits to all of them. Therefore, non-structured site exploration was used as an instrument for the last filtering step. In particular, the intent was to have examples of different built period (in the last two decades); new built, but also refurbishments; different design approaches; different services provided; different morphologies, different age ranges of users, etc. The selected case studies are as follows:

- Regional Centre for Autism, Tirana, Albania;
- Day Care Centre for Autism, Milan, Italy;
- Caudwell International Children's Centre, Staffordshire, United Kingdom;
- Alpine Learning Group, Paramount, New Jersey, United States.

For the analysis of the case studies, other than gathering information through internet, leaflets or magazines and the informal visits, there were organised on-site inspections to each of them and meetings with staff members. The experience in place aimed to closely examine the physical qualities of the environment, to acquire some information about the management aspects[2] and to talk to the working team about their daily routine, that are difficult to obtain in distance. The visits to the different facilities took place between January and June 2019 during the stage experiences carried out in the mentioned countries. Each inspection was carried out through two important actions: first, a visual survey of the building, spaces and equipment; and second, narrative interviews with a one or two employees, mainly therapists, invited to express their personal opinions. The two sources helped to integrate information on describing the building and identifying the main efficiency and critical factors, about the activities going on.

The analysis is guided by a series of questions and the information and documents collected for each case study were reported in sheets. They were integrated with technical designs, diagrams and photographs shot during the inspection. The inquiries were split into four groups according to the kind of info seeking to find out. This was reflected in the datasheet format which is organised in four parts. The first and the last part report information collected from staff members, whereas the second and the third part describe the facility according to the author's point of view.

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[1] For instance, in London, in the Borough of Richmond, children with autism have a few options for getting various treatments. Among them, there can be distinguished the Integrated Service Centre for children "The Windham Croft Centre" and the "Whitton School". The first is a facility part of the National Health System offering therapeutic interventions to children with disabilities, while the second is a school dedicated to children with autism offering the necessary treatments and support.

[2] The management of a structure is a very important component of architecture. It is composed of resources and services. Along with the physical environment, the management contributes to the well-functioning of a facility. Therefore, it is worthy for the research to know more in detail about the management of the selected case studies. However, due to difficulties in examining the quality of the management, the study has been limited to acquiring information on resources and services offered by the facilities.

AUTISM TRAITS	WELLBEING of individuals with autism		
	be SAFE	**be AUTONOMOUS**	**feel MOTIVATED**
altered sensory perception	non threatening sensory stimuli	clear and harmonious sensory stimuli	sensory interests seeking
awkward behaviours and motions	low harming risks	usability	encouraging challenges
focus on details and systemizing obsession	simplicity	order	flexible order
inability to generalise/ resistance to change	stability	comprehensibility	controlled change
weak imagination to foresee	familiarity	predictability	fantasy stimulation
difficulties to engage in social relationship	strangers avoiding	social relationships	control over social interaction
compromised ability to understand and reply	simplified danger notification	communication tools	alternative means of expression
weak short-term memory to perform operations	supervision	orientation & wayfinding	visual support
reduced attention span and planning flexibility	spatial shifting	no distractions	shift time

Tab 3 Specimen of how the quality evaluation table looks like.

A | General data

A short description of the facility organised in a table giving info about:

- name & location
- built year
- focus
- orientation
- services
- age range
- capacity
- human resources
- therapy hours
- funding

B | Building description

In this part, it follows a detailed narrative description of the building characteristics. It starts describing the location of the intervention and showing the way it is reached. It continues with a description of the architectural configuration and the morphology of the building. Thereafter, the internal organisation of the building is explained. The layout is described according to the common functional areas found among the case studies, such as: 1- circulation; 2- administrative spaces; 3- therapeutic spaces; 4- service area; 5- complementary spaces; 6- outdoor spaces. Each functional area is shortly broken down in the spatial units that compound it. A particular focus is given to the therapeutic spaces.

C | Quality evaluation

Here, it is carried out an evaluation of the architectural intervention quality. It is based on the needs of individuals with autism (see § III.2); it checks how the physical environments respond to the demands of people on the spectrum. Their needs can be met completely, partially or not at all. Corollary, this will be reflected on the evaluation paper. The framework of needs identified in the previous part of this research is recalled here, and the satisfaction of each need is graphically demonstrated. There will be three different colours to indicate: brown - the need is met; yellow – the need is partially met; cream – the need is not met. An example is shown in the table above Tab.3.

D | Staff remarks

Based on the everyday experience of delivering treatments in these facilities, member of staff shared their personal opinions through critics on the working environments and suggestions on what it could have done differently. The narrative interviews were recorded and later summarised in a paragraph.

VI.2 Regional Centre for Autism | Tirana (ALB)

Fig 23 Regional Centre for Autism in Tirana

A | GENERAL DATA

name & location	Regional Centre for Autism, Tirana.
built year	Built yearThe Centre regards a new construction built on purpose and opened in 2011.
focus	It serves only to individuals on the autistic spectrum.
orientation	It is a Centre that, even though it stands alone by not being part of national healthcare system, it seems to be oriented more toward the healthcare.
services	The Centre offers the assessment for the diagnosis of autism. It provides a series of treatments for children and support and consultations for their parents. There take place also training sessions for professionals and scientific research on autism.
age range	Children of three to seven years old.
capacity	It has been estimated to assist to over 150 children a year in its 16 therapeutic units. In addition, over 50 professionals receive consulting and training sessions.
human resources	There are 36 employees in total, where 27 of them are clinical staff members. Their roles are as following: 1x Child Neuropsychiatrist; 2x Logopaedics; 2x Child Psychiatrist; 2x Child Neurologist; 2x Cognitive Behavioural Therapist; 18x ABA Therapist of different backgrounds (logopaedic, psychologist, physiotherapist, etc.).
therapy hours	The Centre is opened during workdays from 8am to 5pm. The therapeutic sessions last usually 2 hours. The time spent at the Centre depends on the child's care plan. However, it is not a continuous daily care.
funding	It is an independent Centre in property of the Albanian Children Foundation. It is not part of any public organization and not commissioned by the National Health System. Approximately, 40% of the children interventions are funded by the Foundation through fund raisings, while for the rest, the expenses are fully covered by the parents.

Tab 4 Regional Centre for Autism in Tirana, website: https://www.albanianchildren.org/en/home/

Fig 24 Entry hall of Regional Centre for Autism in Tirana

B | BUILDING DESCRIPTION

The Regional Centre for Autism was built on purpose by the Albanian Children Foundation for multi-disciplinary interventions for preschool aged children. The quality of the architectural intervention and the therapeutic programme provided in this facility make it the first intervention of this kind in Albania. The Centre is located in Farka, part of the Tirana district. It is a small village, approximately 6km south-east of Tirana, on a hilly relief. It is a low-density residential area and most of its land is for agricultural use. This area is a very quiet rural setting and offers beautiful landscape sights. Unfortunately, this part of the territory it is not served by public transportation, but the Foundation has provided a coach that connects the facility with the centre of Tirana.

The way to the site is a dead-end street that leads only to the Centre. Once reached the facility, there is a roundabout that gives the possibility to make a turn and let passengers get off in front of the main entrance in a covered zone; or continuing straight ahead it guides to the parking area. As the intervention is in a sloping terrain, the parking spaces are situated in lowest part. There are a couple of parking slots with no distinction between staff and visitors. To get to the entrance from the parking area, one should walk the way back. There are also two entrances from the lower level – the parking area –, which however cannot be used in the everyday routine, as they are not monitored and serve only in case of special events.

The Centre is a three-store building of an overall area of nearly 1,500m2. It is a modern architectural intervention that intends to immediately catch the attention of visitors, but at the same time, it aims to minimally relate to the hilly terrain. There was an intention to minimise the site transformation and, therefore, part of the building is semibasement or completely underground. The building has a fragmented and diverted rectangular shape. It is interrupted by three different geometrical forms in different levels and points. At the intermediate level, it is cropped with a quadrangular form of one floor height that marks the core of the building; which also highlights the main entrance. At the bottom level, a similar quadrangular reveals the basement and connects it to the parking area. Meanwhile, an oval shaped form intersects the building on the east side on two bottom levels.

Even the vertical development is animated; the north part is structured on two stores, whereas the southern develops on three levels. However, this comes less to sight because both parts are circumscribed by two strips wrapping the building in the north-south direction. The facade is also animated through the combination of different materials and the use of different configurations for the openings. There has been used Corten cladding for the intermediate floor with irregular openings on the exterior side of the facade. For the basement and for the third level, it has been used a dark grey stone cladding with regular opening. The core block of the building which corresponds to the entrance and the oval-shaped part use a curtain wall facade. The strips on top and the cover of the entrance are simply white coloured plaster creating a framework of the building.

Circulation | The main entrance on the west side of the building -in a central position- opens to a big a hall with lots of natural light. In this open space fits a waiting area and, at the left back, there is the reception. On the right there is an open staircase with glazed panels and the lift that connect the three stores. The distribution on plan on all levels takes place through corridors placed perpendicular to the entrance and in the middle of the longitudinal direction of the building. These linear and narrow distributive areas -following the alignment of the building- give direct access to a series of spaces on both sides. The two bottom-level corridors do not receive daylight, whereas the one on top gets

underground floor

ground floor

first floor

Fig 25 Plans of Regional Centre for Autism

administrative spaces | therapeutic spaces | services | complementary spaces

it through the staircase's glass facade. The corridor in the intermediate level is probably the most disadvantaged because it is also the longest, going almost to the extreme sides of the facility. These flow lines, even though they work well on distribution, give a bitter sense of restriction because nothing much happens along, mainly in the intermediate floor, which is also the most important part. In regard to the functional distribution of the spaces it is very clear and ordered.

Administrative spaces | Almost all spaces dedicated to staff members are located on the third level. On this floor, there are: two medical rooms equipped for assessments of autism traits evaluation and follow-up; a meeting room used also as a library; a working space for six researchers; and the direction office. This floor, being used quite exclusively by staff members or for meetings with visitors, it is separated from the flow of the therapy spaces. On the second level, other than the reception, there is a room for staff members and an archive in between them. Therapists can elaborate the data of various treatments for each child in this working space and then archive them in the space next door that they share with the reception.

Therapeutic spaces | The second floor -which corresponds to the main access level to the building- is completely dedicated to treatments. All therapy units are distributed on both sides of the structure. There is an array of thirteen environments of different sizes dedicated to different kind of interventions, different level of social interaction and different professional presence and activities taking place. The therapies carried out in these spaces are interventions based on ABA approach; speech therapy; psychomotor therapy and hydrotherapy. For behavioural treatments, individual sessions are most common trying to focus on each child's needs and minimizing distraction. All spaces are kept pretty simple; only the essential equipment with the necessary teaching material and toys. There are used kids' size furniture, no hanging frames, bright and soft colours, natural light and nice nature outside sights. Therapy rooms have carpet flooring giving a domestic feeling and comfortable sense, other than improving the spatial acoustics. Each room has a flexible arrangement allowing different learning activities. Some of the therapy units have a one-way mirror with a specific room for family members and professionals to observe the treatment sessions. In regard to motor ability therapies, there are three spaces: two for physical training and playing and the other one for hydrotherapy. In the last one, there is a therapeutic pool with changing rooms, showers and the necessary tools for interventions in water working on child's motor capacities. The pool is located on the oval-shape

Fig 26 Gross motor therapy room of the Regional Centre for Autism

Fig 28 Social skill therapy room of the Regional Centre for Autism

Fig 27 Playground of Regional Centre for Autism in Tirana

part of the building that intersects the main structure and it is all glazed with a view of almost 360 degree to the peaceful surrounding woodland.

Services | As regarding the services, they are spread on all levels of the building. There is one block of restrooms in each floor. On the second floor, there is an additional restroom because the other toilet block is kids' size. On this level there are also two small service areas dedicated to the electrical system and cleaning repository. In the basement, there is a large storage space and three technical rooms. One of them, on the bottom of the pool, hosts all its technical plant.

Complementary spaces | At this Centre there are also a series of complementary spaces. There is a dentist office offering dental services dedicated specifically for children with autism visiting the facility. This service is provided in sequence of therapeutic units' array giving, in that way, a sense of familiarity. In addition, on the bottom floor, there are two interesting spaces for leisure and training activities. The arrival plan, as you go downstairs through the staircase or the lift, is at a big hall which includes a bar with indoor and outdoor seats. This common lounge space is mostly used by parents while waiting for their children and by staff members during breaks. They can prepare drinks and snacks while socialising with each other. It also used in case of events as a buffet area. In adjacency, there is a big room that can accommodate 100 people. It is a flexible space and it is nearby a big storage room that allows a multifunctional use. It can be arranged and equipped in various ways for different events such as exhibitions, presentations, large group meetings, training sessions, parties, etc. Having them in the basement it is an advantage because they do not interfere with the therapeutic interventions and have direct access to the parking area.

Outdoor spaces | In this facility, there were designed also several outdoor spaces. On the main level, in continuation to the entrance, there is a covered outdoor area. Children can have part of their therapy session there playing and socialising with other children when the meteorological conditions are not favourable. Otherwise, they can just play there while waiting for their treatment turn. Outside this area, there is a playground immersed in a green area. Children can enjoy the playing time while in direct contact with nature. In addition, on the bottom floor, there is a covered lounge area which is part of the bar. It allows users to relax and socialise in a protected space.

C | QUALITY EVALUATION

AUTISM TRAITS	WELLBEING of individuals with autism		
	be SAFE	be AUTONOMOUS	feel MOTIVATED
altered sensory perception	non threatening sensory stimuli	clear and harmonious sensory stimuli	sensory interests seeking
awkward behaviours and motions	low harming risks	usability	encouraging challenges
focus on details and systemizing obsession	simplicity	order	flexible order
inability to generalise/ resistance to change	stability	comprehensibility	controlled change
weak imagination to foresee	familiarity	predictability	fantasy stimulation
difficulties to engage in social relationship	strangers avoiding	social relationships	control over social interaction
compromised ability to understand and reply	simplified danger notification	communication tools	alternative means of expression
weak short-term memory to perform operations	supervision	orientation & wayfinding	visual support
reduced attention span and planning flexibility	spatial shifting	no distractions	shift time

Tab 5 Regional Centre for Autism in Tirana, an evaluation of the fulfilment of autistic needs

need is met | **need is partially met** | **need is not met**

D | STAFF REMARKS

After the walk around the facility, a small group of staff members participated in an informal talk about the Centre. They expressed their objections regarding the quality of the facility's environments. Referring to the functional layout, they report it has been a good move to separate different functions in different floors. Instead, as regarding the distributive layout, they cannot say it has been efficient. They notice that the distribution based on long corridors, other than creating the idea of an institution and not an intimate space, is anxiety-generator for children with autism. It gives a sense of restriction and also does not help them orientate.

The other remarks from the staff based on their daily experience refer to specific details that could have been done differently. One of the main issues relates to acoustics; the isolation and the noise produced in the therapy environments. The acoustic isolation in between the therapy units it is not optimal; sometimes they can hear sounds from next room if they are being loud. In addition, staff reports acoustic problems due to ventilation and heating/ cooling system. In the facility, there has been used air-based systems for the artificial ventilation and air conditioning. The noise produced by these plants disturb and distract children during the therapy session.

The staff pointed out some observations also regarding flooring, colours and window blinds. The carpet used in therapy environments is very pleasant and comfortable for children, as well as preventing injuries of in moments of aggression. On the other hand, however, it is not the ideal solution due to cleaning difficulties in order to maintain adequate hygiene levels. It must be taken into account that children with autism may vomit sometimes due to possible interferences of proprioception stimuli. As regarding colours, they report that the use of similar light tones and low contrast finishes does not help visual impaired children identify objects in the space. As a last remark, the adoption of roll up curtains as window blinds is a solution not to be suggested. Children tend to pull the curtain or cord and there is a high risk of it falling, as it has happened a few times at the Centre.

VI.3 Day Care Centre for Autism | Milan (IT)

Fig 29 Entrance of the Day Care Centre for Autism in Milan

A | GENERAL DATA

name & location	The Day Care Centre for Autism is located in Milan, Italy.
built year	It is a new built Centre designed on purpose in 2014 in the first two levels of the residential multistore flat.
focus	It serves only to individuals on the autistic spectrum.
orientation	It is part of the San Paolo Hospital and being a clinic, the Centre, therefore, has a healthcare character.
services	The Centre offers a multidisciplinary assessment for the diagnosis of autism and medical follow up. It provides a series of therapeutic interventions, mainly behavioural and motor abilities therapies, but not those related to the language and speech therapies. However, a logopaedic is present for assessments and follow ups. It hosts training sessions for parents and offers social services to their support. The Centre, in addition, trains teachers of children with autism through internships.
age range	Children of two to fourteen years old. The neuropsychiatric follow up continues until they reach eighteen years old.
capacity	The Centre has a capacity of taking charge of neuropsychiatric follow up of approximately 150 children. However, it can accommodate only sixty children for the various intervention and the rest remain in waiting lists.
human resources	There are 13 professionals in service of which: 8x Educational Therapist; 2 x Child Neuropsychiatrist; 1x Logopaedic; and 2x Child Neuropsychiatrist interns.
therapy hours	The Centre is opened during workdays from 8.30am to 6pm. The therapeutic sessions last usually 60 up 90 minutes. Each intervention programme is individual for to the child specific needs. However, the average time spent at the Centre is two-three times a week. It is not a continuous daily care. In agreement with parents and eventual education programmes, children may attend interventions during school hours, or after school.
funding	In regard to the assessment, the access to the Centre is a national service, which means that everyone living in Italy can request an appointment. Instead, as to the therapeutic interventions, referrals are accepted only from the borough of Milan. Being part of the National Health Service, it is a public Centre.

Tab 6 Day Centre for Autism in Milan, website: http://www.retiautismo.it/modello-2-2/

Fig 31 Ground and First Floor Plan of Day Care Centre for Autism

administrative spaces | therapeutic spaces | services | complementary spaces

B | BUILDING DESCRIPTION

The Day Care Centre for Autism is located at Sant'Ambrogio borough, in southwest of Milan. It is a medium dense area and of mixed use. The Centre occupies half of the ground and the entire first floor of a nine-floor residential building. It is situated nearby the San Paolo Hospital and it is part of it, but without immediate connection to hospital spaces. The building hosting the Centre has a rectangular and regular horizontal and vertical development; only on the first floor there is an expansion toward the south and west side of the building. Its position is perpendicular the serving road, which is a pretty quiet two-way road with parking spaces on both sides. The exterior is very simple; it has an aluminium cladding around the ground floor and blue coloured plaster for the rest of the building. The openings are less regular and give to the facade an animated sense. Access to the building comes on the longest side and, therefore, not along the street. The Centre has a separated side entrance next to the flat entrance. Both entrances are similar and dimly marked with a small sign next to the Centre's door, making the access a bit confusing.

Fig 30 Building of the Day Care Centre for Autism in Milan

Fig 32 Entrance hall of the Day Care Centre for Autism in Milan

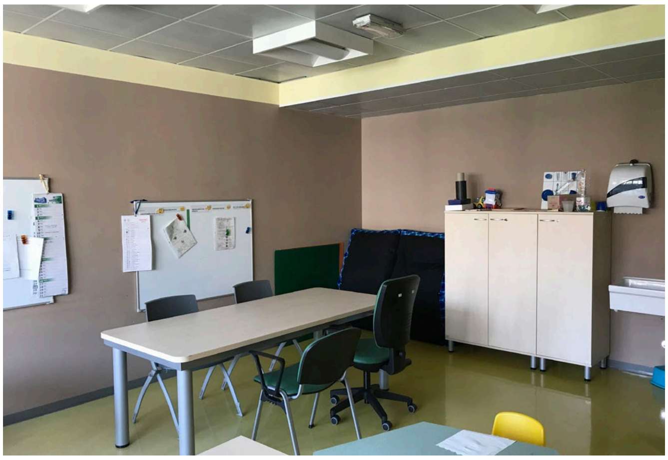


Fig 33 Group therapy room of the Day Care Centre for Autism in Milan

Fig 34 Individual therapy room of the Day Care Centre for Autism

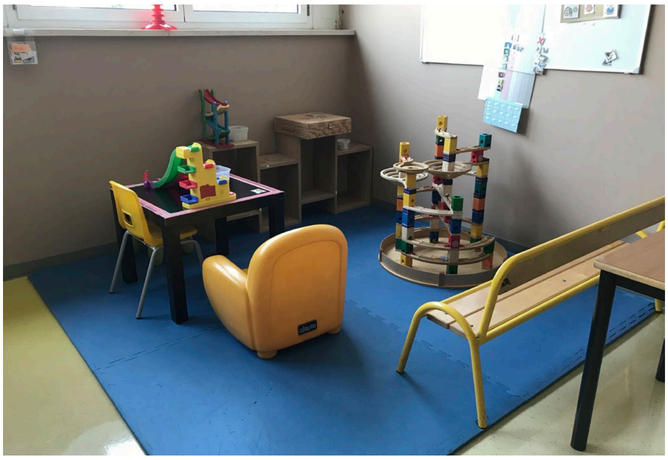


Fig 35 Therapy room of the Day Care Centre for Autism in Milan

Circulation | The entrance opens to a small waiting area, but there is no reception on the ground floor. In front of the entrance there are two big doors. One of them leads to a corridor that develops as an ‘L’ and distributes to a series of therapy rooms. Whereas, the other door gives access to the staircase that connects to the first floor. To get to this level, there is also another possibility which takes advantage of the staircase and the lift of the flat. The only problem is that these last vertical connections are less visible to users. Once arrived on the first floor, there is another waiting area, but smaller. Walking through this level is a bit confusing. The distribution is achieved through two different corridors; a longitudinal corridor that divides in the middle of the building and where also the flat staircase and lift arrive; and another T-shaped corridor perpendicular to the other one distributing to the southern part of the building.

Administrative spaces | All spaces dedicated to staff members are situated on the first floor. Initially, there was a tentative to group them on one side of the building, but over the years the necessity for more therapy rooms made the separation less clear. On the arrival from the main staircase, on the right and giving to the waiting area there is a small room for the logopaedic assessment. On the opposite side there is a room, which has a big transparent surface toward the waiting area, dedicated to the secretary. It is also used as an archive. From this point, the long and straight corridor distributes to various rooms for staff members: a working area for traineeships; a working area for therapist; and two rooms for multidisciplinary team assessments.

Therapeutic spaces | This Centre provides a wide array of environments dedicated to different treatments. These spaces are situated on both levels. On the ground floor, there are located four therapy rooms which require an actively participation and, therefore, are considered noisier: 1- a room for working on motor abilities for older children equipped with various tools and toys for mobility stimulation; 2- a similar room for younger children; 3- water playing room; 4- a kitchen for everyday skills interventions. On the first floor instead, there are situated therapy rooms which require much quite environments and less distracting. There are six spaces for individual cognitive and behavioural skills treatments and two rooms for group therapies. The individual therapy rooms are furnished pretty much the same; a desk with a few chairs of children size, a closet, a mat and several educational material and toys. Each room has different colour and furniture arrangement. The two group therapy rooms are of different size and offer different treatments opportunities; the smaller one has a big meeting table with chairs allowing social skills trainings, whereas the bigger one, provides various therapies to take place at the same room with possibilities for social interaction.

Services | The services are distributed all around the building. There is a group of them downstairs having: two restrooms for visitors and access from the waiting area; a small unisex changing room for children using the therapy rooms on the ground floor; two restrooms for children; and a storage room. On the first floor, there is a group of two unisex restrooms dedicated only to staff members next to their working spaces. On the side of the various therapy rooms, there are three restrooms for children. Diffused in different sides of the core of the building there are two more storage rooms and two technical rooms.

Complementary spaces | In this Centre, due to limited available area, there are not provided additional spaces for complementary functions.

Outdoor spaces | The Centre provides also some modest outdoor spaces on the southern and western part of the building. There can be distinguished two areas: an open and bigger one on the south with access from all therapy rooms facing south; and a covered one on the west with access only from the motor ability room for older children. Both spaces are minimally equipped as playgrounds. In the open playground there is little presence of green areas, yet, not enough for a wider use during hot days because it does not offer any possibility to protect from sun. The covered playground which could compensate that, unfortunately, does not offer a pleasant atmosphere. It is surrounded by a high fence giving a sense of restriction and with no attractive character.

Fig 36 Restrooms of the the Day Care Centre for Autism in Milan

Fig 37 Playground of the Day Care Centre for Autism in Milan

C | QUALITY EVALUATION

AUTISM TRAITS	WELLBEING of individuals with autism		
	be SAFE	**be AUTONOMOUS**	**feel MOTIVATED**
altered sensory perception	non threatening sensory stimuli	clear and harmonious sensory stimuli	sensory interests seeking
awkward behaviours and motions	low harming risks	usability	encouraging challenges
focus on details and systemizing obsession	simplicity	order	flexible order
inability to generalise/ resistance to change	stability	comprehensibility	controlled change
weak imagination to foresee	familiarity	predictability	fantasy stimulation
difficulties to engage in social relationship	strangers avoiding	social relationships	control over social interaction
compromised ability to understand and reply	simplified danger notification	communication tools	alternative means of expression
weak short-term memory to perform operations	supervision	orientation & wayfinding	visual support
reduced attention span and planning flexibility	spatial shifting	no distractions	shift time

Tab 7 Day Centre for Autism in Milan, an evaluation of the fulfilment of autistic needs

need is met | need is partially met | need is not met

Fig 38 Staircase of the Day Care Centre for Autism in Milan

Fig 39 Distribution hall of the Day Care Centre for Autism in Milan

D | STAFF REMARKS

Staff members, during the visit around the facility, reported some of their objections on the quality of the environments. Based on their everyday experience, they suggested more generous spaces in the whole Centre. Therapy units, even though they are used mainly for one-on-one interventions, need to be bigger to facilitate various activities according to the needs of each child. Furthermore, in the years, it has been revealed the necessity to have more therapy units because most therapies are individual. To overcome that problem, two rooms used for assessments were transformed into therapeutic spaces, having to move the evaluation the medical room at the direction and management room. From the therapy units, the motor abilities unit, is the one that mostly needs to be bigger to allow children play together and interact, but also have different individual therapies taking place at the same moment. In addition, the storage spaces are very important for the Centre. There are three storage rooms in the centre, yet they aren't enough. In each therapy unit would be great to have hidden closets allowing to store all the needed material for interventions without distracting the children. A similar problem, about the storage has been verified also for the archiving of clinical documents. Initially, the archive was located at the secretary, but it has ended up occupying all the space due to the huge amount of relevant papers to file. As a result, they would recommend a separate space dedicated only to archive.

The members of the staff pointed out also some observations regarding the layout of the building. They have noticed that it is not easy for parents and children to orientate in the facility. Comments received from them describe it as labyrinthine. All start from the staircase which is not well illuminated and is distressing. At first floor arrival, it is not completely clear the division between therapy rooms and staff spaces. In addition, regarding the organisation of spaces, the staff highlights the mistake of placing the technical plant room next to the therapy units. The rumour produced disturbs children during treatment sessions.

Additional remarks from staff members regard some detailed solutions that are missing or haven't worked so far. One of these problems refers to the one-way mirrors in the therapy rooms. They weren't placed properly and, apparently, not of adequate quality, because they are not completely one-way blind, distracting children during the sessions. The other problem noticed are the sun blinds used in some rooms and the lack of them in others. The last observation regards the missing of a space for sensorial stimulation that could help children recalibrate their senses and relax.

VI.4 Caudwell International Children’s Centre | Staffordshire (UK)

Fig 40 Caudwell International Children’s Centre (Caudwell Children)

A | GENERAL DATA

name & location	Caudwell International Children’s Centre, Staffordshire.
built year	The centre regards a new construction built on purpose and opened in 2019.
focus	It serves only to individuals on the autistic spectrum.
orientation	It is a centre that stands alone.
services	The facility is mainly a Centre for the assessment and workshop-based interventions. It provides family support through the participation of parents in workshops along with their children or separately. The Centre offers also training sessions for professionals and carries out research activity on autism.
age range	Children of four to eleven years old. Youngers with autism up to eighteen years old are invited to participate in some events.
capacity	It can accommodate up to 12 assessments contemporary and several workshops at the same time. It has been estimated to assist to nearly 800 children a month or approximately 7 000 children a year through assessments and interventions.
human resources	Presently there are 61 employees in total. 31 of which comprise employees across the senior management, office, accounts, HR, IT, Marketing, PR and Fundraising. The other 30 are services/clinical which relate to the following roles: 2x Children's Activity Leads; 4x Admin across different departments; 1x Applications; 8x Family Services;1x Governance Lead; 1x Clinical Lead; 2x Occupational Therapists including a Lead; 1x Autism Practitioner; 2x Psychologist; 3x Speech & Language Therapist including a Lead; 3x Short Breaks; 2 x Volunteers.
therapy hours	It is opened from 9am to 5pm Monday to Friday. Usually the assessments lasts two days. The workshop depends on the children and may be half-day or full-day for some days of the week.
funding	It is an independent Centre not part of any public organization and not commissioned by the National Health System. Users follow one of the two funding streams based on their annual income. If the income is lower than the threshold, the Trust funds 80% of the cost and the rest 20% is covered by parents. Instead, if the incomes are higher, the cost are fully covered by the parents.

Tab 8 Caudwell International Children’s Centre in Staffordshire, website: https://www.caudwellchildren.com/

Fig 41 Exterior view of the entrance (Caudwell Children)

Fig 42 Exterior view of the entrance (Caudwell Children)

B | BUILDING DESCRIPTION

The Caudwell International Children's Centre (CICC) is a purpose-built centre for multi-disciplinary therapy programmes for children with autism and research of neurodevelopmental conditions. It is the first Centre of its kind in the United Kingdom, whose project has surpassed the national accessibility standards. It goes beyond what is described under the current legislation on disabilities which are mainly limited to physical impairments. The whole design process was guided by research from the members of the charity's executive team, the C4 Consulting Architects, in consultation with children with autism and parents. The aim of the team was to build an autism-centred building that could accommodate both physical and sensory disabilities.

The CICC is located in Newcastle-under-Lyme, a town of nearly 130 thousand habitants in Staffordshire, England. It is situated within the Keele University campus, at the Science and Innovation Park. It is a newly built area in a peaceful rural setting, approximately 4km from the town centre with good transport links nearby. The site is surrounded on three sides by woodlands. On the north side, the area borders with a vast parking area of the Keele University. The way to the site is a dead-end street along the western side. Once arrived at the Centre, there are two separated pathway: one for the staff on the left which leads to their dedicated parking space on the northern part; the other path approaches to the building for drop-offs near the main entrance and continues following the trajectory of the facility leading to the southern parking space for visitors.

The 5,500m2 Centre features an innovative 'butterfly' design which reflects the charity's logo. Two round edged triangles of different dimensions face each-other intersecting. At the centres of each triangle open two internal courtyards. The vertical development is also dynamic and lively. The two triangles rise up in different heights and are grown in the upper levels of the building. The northern and the bigger triangle develops up to four floors in its extreme, while the other triangle is developed in two floors. The concept of the butterfly in plan is evolved also in elevation through smooth lines and curves. The roofs are curved forming hyperbolic paraboloids, and the cover of the bigger triangle, which is also inclined toward north, overlaps the smaller one. The development of the plans in the upper levels doesn't follow rigorously the lower plans, as the buildings seems to widen toward the exterior and narrowed in the courtyards.

The articulation of the facades is very interesting. It is a combination of stone cladding and glazing on the bottom floors with fixed module of closures and variable rhythm of the transparent surfaces. Instead in the upper floors the facade seems to become lighter and inclined pointing outward through curtain walls. Every floor is highlighted by string course frames which are remarkably cantilever acting as sunblinds, but also covering the pedestrian pathways from the parking space to the entrance. This design creates an iconic, exiting and inviting building from outside, but also, a peaceful space from inside.

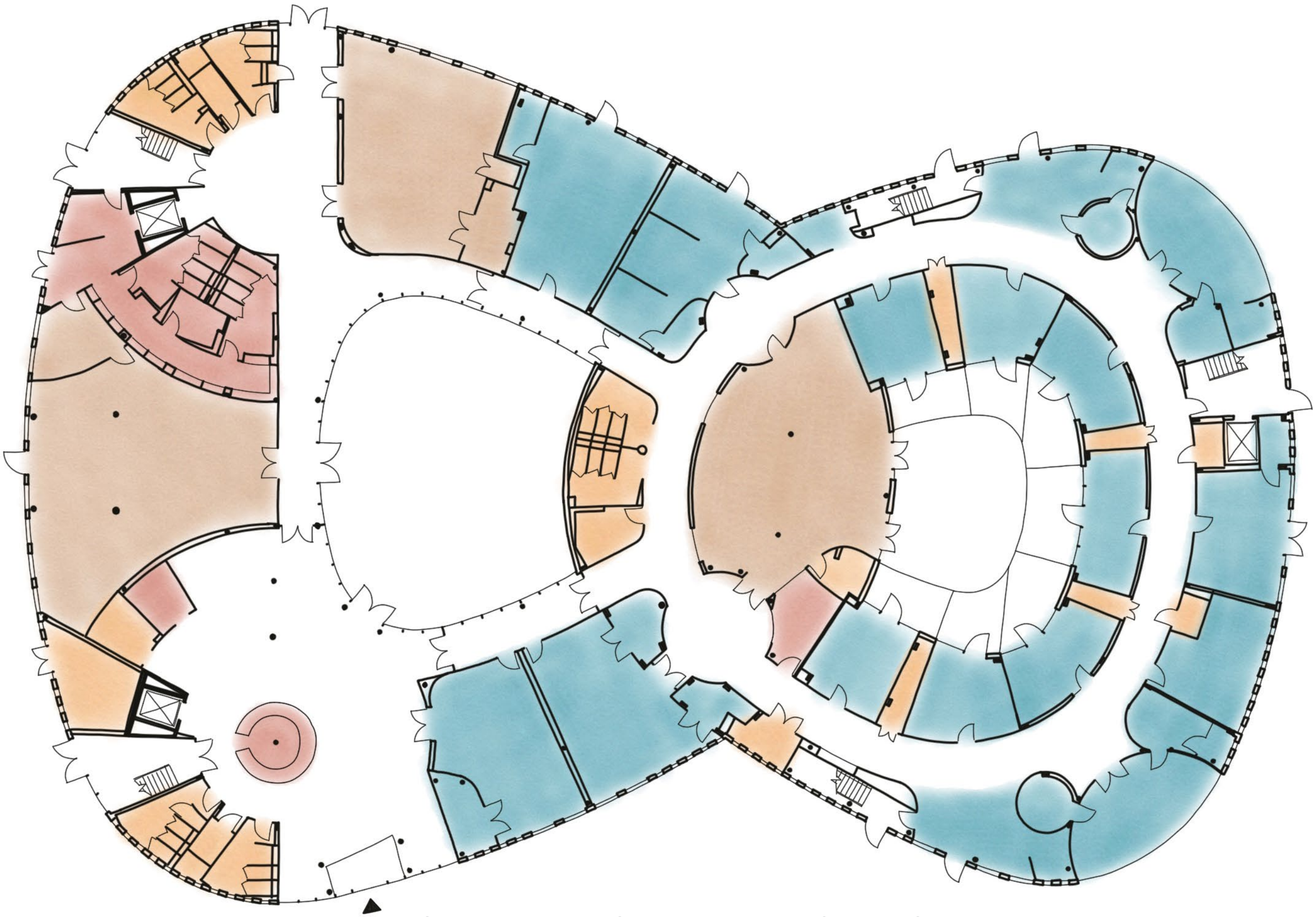


Fig 45 Ground Floor Plan of Caudwell International Children's Centre

administrative spaces | therapeutic spaces | services | complementary spaces

Circulation | The main access to the building is in the northwest side and it is marked by a wood finish door inserted in the glazing facade. It leads to an open area in a double volume space with curve walls and with a circular skylight on top. The projection of the skylight falls on the reception desk. The flow around the facility is organised around the two courtyards. In the first building, or the bigger triangle, the flow is along the open space having a continuous vision on the courtyard and serving to the spaces only on the external side. Whereas, in the other part, the circulation follows the pathway of the building and of the courtyard, but it is collocated in the middle creating two series of spaces: one around the garden; and one other around the outer side of the building. The two pathways are guided by curved lines and encounter a sequence of four nodes with double volumes and skylights to facilitate the wayfinding. In addition, these pathways have a hypothetical fixed width, but however it never gives the sense of the strict corridor, because it repeatedly opens to common spaces. Going back to the access points, the building has another entrance on the back dedicated to being used in case of events, so not to compromise the privacy of children. In addition, there are several emergency-exits around the building. Some spaces have direct access to outside, but they are opened to closed gardens which do not connect to the public area. In regard to the vertical connections, five staircases and three lifts have been planned in various sides of the building.

Fig 43 Reception (Caudwell Children)

Fig 44 Circulation (Caudwell Children)

Fig 49 Administrative spaces of Caudwell Centre

Fig 48 Breakout area (Caudwell Children)

Fig 47 Group therapy room (Caudwell Children)

Fig 46 Withdrawal area (Caudwell Children)

Administrative spaces | The functional distribution is pretty clear and ordered. The administrative spaces are almost all located in the north side of the building and in the upper floors. They are organised in three levels -except from the ground level- and have a view on the courtyard and on the outside landscape. There are a wide variety of spaces in terms of dimensions, viewing, privacy, number of employers planned to work together, activities that could take place. There are various open space offices for therapists, researchers; private offices for the direction and management; meeting rooms; different open areas in common for breaks, archives, etc.

Therapeutic spaces | The spaces dedicated for the assessment and for the therapy are distributed in two levels on the southern part of the building. They are clearly and precisely separated from the administrative spaces through a set of two doors which do not obstruct visibility, but that cannot be accessed by parents or children without the presence of a staff member. On the ground floor, starting from the reception area, there are two large family rooms: one with direct access from the reception and dedicated mostly as a calm waiting area for parents and their children offering them an opportunity to play and relax while waiting to begin the assessment or the therapy; the other one with access from the distributive pathway of the therapeutic area, serving for a similar purpose, so as a waiting area for parents while their children are on therapy sessions. Around the courtyard, there is a series of seven assessment suites and individual or small groups therapy. These spaces are pretty similar to each other and in between them there is quite always a buffer room dedicated to services. All rooms are kept very simple but with careful design on details. They have direct access to the courtyard, which is split in eight parts, where seven of them are private for the therapy units.

At the same level, on the ground floor, but on the outer side of the pathway, there lies another series of therapy space. There are four bigger rooms dedicated to workshops for children offering different themes and group play opportunities. These workshop rooms also have a direct access to private outside gardens. All rooms are connected to hidden closets or spaces that can be used as repository. In addition, in order to help children, feel at their ease allowing them to recalibrate their senses without losing contact with the outer world, a series of withdrawal spaces are provided along the pathway. The last two therapeutic environments are dedicated to the learning of everyday skills in the kitchen. There have been set up a few kitchen facilities and dining areas to help children deal with daily routines of preparing a meal and eating.

On the first floor, there are seven other big rooms for different therapies in groups, where six of them are equipped for workshops and one of them is equipped as a soft room for physiotherapy. In contrast to the downstairs rooms, these spaces are bigger and with no access to outdoor spaces and with no day light willing to attract their attention. All these environments are served with repository spaces. In addition to these spaces, there

Fig 50 Therapy room panoramic view (Caudwell Children)

are six more small rooms for assessments and individual therapies. These therapy units have a view on the surrounding woodland and gardens. On this floor the distribution is realised through a pathway along the inclined glazing facade having a view on the southern landscape.

Services | As regarding the services, they are distributed along the corridors. There are four groups of restrooms divided per gender and for disabled located on the ground floor: one near the reception at the main entrance; two blocks at the back of the main building in service of events taking place there; and the last one central in the therapy area. In addition to the last group, there are two more disabled-friendly restrooms along the pathway on the south side, in between therapy units. In the first floor there two groups of restrooms: one only for staff members; and the other in the intervention spaces.

Complementary spaces | Furthermore, at this facility there are planned some complementary spaces collocated on the ground floor. In the main building, on the staff part, there are planned two big spaces to host various events: one more adequate for presentations, seminars, or training sessions; and the other to celebrate various occasions. Both environments offer a flexible arrangement through movable furniture and spacious repository. There are two blocks of services in their adjacency. In addition, it was planned a second entrance, in line with the main entrance, but on the opposite side, so not to compromise the rest of the activities taking place on the rest of the building and the privacy of the users. Furthermore, at the centre of the therapy area and with a big opening to the courtyard, there is a common lounge space for staff members and families where they can have a break while preparing drinks, snacks or their meals.

Outdoor spaces | The outdoor spaces in this project are numerous and well finished. As mentioned before, there are two internal courtyards. One of them is a multi-use space in connection to the two accesses of the building. The other, on the therapy area, is fragmented among the spaces surrounding it offering a different use opportunity contemporary. Sometimes the assessment of the child takes place in these parts of the courtyard, giving the child

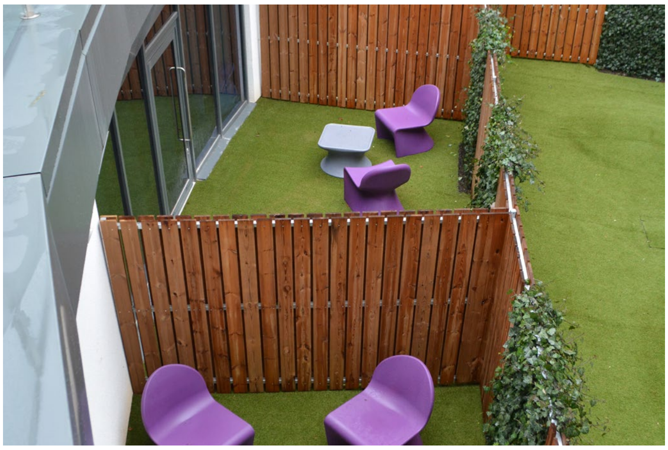


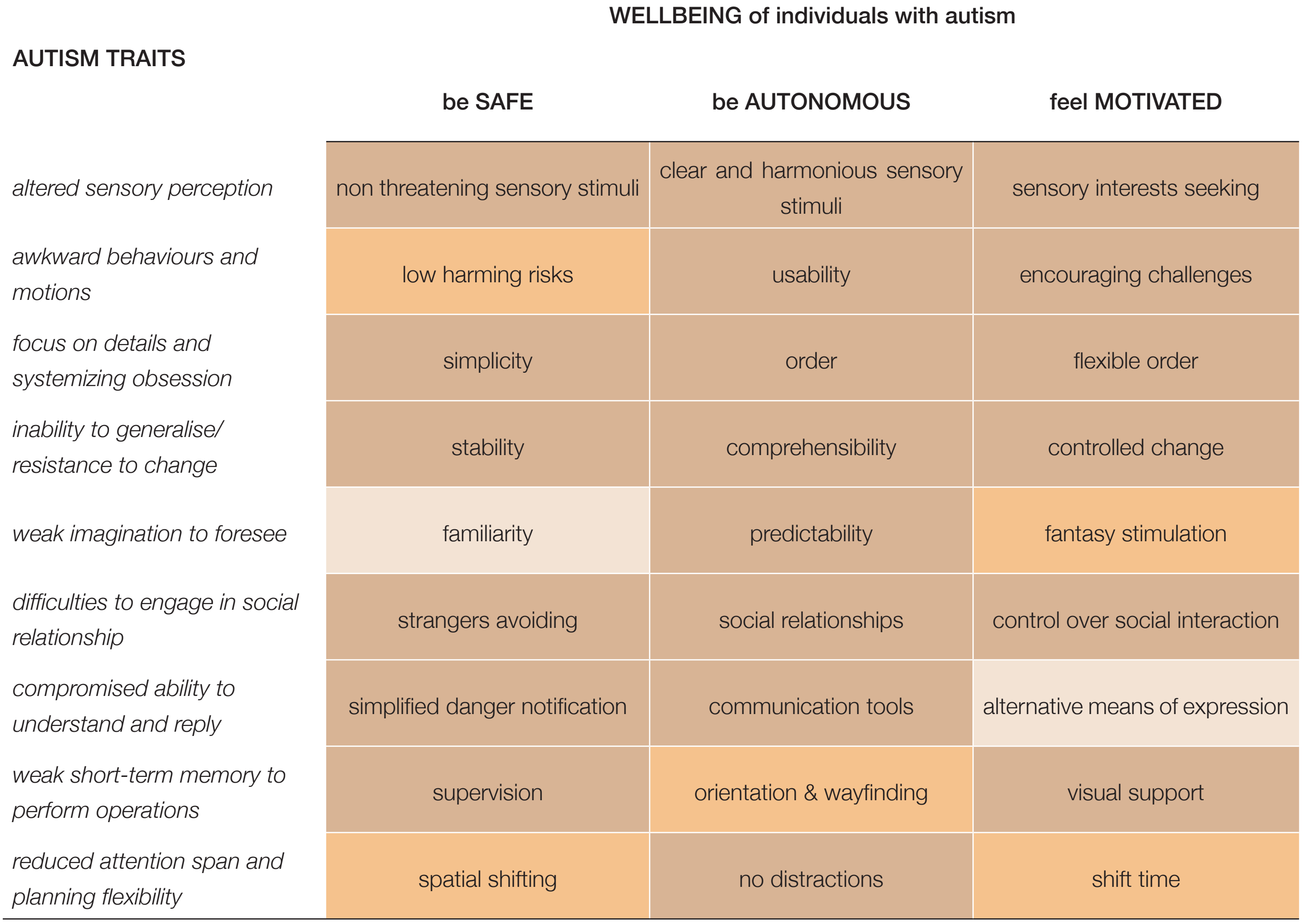
Fig 51 Outdoor area as an extension of the therapy room

Fig 52 Outdoor spaces of Caudwell Centre (Caudwell Children)

Fig 53 Large breakout area (Caudwell Children)

the freedom to choose where he/she wants to be. On the south side of the building there is also a big landscaped garden area with access from the various therapy suites. These gardens are separated from each other to permit their use without distraction of the children in the nearby intervention rooms. However, the flow can be modified in presence of the staff members to allow a wider use of the different sensory gardens and playgrounds.

C | QUALITY EVALUATION



AUTISM TRAITS	WELLBEING of individuals with autism		
	be SAFE	**be AUTONOMOUS**	**feel MOTIVATED**
altered sensory perception	non threatening sensory stimuli	clear and harmonious sensory stimuli	sensory interests seeking
awkward behaviours and motions	low harming risks	usability	encouraging challenges
focus on details and systemizing obsession	simplicity	order	flexible order
inability to generalise/ resistance to change	stability	comprehensibility	controlled change
weak imagination to foresee	familiarity	predictability	fantasy stimulation
difficulties to engage in social relationship	strangers avoiding	social relationships	control over social interaction
compromised ability to understand and reply	simplified danger notification	communication tools	alternative means of expression
weak short-term memory to perform operations	supervision	orientation & wayfinding	visual support
reduced attention span and planning flexibility	spatial shifting	no distractions	shift time

Tab 9 Caudwell International Children's Centre in Staffordshire, an evaluation of the fulfilment of autistic needs

need is met | **need is partially met** | **need is not met**

D | STAFF REMARKS

In regard to this section, there wasn't quite anything to say. The designing and construction process lasted almost 10 years with a very strong relationship with the stakeholders who actively participated in the co-design of the facility. The Centre was finished relatively recently in relation to the survey. The last took place in May 2019, a few months after its opening for testing and just one week after the official inauguration. Therefore, for members of the staff who accompanied me during the visit, it was hard to identify things that could had been done differently. So far, there was a room planned as a laboratory space for researchers, which turned not to be useful and it is in process of refurbishment a therapy room. Furthermore, they report that a laundry inside the facility could have been worthy, instead of making use of external services.

VI.5 Alpine Learning Group | New Jersey (USA)

Fig 54 Alpine Learning Group in New Jersey

A | GENERAL DATA

name & location	Alpine Learning Group is located in Paramus, in New Jersey.
built year	The centre regards a new construction built in 2000.
focus	It serves only to individuals on the autistic spectrum.
orientation	It is an autism education centre.
services	The facility offers an array of diagnostical and services along with educational interventions based on behavioural approach (ABA). It provides also training sessions for parents and professionals and in-home services. Furthermore, it undertakes also research initiatives.
age range	Children and young adult from the age of three to twenty-one.
capacity	It can accommodate 35 children divided in seven age groups of five children.
human resources	There are approximately 50 employees working at this Centre. Nearly 13 of them work on the management and development, whilst the rest 37 of them are ABA teachers and behaviour analysts.
therapy hours	Children: 9am to 2.45pm. Youngers: 9am to 4pm. Monday to Friday.
funding	It is a non-profit organization funded by the district and through donations.

Tab 10 Alpine Learning Group is located in Paramus, in New Jersey, website: https://www.alpinelearninggroup.org/

Fig 55 Ground Floor Plan of Alpine Learning Center

administrative spaces | therapeutic spaces | services | complementary spaces

B | BUILDING DESCRIPTION

The Alpine Learning Group is located in Paramus, a borough of nearly 26 thousand habitants in Bergen County, in the northern part of New Jersey. It is only 13 km west of Upper Manhattan of the New York City. It is situated in a residential area and it is immersed in a dense green area. The facility is served by a main road going north to south of the borough. The access from the road leads to a big parking area for visitors and employees which surrounds the building on all sides. The main entrance is positioned facing the main road and it is marked by this roofed area providing a protected zone for the arrival and departure of pedestrians and vehicles. Part of the campus, it is also the Ely Center for Adult Learning. It is a separate building situated north, which was opened in 2015 for the treatment of adults with autism.

The facility is a one-floor building with an almost perfect rectangular shape. It is oriented east-west according to the main entrance and to its longest side. The building presents a few irregularities in plan having an elongated structure to facilitate the entrance and an extension at the back. It also marks a not continuous development in height. It is divided in three strips along the long side with the central part being higher than the lateral ones and with a flat cover. At the back there is a regular volume which stands higher from the rest of the building. The exterior is composed of regular openings without any particularity, other than the brick cladding present only in the main facade.

Circulation | The main access to the building is on the east side and it is not central. It opens to the reception and the waiting area. It is the only way to access the building, even though it has several fire-exits on the southern and western side opening to an outer circular path which goes around the facility. The continuation of the pathway aligned to the entrance guides to an inner corridor. It has a rectangular path and follows the form of the building leading to a simple and regular layout. The internal spaces are organised in sequence along this loop distributive area on both sides. There is an outer ring of environments going through the perimeter of the building and inner island of spaces opening to the corridor. The access to these environments is usually intermediated through indentations along the circulation zone.

Administrative spaces | The first group of spaces in proximity to the entrance is the administrative spaces. On the outer ring there is a series of management offices and rooms for the staff members in continuity to the reception. Whereas, in the inner ring, there are two rooms dedicated to the evaluation for the diagnosis. In addition, there are three rooms used for the supervision and the elaboration of pupils' data which are located in the inner part of building. These spaces have transparent closure and face toward the classrooms.

Therapeutic spaces | The therapeutic spaces are located on the sides of the building on the outer ring. They are distant from the entrance and it can be noticed a progressive distance in relation to the group age. The youngest have their space closer to the entrance. The therapeutic units on the northern part are organised in seven classrooms hosting five pupils each. These educational spaces are divided according to the different age ranges from the age of three to twenty-one. Each classroom is arranged to offer different learning opportunities and spaces through zoning giving the possibility to have five contemporary one-on-one teaching sessions. Between two adjacent classrooms, there is a small box-room blind glassed to permit parents or staff members observe the learning process and the child behaviour without being noticed. However, with the updated technology, these spaces are used now as calming spaces to allow children adjust the sensorial perception and emotional feelings. At the end of the classroom series, there is a common therapeutic kitchen which is used for the preparation of meals and as a space for socialising. Part of the therapeutic spaces, there are also two spaces located on the opposite side of the building. These two spaces are dedicated to the physical training in order to work the motor abilities of the individuals with autism. Hosting noisy activities, these spaces are placed distant from the classrooms in order not to interfere with the learning process.

Services | The service areas mainly grouped in the central part of the building. In this group there are the restrooms for the staff members, the restrooms for the pupils, a bathroom for therapeutic purposes, washers and driers. For the youngest children, there is a restroom in common in between the two classrooms having access from both of them. In addition, near to the entrance, there is an enclosed space with lockers for the pupils and the staff.

Complementary spaces | At the back of the building, in between the kitchen the and the gym, there is a complementary space. It is a multifunctional big room with large windows. It is used for various activities, such as training sessions, presentations, large group meetings. Being in adjacency to the kitchen and having direct access to it through a movable wall, it permits to host also various events.

Outdoor spaces | In regard to the outdoor spaces, there is a playground in the southern part of the complex. It is a pleasant space because it is surrounded by dense and nice green area, but it is not in continuity to the building. The parking area separates the two environments making it harder to reach from the classrooms.

Fig 56 Circulation at the Alpine Learning Centre

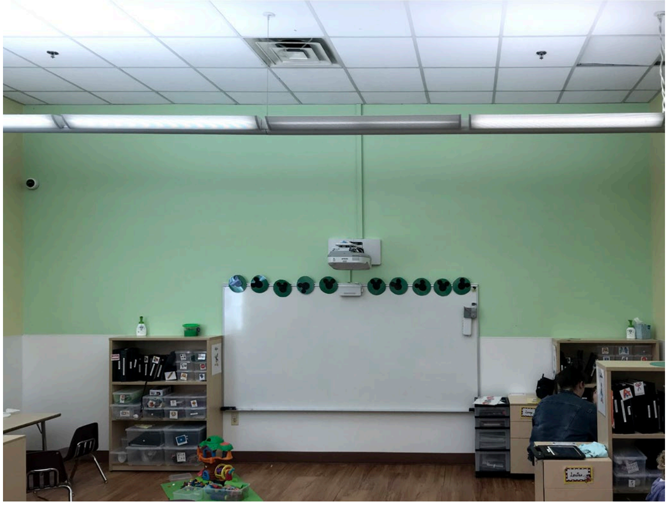


Fig 57 Therapy room at the Alpine Learning Centre

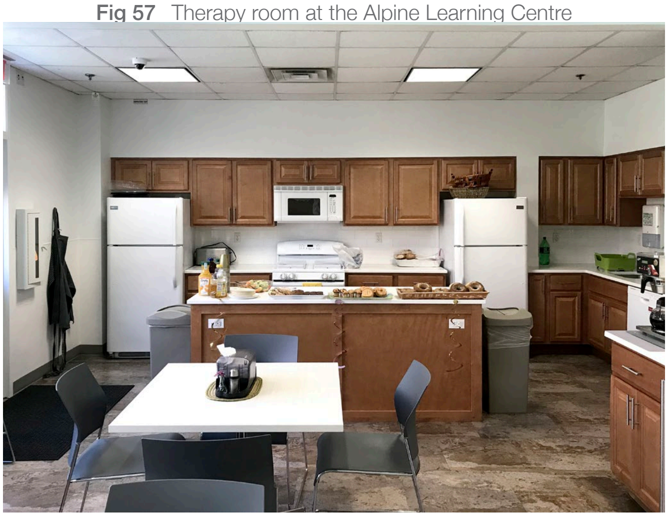


Fig 58 Therapeutic kitchen at the Alpine Learning Centre

Fig 59 Therapy desk at the Alpine Learning Centre

Fig 60 Gross motor room at the Alpine Learning Centre

C | QUALITY EVALUATION

AUTISM TRAITS	WELLBEING of individuals with autism		
	be SAFE	**be AUTONOMOUS**	**feel MOTIVATED**
altered sensory perception	non threatening sensory stimuli	clear and harmonious sensory stimuli	sensory interests seeking
awkward behaviours and motions	low harming risks	usability	encouraging challenges
focus on details and systemizing obsession	simplicity	order	flexible order
inability to generalise/ resistance to change	stability	comprehensibility	controlled change
weak imagination to foresee	familiarity	predictability	fantasy stimulation
difficulties to engage in social relationship	strangers avoiding	social relationships	control over social interaction
compromised ability to understand and reply	simplified danger notification	communication tools	alternative means of expression
weak short-term memory to perform operations	supervision	orientation & wayfinding	visual support
reduced attention span and planning flexibility	spatial shifting	no distractions	shift time

Tab 11 Alpine Learning Group is located in Paramus, in New Jersey, an evaluation of the fulfilment of autistic needs

need is met | **need is partially met** | **need is not met**

D | STAFF REMARKS

Staff members, during the visit around the facility, reported some of their objections on the working environment. Based on their everyday experience, they suggested more generous spaces in general, but mainly where a one-on-one assistance is required like in the restrooms, or in places that might get crowdy such as the lockers area. In the classrooms, in particular, it is important to have large storage spaces, so the classroom can remain tidy and only with the needed objects. Another important feature in the classrooms is the flexibility of the furniture, which permits a flexible use of the space. Regarding the restroom of the early years children, it is not enough having only one for two classrooms of five pupils. The time in the restroom of a child is longer than at a normal nursery school, because children need assistance and it is also a learning moment how to use the toilet. In addition, referring to the restrooms, the number of toilets per gender, it is well proportioned. In this kind of facilities, the majority of the team, if not all of them, are female workers, whilst, regarding the children on the spectrum, the ratio is inverse. There are nearly four times more males than females. The last remark was about the box-room in between the classroom planned to be an observation point for parents and staff. Since in the beginnings, these spaces didn't have a wide use. But with the installation of webcams in all classrooms, it lost completely its function. They have now been adapted as isolation rooms to help children with challenging behaviours calm down from the overloading. However, the adaption hasn't been successful. There were installed padding walls which gives a psychiatric institutional look and making the space less welcoming. Furthermore, it is a very small space and overall, it doesn't help children relax.

Fig 61 Modified chair at the quite room

VI.6 Conclusions

Analysing case studies was a great experience to see how it faced the problem of autism in the early years in different contexts; the typology of architectural interventions; how much design had contributed to meet the needs of children with autism; and what members of the staff think of these structures. Even though there were reported and analysed in-depth only four case studies, the exploration of other examples (see § VI.1) has strongly contributed to have a wider overview and enrich the vision on this part of the research.

Since the beginnings, it was clear that studying autism in the early steps – from diagnosis to interventions and support – could emerge similar issues everywhere, no matter of gender, race, religion, provenience, social or economic status. Despite that, it was also somehow clear that the way the issue is affronted would be different in different contexts. It would be different, of course, among different countries and maybe slightly different among different regions of a country, which is obvious due to different policies and resources. However, it was surprising for the research to find out big differences on the way the problem was dealt with even among neighbours of the same city. From the investigation, it emerged that this part of the care chain for autism is almost completely unregulated.

This experience revealed that there is no common ground on the way how care is provided to children with autism. Services lack consistency on how they are programmed and managed. It seems that there is no unity on how to deal with autism in the first years, where to do it, who is involved in the process, how they are involved, what kind of treatments, whom are they addressed, and how an intervention is delivered, etc. Some of these, if not all, might appear inappropriate in a research in architecture, but they are all indirectly connected to the architectural intervention. They influence the design process and dictate a certain architectural solution more than another.

In this investigation process, it came out also that it is difficult to identify a typology of architectural intervention. The variety of aforementioned elements combined with local influences and the lack of previous experiences and of a tradition it is reflected in the ambiguity of facility character. The architectural solution is mostly left to designers' own interpretation. It can be noticed how design outcomes widely range from the healthcare model to educational environments or structures that have no resemblance of anything seen before.

This vagueness somehow affects also the fulfilment of needs of individuals with autism; sometimes it misleads or distracts the attention of designers. In this situation, it is easy to lose the main focus: designing for autism. The analysis of case studies showed different levels of awareness of design to meet the needs of autistic users. It can be deduced that the generally raised awareness on autism among the society has contributed to the additional attention of designers on fit for purpose solutions. More recent architectural interventions – although not always – appear to be more autism-friendly designed.

Lastly, in this part of the research, the contribution of staff members of case studies was priceless. Their remarks pointed out very useful considerations, which are sometimes not that obvious to be taken into account, like for instance, the ratio of restrooms for each gender.

CHAPTER VII
INTERVIEWS WITH PARENTS

This chapter attempts to collect experiences of parents of children with autism and their vision fur future developments. In the first section, it is described the methodology applied; how parents were selected, the reason why they were selected, and the questions directed to them. In the following paragraphs, there are reported the four interviews and the chapter concludes with a series of final considerations pointed out through this experience.

VII.1 Objective and framework

The second survey is about getting to know what the perception of those directly affected by the care system for autism is; parents and children on the spectrum. Considering the delicate age and the complex autistic nature, it is difficult to have the contribution of children with autism in the first place in the investigation process. However, their caregivers – their parents in this case – in quality of end-users and being directly involved in the assistance of their children, can be trusted representatives and can give a valuable contribution to the research. In addition, two of them were also diagnosed with autism, so they could express their thoughts as parents and as people on the spectrum. The aim is to learn from their daily routine and their experience in rearing a child affected by autism and to understand what their vision for the future therapeutic interventions is.

This step is structured differently from the previous one; it is not based anymore on observation tools, but on storytelling through dialogue. In literature, they are known also as in-depth interviews (Laurìa, 2017b). The lasts allow a different kind of investigation of the quality of the environments and services. There is a shift in the kind of information and in the way it is acquired (Costa, 2014). The in-depth interviews help to understand the point of view of an interest group predominantly in non-reflected dynamics of the space used. This contributes to assess the degree of congruence between the potential of a space or service and the intention of planners and designers. It is obvious, that a 'low' degree of congruence is an indicator that the design has missed the target.

To complete this task, there had to be chosen parents in the four selected countries: Albania, Italy, the UK and the US. It is impossible to get the opinion of all parents of children diagnosed with autism in these countries. It is also worthy to notice, that each person has his/her own personal experience, due to several factors such as: medical, social, cultural, geographical, political and economic conditions; but also, different ways of thinking and lifestyle. Nevertheless, it is as difficult to identify a representative group of interest. That means that the research does not aim to understand the whole system, which is utopic to look for, but just to get closer to the reality that stakeholders face in the everyday life. For that reason, instead of choosing a few parents in each country, it was thought to choose a person that, other than being a parent of a child on the spectrum, has a certain influence and contribution in raising the awareness of autism in his/her country. These people have an in-person experience, but they are also public figures and in everyday contact with other parents of the autistic community. So, their contribution can give very insightful considerations.

The selection of the participants, in this case, was more limited, but yet subjective because it was based on the relationships created with these individuals in various events on autism. The parents involved in this investigation phase are listed in the Tab.12. A more detailed profile of them is given in the following paragraphs along with their contribution. The in-depth interviews were conducted at their working place in their countries between April and June 2019. The conversations were conducted in the official

	parents	profession
Albania	Artan Hoxha_father of P. 18 yr. old	economics expert
Italy	Gianluca Nicoletti_father of T. 30 yr. old	giornalist
United Kingdom	Carly Jones_mother of H. 17 yr. old	activist
United States	Shpresa Xhakli_mother of A. 31 yr. old	doctor

Tab 12 List of the parents who participated at the survey.

languages of each country of provenience, and then they were translated in English by the author.

What this study wants to know from parents of children with autism can be broken down into the following topics and questions. As each of these parents has his/her own story to tell and in order to give the right amount of space for the answer, the questions are willingly composed to be vague and to lead to an open discussion regarding these topics. Therefore, to all parents, there will be asked the same question and their answers will be reported based on the topic remaining faithful to their storytelling. All questions will start with: ‘Based on your own experience with your son/daughter and the shared stories of other parents you have been in contact in this trail, …’

diagnosis	what are the biggest issues that a parent faces in regard to the diagnosis? (hints: lack of info; low professional competences; bad coordination among professionals; long waiting times; referrals; high costs; other)
treatments	what does a parent struggle mostly in getting the right treatment for his child? (hints: the kind of therapies; not enough therapeutic hours; bad coordination to the mainstream activities for the child; not adequate environments; other)
counselling	what services are offered to support families and what do you think is still missing to provide the right care? (hints: social services; educational services; healthcare services)
aspirations	how do you imagine an ideal centre for children with autism?

Tab 13 List of the topics and questions that were at the base of the in-depth interviews with parents

In the following paragraphs, there will be presented the in-depth interviews of the four participants and the outcome of this part of the research. The individual answers will be preceded by a short description of their profile and of their contribution to autism, followed by a photo during these meetings.

VII.2 Interview with Artan Hoxha | Tirana(ALB)

Fig 62 Prof Artan Hoxha

Prof Artan Hoxha – is a well-known economics expert. He was the Minister of Commerce and Economic Cooperation (1992-1993) in Albania. During his career, he has carried out several important roles like: former Director and later, President of the Institute of Contemporary Studies (ISB); Member of the Board of Directors of the University of Tirana; member of the Board of Trustees of the South East European Research Center (SEERC) in Thessaloniki, Greece; member of the "Ora News" Private Television Council Assembly; member of the Review Board Council of the Monitor Magazine. Actually, Hoxha is the co-founder and the President of Tirana Business University. Throughout his almost thirty-year career he has contributed to the drafting of the most important policies, strategies and laws relevant to economic and institutional reforms. Hoxha is also a well-known analyst in TV broadcasts and a columnist in written media.

Hoxha is the father of an eighteen years old girl P. with autism. Since her diagnosis on the autistic spectrum, he has been actively involved in autism awareness raising projects. He collaborates with Albanian Children Foundation, which deals with children with autism and, every year, they organize events to bring together experts on autism and parents of children on the spectrum to share their experience.

Diagnosis | Based on your own experience with your daughter P. and the shared stories of other parents you have been in contact in this trail, what are the biggest issues that a parent faces in regard to the diagnosis?

« Parents, who face autism for the first time in their child, are more likely not to have ever heard about it before; their close relatives and friends, probably, haven't either. Sometimes, it is even worse if they have heard something not clear, that might be more disorienting than helpful.

From the moment when parents start noticing an unusual development of their child (mainly in speech development and paying attention) until the diagnosis of autism, there usually passes a very long, troublesome and stressful period for parents. Autism, due to the lack of information, is considered as a terrible misfortune, an eternal and hopeless suffering; making parents feel devastated.

While the diagnosis of autism has seen improvements in Albania in the last 15 years, I think that in this first phase of coping with autism, those who mostly need help are the parents. Parents need counselling and psychological support to overcome the first *stage of recognition, so that it is not that dramatic till to the point of breaking down. »*

Treatments | Based on your own experience with your daughter P. and the shared stories of other parents you have been in contact in this trail, what does a parent struggle mostly in getting the right treatment for his child?

« Over the years, the supply of services for children with autism has increased quantitively and has improved qualitatively by private providers, while the public facilities remain unable to satisfy the demand in terms of quantity and provide adequate services in terms of quality.

The main problems are not on the side of the offer, but on the resources to finance these services; thus, the potential of families to cover privately the costs. Most of the families of children on the spectrum have financial difficulties to pay, private donations are still modest, whereas public funding for autism are non-existent. The government should financially support families with an autistic member who, most likely, will need not only funding for everyday basic needs such as food, clothing and treatments, but also for a lifelong caregiver. »

Counselling | Based on your own experience with your daughter P. and the shared stories of other parents you have been in contact in this trail, what services are offered to support families and what do you think is still missing to provide the right care?

« Healthcare services are the most problematic ones, starting from the tooth care. It is very hard to make a child with autism sit down on the dentist's chair; therefore, he/she should be treated under the anaesthesia. The problem is that most of the dentists do not provide this service. »

Aspirations | Based on your own experience with your daughter P. and the shared stories of other parents you have been in contact in this trail, how do you imagine an ideal centre for children with autism?

« First of all, I think we need to clear out the main goal of a Centre for children with autism; it is not about treatments like in other fields of medicine, where for example you take some antibiotic which fight the problem for several days. The aim should be to work closely and continuously to make children diagnosed on the autistic spectrum -as much as possible- autonomous in the everyday life. Thus, children with autism should practice with persistence how to eat, wash, clean, bathe, speak, talk in groups, socialise with others, etc. and then how to read, write, draw or sing. They need to interact with others; thus, the Centre doesn't need to be dedicated exclusively to them. However, a certain level of differentiation based on the particular needs of each child it is important to be done to provide personalised treatments. Furthermore, providing different kinds of treatments at the same facility has the advantage to understand the efficacity of each intervention. In addition, in order to offer a complete range of services crucial for children on the spectrum, it would be great to have also clinical services, if that is possible. »

VII.3 Interview with Gianluca Nicoletti | Rome (IT)

Fig 63 Gianluca Nicoletti

Gianluca Nicoletti - is a very famous Italian journalist, writer, radio and television presenter. Currently, he is a speaker on Radio 24 and a columnist for La Stampa. Nicoletti started working in radio in 1983 and since then has covered different roles such as correspondent, author and presenter of several programmes. He was described as a "… Fine writer, television and costume critic, a representative of excellence of the Italian radio". He has collaborated also as an author, host, presenter and analyst with various television programmes in the years. Nicoletti has a long experience on journalism and has edited and directed various online projects. He has experimented in theatrical activities designing a performance "La macchina per entrare e uscire dal mondo".

Nicoletti has been diagnosed with autism and is the father of a son also on the autistic spectrum. He has been actively involved in spreading awareness on autism and neurodiversity. Since 2013, Nicoletti has written three books regarding his experience with his son Tommy: "Una note ho sognatto che parlavi", "Alla fine qualcosa ci inventeremo", and "Io, figlio di mio figlio", where the first two were best sellers. He has directed the film "Tommy e gli altri". Nicoletti has designed and manages a website on autism "Per noi autistici" built with the contribution of the Ministry of Education, University and Research. He is the president of the non-profit organization Insettopia, an association that is committed to creating and supporting projects capable of providing useful services to the families of individuals with autism.

Diagnosis | Based on your own experience with your son T. and the shared stories of other parents you have been in contact in this trail, what are the biggest issues that a parent faces in regard to the diagnosis?

« I belong to a completely different generation of parents; I was told for the first time about the possible presence of autism traits on my son when he was already thirteen years old. The problem was that nobody could tell us exactly what the problem was. Fortunately, that is not the actual reality. Nowadays, most of the children with autism in Italy receive the diagnosis before entering primary school. Therefore, with the raised awareness of autism among parents and better qualified professionals, the problem of early evaluation seems overcome. Yet, one of the biggest issues is what to do next, what the child needs and what parents can do. I started hearing about ABA treatments only after many years, when T. was at that time an adult. »

Treatments | Based on your own experience with your son T. and the shared stories of other parents you have been in contact in this trail, what does a parent struggle mostly in getting the right treatment for his child?

« In Italy, the problem is that there is not a common thinking on evidence-based treatments. First of all, there is a lack of basic scientific culture on how to approach autism among different professionals. This gap fuels parents' uncertainties who find them-

selves in a crossroad with thousands of doubts about which path to take. Interventions are administered randomly. If you are lucky enough to be born in the right place, everything might go well; otherwise, it is quite difficult, or impossible to get what it is up to your child, unless you fight hard through legal battles. »

Counselling | Based on your own experience with your son T. and the shared stories of other parents you have been in contact in this trail, what services are offered to support families and what do you think is still missing to provide the right care?

« We are missing a crucial thing: a laic and scientific approach to autism. The community lacks neuropsychiatrists having a homogeneous vision on evidence-based interventions and a national strategy in dealing with autism. Politics and policies, so far, have been oriented in a demagogic and, often, in a clientelism way. One of the relevant issues in a local level, as well as at a national one, is favouring organizations that administer treatments of doubtful efficacy. »

Aspirations | Based on your own experience with your son T. and the shared stories of other parents you have been in contact in this trail, how do you imagine an ideal centre for children with autism?

« First of all, it should not have that denomination… The key word should be inclusion. I imagine a personalised and protected place, however opened and not structured as a hospital or 'sweetened' mental institution. A great and beautiful place that welcomes every neurotypical, but it is adjusted according the different abilities and needs of individuals with autism. It should be a place that highlights the dignity of each child, which is the core of self-esteem, of social relationships and of the perception of belonging to a community. »

VII.4 Interview with Carly Jones | London (UK)

Fig 64 Carly Jones

Carly Jones - is a British Autism Advocate who has worked for the inclusion of autistic women and girls since 2008. She is mother of two girls on the autistic spectrum and, recently, also she has been diagnosed with autism. She has been speaking on News channels, Universities and Parliament, and was the first British Autistic woman to address the United Nations on autistic females' rights. Jones proudly holds a public appointment of a member of the UK Honours Committee and is an independent panel member for the Ministry of Justice. Her aim to create social mobility and elevate the most diverse talents in the UK to ensure no talent is overlooked. Jones created a free online safeguarding course for autistic girls and has made award winning disability films shown around the world and in Cannes Film festival. Jones was made an MBE in the 2017 New Year's Honours list for services to those with Autism.

Jones has a rich and valuable contribution in several publications. She is among the co-authors with National Autism Charities on Government Safeguarding Guidance on Online Safety, Prevent Terrorism and Child Sexual Exploitation. She has been working also on the female specific briefings for the Autism Acts Strategy 10th Anniversary. Jones' work has been accepted and published also by the UK Parliament and the United Nations Human Rights office.

Diagnosis | Based on your own experience with your daughters and the shared stories of other parents you have been in contact in this trail, what are the biggest issues that a parent faces in regard to the diagnosis?

«The problem that many parents face when trying to achieve a diagnosis of autism for the young person is the very long waiting time. This is because they're trying sometimes to get a diagnosis in an area which happens to have a high demand. The demand comes from not only very good awareness among parents and caregivers about autism, but it also comes from a lack of National Health Service psychologists and clinical professionals to give that diagnosis. Many National Health Service clinicians are going to private facilities because they can earn a lot more and quicker. Presentations of autism sometimes appearing differently in males and females means that young women are often not seen until they have experienced a mental health crisis. Autistic boys generally are diagnosed much sooner than their female counterparts. »

Treatments | Based on your own experience with your daughters and the shared stories of other parents you have been in contact in this trail, what does a parent struggle mostly in getting the right treatment for his child?

«It's imperative that treatments offered to autistic young people via their parents do not cause harm. Recent research now shows that autistic adults who have had ABA during childhood, also known as PBS, now suffer from post-traumatic stress disorder as a direct result. After diagnosis parents automatically feel that they need to support and to a degree to fix the problem. There are much more organic ways to support an autistic child such as speech and language therapy and occupational therapy. The waiting lists for these treatments, however, are long and disjointed. »

Counselling | Based on your own experience with your daughters and the shared stories of other parents you have been in contact in this trail, what services are offered to support families and what do you think is still missing to provide the right care?

«Counselling for individuals on the spectrum and, particularly, for their parents after receiving an autism diagnosis does not often happen. Parents, therefore, seek advice support and to a degree counselling via social media sites and other families that share the similar concerns and are more experienced. The problem with social media sites is that they can spread myths about autism and parents are vulnerable to snake oil salesmen. »

Aspirations | Based on your own experience with your daughters and the shared stories of other parents you have been in contact in this trail, how do you imagine an ideal centre for children with autism?

«An ideal centre for children under five years old who are going for an autism diagnosis would be one with fantastic sensory input. There should be no bright lights. It needs to be a calm place, hopefully with animals or fish or perhaps therapy dogs. Also, it would be important that it is understood that some of the parents may also be autistic themselves, so appointment times would be clear and explicit. All treatments would be under the same roof and the waiting times would be made shorter by the fact that there would be seamless communication between professionals, as it needs to be one multidisciplinary team. Parents and children would be safeguarded against therapy that can cause more harm than good and given professional autistic lead guidance. Autistic professionals and mentors need to be strongly recommended as staff. »

VII.5 Interview with Shpresa Xhakli | New Jersey (USA)

Shpresa Xhakli – a medical doctor by profession, who lives in New Jersey. Her plans for the future and her life changed forever when Arben, her son, was diagnosed with autism. Being a doctor, but unable to do anything to get a hug from her son or to hear him calling mum, Xhakli made a promise to him and herself that she was going to fight to see a smile in his son's face and his peers. She got dedicated in a mission to raising the awareness of autism around the world. She started a Foundation named "United for Autism" to help individuals with autism and their families. Xhakli has been quite active and has contributed in first-person and through fund raisings to build therapeutic centres and professional training for therapist. Her moto in this journey is: "Autism is not a fatality – ignorance is".

Fig 65 Shpresa Xhakli

Diagnosis | Based on your own experience with your son A. and the shared stories of other parents you have been in contact in this trail, what are the biggest issues that a parent faces in regard to the diagnosis?

« In this era, it seems we know so much about autism, yet at the same time, it seems also we know little about it. In the beginning it is difficult to find someone to tell you what you need to do and where you need to go. Apparently, there are not enough services in support to parents and their children. There are different professionals involved in the assessment which often have different opinions, which might misguide the evaluation. It takes usually more than six months, between the different appointments, to finish the evaluation. And, if you want to have a faster process you have to visit private clinics, which not everyone can afford it. Still, even after getting the diagnosis, parents are unsure of what to do next. It feels to be fighting alone in all this. No one understands what you are going through. »

Treatments | Based on your own experience with your son A. and the shared stories of other parents you have been in contact in this trail, what does a parent struggle mostly in getting the right treatment for his child?

« There are so many treatments claiming the success, but you cannot submit your child to all of them. As parents, we are vulnerable because we want to get the best treatment for our child; we, therefore, we feel overwhelmed, under pressure and uncertain what to do. Another problem is related to financial issues; it is hard to find financial support and almost unaffordable for most parents to pay for all the therapeutic hours the child needs.

Child activities for those on the spectrum are limited and their integration in the society or with other children it is far from what it is claimed and supposed to be. Children with autism are still looked as different and feel excluded. Sometimes, there is little understanding even from parents of other neurotypical children who do not let them play together because they are afraid. »

Counselling | Based on your own experience with your son A. and the shared stories of other parents you have been in contact in this trail, what services are offered to support families and what do you think is still missing to provide the right care?

« There is a raising rate of prevalence of autism which highlights everyday more the spectrum of needs of children on the spectrum and the high demand for services and support. The reality is often sad, because the offer widely mismatches the demand.

We, parents of children with autism, are left pretty much on our own to gather information about autism, learn about our child's needs, find services and the financial support. Often, we need to even hire a lawyer because our child's rights are not met, and we have to fight for better services. A service that I find it commonly missing is the medical care. Sometimes even for mild interventions such as the medication of depression or seizures, we need to go to the hospital through different levels of care, which is an unpleasant environment for individuals with autism. »

Aspirations | Based on your own experience with your son A. and the shared stories of other parents you have been in contact in this trail, how do you imagine an ideal centre for children with autism?

« In the past years, in part because of my interest to find the best options for my son and in part due to commitment in raising autism awareness and contributing to the opening of facilities for individuals on the spectrum, I have had the opportunity to visit tens of Centres for autism, dedicated to different age ranges and of different typologies and services. One of these Centres that has remained in my memory is the Shaffallah Centre, in Qatar, which provides care for people with intellectual disabilities, mainly autism spectrum disorders. Trying to collect the best features of those visited, a Centre should offer a wide array of services and treatments. In order to give an assistance and support as complete as possible, it should offer educational and social services mainly, but also first care medical services. The interventions dedicated to children with autism must cover not only a series of therapeutic treatments, but also a wide offer of activities, such as sports and workshops, based on play and they should engage also their parents. »

VII.6 Conclusions

Meeting parents of children with autism and having a conversation with them enriched the investigation part of the research. It is difficult to get some kinds of information or to understand what is really happening just from reading an article or looking from outside. Only those who have gone through over that experience know what it means to rear a child with autism; only they can tell the efforts needed to get along with that situation. Parents suffer at first person all the burden of care, so they are privileged stakeholders. But at the same time, they are also very fragile as they feel abandoned and have seen their lives change completely after they got to know the diagnosis of their child. Therefore, this part of the research, other than being very helpful, was also very emotional.

As it was expected, it is hard to have a certain degree of objectiveness in this kind of investigation. There were organised tenths of informal meetings with parents of children with autism and there were formally reported only four of them; those of parents carrying an important role in raising the autism awareness in the society and which could refer the voice of many other parents. Yet, every in-depth interview is coloured by the personal experience, and of course, it is highly personal and different from all others. As a result, these talks with these parents did not help to understand completely the situation, however, they were very useful to touch the reality. During this trail, there emerged interesting cues and viewpoints that could fuel further discussions and analysis. It was interesting to see how the same issue is perceived in different countries, where sometimes it is found a common accord, whereas for others the answers reflect the national spirit and climate of services and their efficiency.

For instance, as regarding the diagnosis, the problems that parents face were mostly different. It cannot be said anymore that there is a lack of training of the professional figures compared to a few years ago. However, in some places, it is still verified bad coordination among different experts, which has resulted in long waiting times or misdiagnosis in the worst cases. In other contexts, the biggest problem remains the awareness of parents on autism.

Whereas, for the treatments there is a greater consensus. Other than common problems, again that of long waiting times, or alternatively the high costs of such treatments, because there are predominantly offered by the private sector in some countries, the concern regards the high number of treatments that are not tested, but which pretend to cure autism or help individuals on the spectrum. Providers take advantage of the desperation of parents filling them with false hope and costing them a lot of money.

When talking about the services that are still missing in the care chain, parents more than one time confirm the necessity for personalised medical care. Mainstream healthcare is not yet able to adequately assist their children. Besides, they demand for more qualified social-moral-informative support, because the informal help they get through social networks is very useful to share personal stories but can misguide parents.

Lastly, like their stories, also their viewpoints and aspirations on future developments of care segments for children with autism range in different directions. However, here can be listed a few keywords emerged that could somehow describe it, such as: inclusive, personalised, multidisciplinary and multifunctional.

CHAPTER VIII
INTERVIEWS WITH AUTISM EXPERTS

This chapter aims to report the viewpoint of different professional figures on autism regarding therapeutic interventions and the environments where they take place. In the first section, it is described the methodology applied; how autism experts were selected, the reason why they were selected, and the questions directed to them. In the following paragraphs, there are reported the four interviews and the chapter concludes with a series of final considerations pointed out through this experience.

VIII.1 Objective and framework

The third survey concludes the investigative phase with talks to qualified persons on autism, to people who have dedicated their professional life on studying autism and working with individuals affected by the autistic condition. Having matured a certain experience on autism, their know-how can have a relevant role in highlighting issues of assistance for autism and helping set the basis in giving a response. They are involved to participate with their critical thought in this investigation phase on the way care and support is provided to preschool aged children with autism and their parents.

Being an unexplored and unsystematised area, to the best of my knowledge from the analysis phase, some questions emerged. From the previous studies and surveys of this research, it seems that there is a large number of arrangements providing care for children on the autistic spectrum which has produced almost the same number of varieties of care models. For instance, the same service for children with autism is offered in different facilities: at educational spaces, as part healthcare structures, at specialised centres, etc.; or the same service at a certain place may be opened: to specific diagnosis, to a certain group of similar disabilities, to all cognitive disabilities; or to different kinds of disabilities. These issues and a few others arise a series of dilemmas on planning facilities for children with autism, which indirectly highly influenced their design. Therefore, instead of asking these professional figures the general question how they imagine an ideal centre, as it was done with parents, it was chosen to guide the discussion through the series of questions that emerged. The unveiled dilemmas for the conception of care centres for children diagnosed with autism are described in the Tab.15. They are presented with a short introduction of the context followed by questions.

Willing to know the perception and the vision of different experts on autism on these matters, in-depth interviews were chosen as an investigation tool. The professional persons were invited to give their personal opinions, criticism, aspirations and suggestions based on their daily experience in taking care of individuals on the spectrum. Even in this case, to participate in the survey, there were chosen expert profiles on autism in the four contexts taken into account. In each country, it was identified through personal contacts and with the help of the autistic network enriched in these years of research, a highly-skilled professional with a well-known contribution to autism diagnosis and/or treatments. They were contacted, and they have shown willingness to participate in this study. They come from different backgrounds, but all of them have rich experience in research on autism and in dealing with individuals on the spectrum. The autism experts selected to share their knowledge and their personal opinions on the perspective of care for autism are listed in the Tab. 14.

	autism expert	**profession**
Albania	Prof Dr Ariel Çomo	child neuropsychiatrist
Italy	Dr Luigi Mazzone	child neuropsychiatrist
United Kingdom	Cherry Hall	early years local manager
United States	Dr Bridget A. Taylor	psychologist

Tab 14 List of autism experts who participated at the survey

These meetings took place between April and June 2019 at the offices of the above-mentioned personalities. The conversations were conducted in the official languages of each country of provenience, and then they were translated in English by the author. In the following paragraphs, there will be presented the in-depth interviews of the four participants and the outcome of this part of the research. The individual answers will be preceded by a short description of their background and their actual position, followed by a photo of these meetings.

diagnosis	Considering that the current health management structure is usually organised around single episodes of care and considering the problems that parents of children later diagnosed with autism face during the diagnosis and immediately after, such as: lack of info, long waiting times, bad cooperation among professionals, and low coordination about the next step; in order to overcome the disorientation of the family and operators involved in the diagnosis and formulation of the therapeutic project: *do you think there should be an effort to make all relevant figures in the diagnosis examination work together and be present at the same centre where the treatments take place so they can follow-up every child? In less words, do you think the diagnosis centre and therapeutic centre should be on the same place?*
treatments	There is a wide range of treatments for individuals affected by the autistic condition, among which there can be mentioned behavioural therapy, speech-language therapy, occupational therapy and social skills training. As to now, they are found to be offered in different structures and combinations. In an optic of facilitating the life of those affected and their caregivers, and favouring a better organisation and integration of the different therapies an individual with autism might need to seek during a certain period of time: *do you think all evidence-based treatments should be offered at the same centre, or it is not that necessary because several specialised centres on specific therapies can be as fruitful?*
focus	The available therapies for autism are useful also for the treatment of other disorders or disabilities. For instance, physiotherapy is applied even for neurotypical having backpain, or speech therapy is carried out for social-communication disorders for example. Bearing in mind facts such as that: individuals with autism need a particular way of assistance and treatment, even though speaking for the same kind of therapy; but also economic issues on providing and managing these kind of facilities; *do you think Care Centres should be focused exclusively on autism, specialised to a particular group of disorders, opened to different kind of disabilities, or simply opened to everyone who needs a treatment?*
age range	Autism can be diagnosed usually between the second and the third year of life of a child and it has been characterised as a chronic disorder with lifelong presence of the condition. Therefore, individuals on the spectrum will require care for the rest of their life. Some treatments are usually applied mostly in the early years while others for long periods. One of the problems that is enlightened is the age range the services should be dedicated in certain facilities. The first problem, but of less importance in this occasion is when to consider a person as an adult, whether at his/her 18th birthday, or when turning 21 or 25. The second issue, significant for this research, is: *do you think care centres offered to children with autism should be differentiated per age range, or at least the preschool aged children, being more delicate, should be cared separately?*
character	A care centre for children with autism, from the existing examples found on site, can be found in several forms, such as: annexed to school environments, as part of the hospitals; or just have traits of institutional spaces. Willing to have a more welcoming aspect, of course in congruence with its function, *how do you see a care centre for children on the spectrum as more oriented or characterised architectonically: as educational spaces, as healthcare facility, as a community centre, or something else?*
clinical services	It is hard to say that the experience in the hospital should be pleasant due to the main reason why a person is headed to healthcare facilities. However, in particular the experience of children with autism is often dramatic. Sensory overloading such as the characteristic smell of hospitals or chaos, long waiting times, and the lack of awareness of staff of how to deal with autistic cases, are just some of the reasons. Considering also that children on the spectrum, due to the complex nature of autism and the presence of comorbidities: *do you think basic healthcare services, such as paediatrician visits, first aid services, dental offices, etc, should be included in a Day Care Centre for children, so they don't have to go to the hospital each time they don't feel well?*
integration	There is a big ongoing debate on what is to be done: mainstream or special. Both options are exposed to serious criticism from parents and experts. According to your vision: *how do you think there should be the relationship of these Centres to mainstream facilities of their peers? Should they be fully integrated, partly connected or completely separated?*

Tab 15 List of the topics and dilemmas that were proposed at autism experts

VIII.2 Interview with Ariel Çomo | Child Neuropsychiatrist in Albania

Prof Dr Ariel Çomo – is a child neuropsychiatrist and, currently, he is the Head of Psychiatry Division of the Department of Neuroscience, at the Tirana University Hospital "Mother Tereza". He is a Professor of Psychiatry and the Deputy Dean of the Faculty of Medicine, at Tirana Medical University. Çomo is also a member of the National Steering Committee on Reforming the Mental Health Sector and a member of a working group on developing inter-sectorial strategy on Child and Adolescent Mental Health. Since 2010, he is the Albanian Coordinator at the South East European Autism Network and Scientific Director of the Tirana Regional Center on Autism. Çomo has widely contributed in training sessions for professionals for the diagnosis and treatments of autism.

Fig 66 Prof Dr Ariel Çomo

Diagnosis | Do you think there should be an effort to make all relevant figures in the diagnosis examination work together and be present at the same centre where the treatments take place so they can follow-up every child? In less words, do you think the diagnosis centre and therapeutic centre should be on the same place?

« First of all, we must clear out two important key things: the target of diagnosis and the age of children to be assessed. If we think of the diagnosis as a process just to let us know a diagnostic conclusion, there is nothing odd that the assessment for autism evaluation can be delivered by a single expert, especially for children over four years. Dealing with younger children, in between 18 and 30 months, it is less likely that a single person could do it efficiently; the younger the children, the more complicated and sophisticated the investigation process becomes. Therefore, the assessment might need the presence of more experts and profiles. But, if we add at the merely diagnosis task the objective of defining what the next step is – so, what kind of treatments- that is a bigger marker that we need more people of different expertise.

Whether this group of experts should be at the treatment Centre or not, it is not a standardised procedure, but it depends on many factors, such as institutional organization, geographical area, population, etc., which influence and modify the service supply. However, what it can be said is that it is not highly necessary. Experts, who might work in bigger health institutions, can decide on the intervention strategy and elaborate the care plan. On the other side, therapists who execute experts' indications and work closely with the child, can report to these experts on regular basis. At the end, the results of treatments are not immediate. »

Treatments | Do you think all evidence-based treatments should be offered at the same centre, or it is not that necessary because several specialised centres on specific therapies can be as fruitful?

« The question could be interpreted this way: having to build a new Centre, it is worthy to invest all the economic resources in refining or perfecting one model, or it is better to provide all the evidence-based models. First of all, we must acknowledge that, so far, evidence-based treatments for autism can be counted with one hand's fingers. For that reason, personally, I think it would be ideal to tend toward providing a complete offer with all these interventions. However, we must also bear in mind that the specific weight of the studies of evidence-based models, which determines the potential of data and conclusions, is relative. Thus, offering a variety of current evidence-based treatments

should also consider possibilities of what future developments can provide, which might be different interventions. »

Focus | Do you think Care Centres should be focused exclusively on autism, specialised to a particular group of disorders, opened to different kind of disabilities, or simply opened to everyone who needs a treatment?

« It is a tricky question because it would be easier to say dedicated only to autism, but it would be very difficult to justify the reason why. In a bigger overview, it is a matter of general philosophy of life decisions that influence the way systems are built and integrated. Unfortunately, when it comes to human values of social growth, we are not prepared for that; we do not have a well-defined standard. Just to provide an example, we teach computer science to children, but we do not know whether it is better than teaching them farming or pet caring, or vice versa. Talking about ideal facilities, consider how great it would be having paediatric hospitals in the healthcare chain, nursery school in the education chain, and community centres in the social support chain, that are embroidered in such a way to fulfil every personal desire and need of every person. That means that, if there is an identified need of a certain category, the environment has all particular precautions and all the best tools to give him what he needs. »

Age range | Do you think care centres provided to children with autism should be differentiated per age range, or at least the preschool age children, being more delicate, should be cared separately?

« Not necessarily. Categories like age range are conventional things based on a series of cultural, social, economic, etc. factors that make our life easier. In this case, treating preschool age children in a separate facility from those who have even a few months more it is not mandatory. It is difficult to say which one is worthy, as long as their personal needs are met through personalised interventions. »

Character | How do you see a care centre for children on the spectrum as more oriented or characterised architectonically: as educational spaces, as healthcare facility, as a community centre, or something else?

« Children with autism should go to educational environments just like their peers, but the history of these years shows how unprepared we are as a society to welcome those on the spectrum. We are unable to pay the financial bill to create friendly spaces and end up hiding behind a finger and finding justifications for alternative unusual 'inventions.' Private businesses take advantage of this gap and make a run to be the first to fill it by interpreting the way they want; which quite always, it is not the way it should be, but the way that brings the highest profit. »

Clinic services | Do you think basic healthcare services, such as paediatrician visits, first aid services, dental office, etc, should be included in a Day Care Centre for children, so they don't have to go to the hospital each time they don't feel well?

« The most obvious answer would be: 'yes, absolutely'. Then if you start thinking of it, the answer becomes: 'it depends'. In fact, it depends on many factors, such as the number of children, children's characteristics, location of the centre, costs, etc. For instance, if there are many children that present epileptic seizures it may make sense to have a doctor. But, if the number of these children is as large as it would require the presence of a neuro paediatrician for less than two hours a day, maybe it is worthy that this doctor stays at the hospital and take care to a larger group of patients. And instead of a neurologist, it may be more important to have the figure of a geneticist in that Centre. We are talking about parents whose child is somewhere in between two and six years old, and these parents might be thinking of having another child. Thus, the genetic consultation is very fundamental to help them clear every doubt. However, this might not be a suitable case, if the hospital is nearby the Autism Centre. In conclusion, this issue is related to the specific needs of a specific context. »

Integration | How do you think there should be the relationship of these Centres to mainstream facilities of their peers? Should they be fully integrated, partly connected or completely separated?

« Each of these models is possible and might work well. Children with autism spend a notable amount of time at treatment Centres, therefore, it is very important the quality of the time spent there. Children on the spectrum have some particular needs which should be met. Each of the settings' models can accommodate their needs completely, partially, or not at all. As a result, first of all, no matter where, the stay at these facilities should be pleasant. The management and the environmental organisation contribute to that; the profile of teachers, the presence of support teachers, the number of children, spatial solutions that fulfil various needs, etc. Beyond that, we can ask for more profitable environments. Of course, it would be perfect, once you have reached to the point to offer to the autistic child what he/she needs, to naturally blend in one the special with the mainstream. »

VIII.3 Interview with Luigi Mazzone | Child Neuropsychiatrist in Italy

Fig 67 Dr Luigi Mazzone

Dr Luigi Mazzone – is a child neuropsychiatrist. He is a permanent doctor at the Complex Operative Unit of Child Neuropsychiatry of the University Hospital of Tor Vergata. Mazzone is the founder and CEO of the Scientific Centre of Neuropsychiatry AITA, the Association *Progetto Aita* ONLUS and *Scherma* LIA Academy, which works with children diagnosed with autism. He is also the founder and member of the scientific committee of the Italian Association of Research on Autism. His work and research on neurodevelopmental disorders -with a particular focus on autism- have been nationally and internationally awarded. Mazzone is the author of numerous peer reviewed articles and books. He has recently published two books: *An autistic in the family*; and *Psychiatric Symptoms and Comorbidities in Autism Spectrum Disorder.*

Diagnosis | Do you think there should be an effort to make all relevant figures in the diagnosis examination work together and be present at the same centre where the treatments take place, so they can follow-up every child? In less words, do you think the diagnosis centre and therapeutic centre should be on the same place?

« The first superficial thought probably is that assessment and therapeutic intervention should be placed together in order to provide a care and assistance continuity. On the other side, if the same team works on the assessment, consequently on the follow up, and on the treatments, the risk of subjectivity is higher. In re-evaluating each case, the team might know more about each child, but they can also be influenced by their work. Therefore, diagnosis and treatments might also be two separate things, however, preferably at the same building. In regard to the assessment team, it is highly suggested to have a multidisciplinary group of professionals, so the diagnosis and the care plan is more complete and more coordinated. »

Treatments | Do you think all evidence-based treatments should be offered at the same centre, or it is not that necessary because several specialised centres on specific therapies can be as fruitful?

« In my opinion, a Centre for Autism must provide a wide range of treatments in order to offer a complete opportunity of interventions. Being specialised in a single therapy creates a gap in the overall care plan, because it is hard to be aware and evaluate if that is the right treatment; if that is working correctly; if the follow up is performing adequately or not. When you have a series of different treatments that work on the same symptoms but with different approaches, other than different therapies for different difficulties, as a therapist you can understand that a child needs a DENVER therapy rather than an ABA, or TEACCH. It is important to offer all the evidenced-based therapies and they must be a synergy between them. »

Focus | Do you think Care Centres should be focused exclusively on autism, specialised to a particular group of disorders, opened to different kind of disabilities, or simply opened to everyone who needs a treatment?

« The prevalence of autism strikes over 2% of new-borns, which is almost higher than all other disorders and disabilities taken together. Considering also that autistic condition is a complex world, I would suggest that a Centre should deal only with autism. If you want to do it right, you have to do it specialised to autism. »

Age range | Do you think care centres provided to children with autism should be differentiated per age range, or at least the preschool age children, being more delicate, should be cared separately?

« Given that the needs of children during their childhood change and that the facilities should respond and be suitable to each age, it seems obvious that the best thing to do is to divide the services and facilities per age range. At least, it would be necessary to distinguish three age ranges: preschool age; school age up to eighteen; adulthood. The preschool age is a very delicate moment and a transition phase; therefore, it must be treated with a particular attention. »

Character | How do you see a care centre for children on the spectrum as more oriented or characterised architectonically: as educational spaces, as healthcare facility, as a community centre, or something else?

« As we are talking about a Centre that should host preschool age children, regardless of the fact that some of the services have a healthcare nature, it should offer playful environments, preferably similar to nursery schools. The most important thing is not to forget the final user, the child with autism. The facility should be based on play, but without exceeding the fantasy because then it may become overwhelming. A simple environment transmitting a sober atmosphere is the best thing to do. »

Clinic services | Do you think basic healthcare services, such as paediatrician visits, first aid services, dental office, etc, should be included in a Day Care Centre for children, so they don't have to go to the hospital each time they don't feel well?

« Absolutely yes. It is fundamental to have some important medical figures for individuals with autism, such as a neuro paediatrician, cardiologist, dentist and especially a gastroenterologist. Probably, it would not be necessary for continuous presence. However, they can alter their available days and share the same medical room. »

Integration | How do you think there should be the relationship of these Centres to mainstream facilities of their peers? Should they be fully integrated, partly connected or completely separated?

« Considering the spectrum of needs of children with autism and considering the reality around us, it seems utopic to think of completely integrated structures. On the other side, we don't want to separate these children from their peers and enclose them in their world. I believe the best thing to opt for is partly connected facilities. These structures can work hard on basic life skills providing a compensatory form of intervention; mainstream activities are integrated with special treatments for the rest of day. »

VIII.4 Interview with Cherry Hall | Early Years Locality Manager in United Kingdom

Fig 68 Cherry Hall (on the right)

Cherry Hall – is a manager of strategy and development for Early Help & Communities in Bracknell Forest Council, one of six unitary authority areas within Berkshire in southern England. Her focus of the last 30 years has been working with Early Years children in a variety of different settings. In her early career, she developed a special interest in children with additional needs and, about 20 years ago, undertook professional training around autism. As part of her role as manager for the local authority, Hall helped to set up a local resource for pre-school age children with autism. She took over the running of the Child Development Centre "Margaret Wells-Furby" with the intention to give children on the spectrum up to five years old a steppingstone into a successful mainstream education.

Diagnosis | Do you think there should be an effort to make all relevant figures in the diagnosis examination work together and be present at the same centre where the treatments take place, so they can follow-up every child? In less words, do you think the diagnosis centre and therapeutic centre should be on the same place?

« From the experience in Bracknell Forest, I can say that it is a great thing to have a centre where multi-professional assessments are undertaken. This brings together health and education experts enabling families to access diagnosis and some interventions under one roof. Families have commented on the positivity of this service as it is delivered locally, relatively easy to access and a number of professionals can be seen during one appointment. Diagnosis and interventions are not undertaken in one place for children over five and I think this would be worth investigating given the opportunity. »

Treatments | Do you think all evidence-based treatments should be offered at the same centre, or it is not that necessary because several specialised centres on specific therapies can be as fruitful?

« My personal view is that all interventions should be based on the needs of the child/young person/adult and not diagnosis driven, therefore having a variety of approaches/interventions/therapies available would be the best option to meet the needs of all who are able to access. »

Focus | Do you think Care Centres should be focused exclusively on autism, specialised to a particular group of disorders, opened to different kind of disabilities, or simply opened to everyone who needs a treatment?

« I believe there is an argument for either options; this again will depend on the needs of the individuals, but also on the needs of the community. Based on the experience at the Child Development Centre, focusing mainly on autism has worked very well. However, this could be due to young age range catered for and the fact that our reach area is quite small, nearly 7000 under-fives. In another context, which might be smaller, thinking of specific centres for each disorder or disability, may not be sustainable. »

Age range | Do you think care centres provided to children with autism should be differentiated per age range, or at least the preschool age children, being more delicate, should be cared separately?

« At the Child Development Centre, we work with pre-school age children and the centre that we have is only suitable for that age range. We do offer some workshops for parents of children up to 8 years; however, these are for parents only, not for children. If a centre was large enough there could be different services for different age ranges provided but I still feel there would be a need for separate areas, this could be chronological age related or needs related. I would say that one size doesn't fit all, everyone is unique, and services need to be responsive to need. »

Character | How do you see a care centre for children on the spectrum as more oriented or characterised architectonically: as educational spaces, as healthcare facility, as a community centre, or something else?

« I am not in favour of healthcare/medical model facilities. Centres to me should be family friendly and could offer both educational and recreational services; this again would be dependent on the building and space available and how that might be divided to cater for individual needs. Parents and their children need to feel a warm hug from the services and environments, and they must feel belonging to it, being themselves and not different. The Centre must develop a sense of calm, inviting and welcoming, where children can be themselves playing and learning to their ability; and where parents can meet others and share the good times and the bad times, cry, laugh, have fun and feel supported. »

Clinic services | Do you think basic healthcare services, such as paediatrician visits, first aid services, dental office, etc, should be included in a Day Care Centre for children, so they don't have to go to the hospital each time they don't feel well?

« I think it is important to provide all services that facilitate the life of everyone involved and improve the overall quality of management. Providing some elementary clinical service is one of them. For example, the presence of a paediatrician at the Centre, that keeps an eye on their growth and development during childhood, is essential. These services need to be sized in base of the number of children and context where the Centre is inserted. »

Integration | How do you think there should be the relationship of these Centres to mainstream facilities of their peers? Should they be fully integrated, partly connected or completely separated?

« It is a real dilemma. I think everyone would like a complete integration of children with autism, and not only them, all children to be treated the same and to be given the same opportunities. The problem resides on the fact that mainstream environments are not fit for this purpose. For instance, schools -even though there have been some attempts to be inclusive for all- are yet unable to offer to all pupils a safe environment, leaving this way the headteacher and local authority exposed to reasonable criticism, particularly in the event of an accident that could have been avoided. »

VIII.5 Interview with Bridget A. Taylor | Psychologist in New Jersey (USA)

Dr Bridget A. Taylor – a licensed psychologist and a Board-Certified Behaviour Analyst. She has a master's degree in early childhood special education and holds a PhD in Psychology. In 1988 she co-founded the "Alpine Learning Group", and currently serves as CEO. Taylor has specialized in the education and treatment of children with autism for 30 years. She currently serves on the editorial boards of the Journal of Behavioral Interventions and Applied Behavior Analysis, where she recently completed a term as associate editor of the last. Taylor is President of the Behavior Analyst Certification Board and serves on the Autism Advisory Group for the Cambridge Center for Behavioral Studies.

Being active in the autism research community, Taylor has published numerous peer reviewed articles and book chapters on effective interventions for autism. She is a national and international presenter and serves in an advisory capacity for autism education and treatment programmes both locally and abroad. Taylor was recently recognized by the Association for Applied Behavior Analysis International for her outstanding contributions to behaviour analysis and was given ABAI's Fellow designation. Taylor is considered a leading authority on effective, and innovative interventions for autism.

Fig 69 Dr Bridget A. Taylor (http://www.alpinelearninggroup.org/)

Diagnosis | Do you think there should be an effort to make all relevant figures in the diagnosis examination work together and be present at the same centre where the treatments take place, so they can follow-up every child? In less words, do you think the diagnosis centre and therapeutic centre should be on the same place?

« I think there is no doubt that a multidisciplinary team makes a more complete assessment. Having different points of view from different experts gives a wider overview on the evaluation and helps to compile a more personalised treatment plan. Whether to have that team working on the therapeutic Centre, depends on the Centre itself. It might be possible that a Centre doesn't offer all the necessary treatments for a child or it is specialised in one direction, therefore, the team is unable to follow up continuously. Referrals for outer services and feedback from them need a coordination team that checks up the progress of the interventions. »

Treatments | Do you think all evidence-based treatments should be offered at the same centre, or it is not that necessary because several specialised centres on specific therapies can be as fruitful?

« There aren't many treatments that are evidence-based, and their intervention potential is relatively known. Due to the complex nature of autism and due to the short experience of applying these treatments to autism, it is hard to evaluate the specific weight of each treatment. However, I would say that providing a variety of evidence-based interventions depends on the human, financial and asset resources. In a small-medium context, I would suggest investing all resources in specialising in a certain direction in order to provide a more efficient intervention. »

Focus | Do you think Care Centres should be focused exclusively on autism, specialised to a particular group of disorders, opened to different kind of disabilities, or simply opened to everyone who needs a treatment?

« At first sight, it doesn't seem anything wrong of having a wider inclusion of forms of disability. However, if we consider the trend of autism rates over the years and the spectral presentation of autism condition, it looks quite self-suggestive that there is nothing wrong of having a specialised treatment for individuals with autism. With a prevalence that high, thinking of autism-dedicated facilities it is sustainable intervention. In this way, I think a person with autism is better assisted and supported. »

Age range | Do you think care centres provided to children with autism should be differentiated per age range, or at least the preschool age children, being more delicate, should be cared separately?

« Age ranges have a conventional meaning; they are used to help communities organise services and support, even though nothing special happens at a precise age of every person. Regarding autism, it is the same thing. It is a condition that it is noticed during childhood, but which accompanies that person for the rest of life. It is a condition that demands for support; a continuous support through the lifespan. Therefore, unlike their peers, individuals with autism will continue to ask for help in their daily routine. Considering also the difficulties they present in making transitions in life, the idea of separate care in base of age ranges fades away. Therefore, I think it is more advantageous to guarantee this continuity inside the same facility. »

Character | How do you see a care centre for children on the spectrum as more oriented or characterised architectonically: as educational spaces, as healthcare facility, as a community centre, or something else?

« The typical place where children spend most of their time and learn is the school environment. Children with autism are learners, too. They might be learning in a different way, different things, with a different teacher, in different kind of classrooms, but in the end, we can't forget they are learners. As a result, I think we cannot ignore this fact; a centre for autism should be a learning environment in all its being. »

Clinic services | Do you think basic healthcare services, such as paediatrician visits, first aid services, dental office, etc, should be included in a Day Care Centre for children, so they don't have to go to the hospital each time they don't feel well?

« To answer this question, first of all, we must understand how much clinical it should be or we want it to be, and the professionals involved. In order to provide a complete offer of healthcare services, the Centre should have everything related to primary care and every special care for autism; including nursery nursing as well as child neuropsychiatrist or dentist specialised to treat child with autism. At this point, I think it is not anymore what we wanted it to be. It is not, anymore, an educational environment, but it has become a healthcare institution. Therefore, I believe, there should be a careful evaluation of the clinical services to include based on the specific needs of the surrounding context. »

Integration | How do you think there should be the relationship of these Centres to mainstream facilities of their peers? Should they be fully integrated, partly connected or completely separated?

« Difficulties in social interactions are one of the major issues of individuals with autism. I believe that everybody thinks that we should try to integrate them as much as possible. However, integration -in my opinion- doesn't mean just putting them together with neurotypicals. It is about helping them overcome their difficulties by working with them day by day and creating a pleasant atmosphere. Therefore, placing these activities in mainstream facilities may be not the best option for all; some might need some time to get used how to engage in social relationships, while others might need a much longer times. As a result, I think we should never push them beyond their limits trying to make them act in a way we would like to see them, and which is not what they want to do or what makes them feel comfortable. »

VIII.6 Conclusions

Talking with experts on autism was the last step of the investigation phase. It was a very fruitful experience because it helped clear up some doubts on the therapy environments that came out during the research progress (see Tab.15). It was important to speak with them and understand their professional point of view on these facilities as they know them very well. Other than having a rich knowledge on autism, they have a key role in the care plan of children with autism and these spaces are their working environments. The professional figures know well how these facilities work and they can tell what it is important to take into account when thinking of these structures.

Of course, they come from different backgrounds and work in different contexts, so there were no expectations to find a complete consensus on the subject. Sometimes, they have even completely different ways of thinking and facing some issues. It was however interesting to get different opinions from qualified people on the same topic, so it can be seen under as many shades as possible. And in this way, the interviews gave some inspiring spots for further rational thinking on the problem. Without stopping to comment all replies from the reported in-depth interviews, there will be annotated some remarks.

The best lesson learned from this phase was that it is impossible to say this is the way it has to be done or it should be done. The right answer for each question depends and behind every choice, there is a philosophy of intervention. One might be more favourite toward a certain solution; another might tend toward the opposite direction. It is hard to understand which one is right and which one is wrong because probably there is no right and wrong. There is something true and valuable in each answer.

In this world of relativeness, it is important to go out even of some of what can be considered or taken as axioms. It will never be a 100% gain, but it is probably giving up from something to achieve something else. It is the overall result that matters. The therapeutic intervention it is not about the treatment in itself, but it regards everything related and around to that child; the therapy, the environment, the staff, the parents, the outside reality, the day and the night, etc. So, we must understand that it is the totality of single elements that contribute positively. But at the meantime, we should change the reference point; we think we know what individuals with autism want to be, but maybe it is not what they need and want to be.

Another consideration can be related to the sustainability of these interventions. No one knows what to expect from the future, no one can foresee the changes; therefore no one can say that this is the right direction. Also, not everything we might believe it is helpful to those on the spectrum, it is an affordable and sustainable solution.

PART III

STRATEGY FOR AUTISM-FRIENDLY DAY CENTRES

The last phase sets forth my proposal. It involves the processing of data that were gathered in the previous steps and the drafting of programming and designing strategies of Day Centres for children with autism. The method used is the description of the structure of the Day Centres in a narrative way following the overall research approach, which is based on the qualitative interpretation of facts, evidence, experiences, and hypotheses. The reason for this choice stems from the complex, spectral, and, sometimes, even conflictual nature of autism. Thus, the products of this research use the concept of the spectrum and balance to describe the wide range of possible configurations that a Day Centre may assume in different contexts. It attempts to identify the variables, and their spectral range, which are significant factors of the wellbeing of those on the spectrum and of the project equation. At the same time, it promotes the finding of an equilibrium between the various choices, so to balance the adaption of children with autism to the environment with the adaption of the environment to their specific needs.

CHAPTER IX
ELABORATION OF THE STRATEGY

This chapter reviews the data collected and provides a qualitative rationale on the outcome of the research in three sections. The first section discusses the approach to the definition of the strategy for Autism-Friendly Day Centres. Section two delineates the planning and the management strategy in more details, offering a broader overview of the problem. The final section concludes with the presentation of a design strategy, providing a useful insight for creating therapeutic environments.

IX.1 Strategy definition

To recap, the focus of this research are children with autism at preschool age and the interventions dedicated to their treatment and support. The choice of this age range was based on the usual diagnosis age of autism and the importance of the diagnosis moments for the children and their families. These moments are crucial given the efficiency of early therapeutic interventions. As my research has been developed through an architectural lens, attention was oriented towards environments where the necessary interventions take place. The primary goal was to examine these architectural interventions, understand which design features have an impact on children's wellbeing, and analyse relevant components that could help the identification of a typology for these kinds of facilities. The name of these establishments, Day Centres for children with autism, does not belie their main function– taking care of children. Therefore, the final research question that emerged was, "how should an Autism-Friendly Day Centre for children look like?"

After studying in detail the most significant aspects of autism, depicting the spectrum of needs of individuals with autism, analysing the network of services dedicated to those on the spectrum, examining the relationship of the latter with architecture and the architecture's impact on people diagnosed with autism, exploring how services dedicated to children with autism in the early years are handled – in architectural terms, conversing with parents to understand the difficulties they have encountered and their aspirations for better services and structures, consulting experts on autism, the goal was to describe a Day Centre for children with autism that fosters their wellbeing and contributes positively to their growth by boosting the efficiency and effectiveness of the therapeutic interventions.

This study purports to conceive a suitable typology and to define its remarking features. While this research is inherently limited, given its object, to issues concerning the design of Day Centres, it does not engage solely with design as such, but, also, with elements that indirectly influence design decisions, such as planning and management issues. A correct approach to planning and management increases the overall efficiency of the offered services and activities. Second, this consideration is limited with respect to its study group, i.e., it evaluates only the features that are particularly important to children with autism and not every other possible and generic consideration. To sum up, defining the typology of the Day Centre for children with autism consists in developing a strategy in regard to planning and management, and design of these facilities.

Whatever its limitations, this research provides an important contribution to the said research field. First, it has clarified how difficult it is to define autism. The first part explicated how every notion relevant to autism can lead to ambiguities, i.e., different ways of evaluating the problem by professionals engendering endless quandaries. The first inflection point is related to the definition of autism, some see it as a neurodevelopmental disorder, others as a condition. Another controversy involves the epidemiology of autism where some believe that it has reached rates up to 2,5%, while others think that the numbers have been overestimated and that a fair prevalence rate is closer to 1%. As for the aetiology, the classical quandaries involve questions on whether autism is due to genetics or external factors, whether it is a lifelong condition or there is a chance of getting out of the spectrum, and whether the existing treatments, even the few that are evidence-based, are effective. Last, the debate continues also regarding the explanation of the internal mechanisms of autism, where, at least, four theories attempt to explain autism. As a result, the problem encroaches on the design approach, highlighting to two contrasting ways of dealing with projects dedicated to individuals on the spectrum-the sensory sensitive approach and the neurotypical approach.

Also, the outcome of the second part of the research was surprising; this being the investigation phase. I have analysed several facilities realised over four different geographical contexts in order to see how the therapeutic interventions were offered to children with autism. A much wider variability emerged, in terms of presentation of the quote-on-quote Day Care Centres than expected; due to the different possible sensitivities described above and/or due to local policies. It was verified I also noticed a dissent among parents and professional experts on autism regarding various topics related to these facilities. Even though it is a common problem everywhere, it was difficult to find a common ground of answers.

This leads one to think that it is hard to define something. With so many uncertainties – between the scientific disagreements, the discord of viewpoints and the wide range of architectural interventions – it needs a lot of courage taking charge of defining something as delicate as a Day Centre for children with autism. Therefore, the research had to take a turn, using a different strategy. The best way to sort it out was to continue by its natural trend; getting inspired by the term ‘spectrum’ and materialising the strategy through ‘flexibility’. In a system of a *spectrum of needs*, that demands for a *spectrum of answers*, remaining flexible seems to be the right way forward. As such, instead of defining the typology of Day Care Centre through prescriptive indications, a good compromise could be describing it through the dilemmas that put its definition in crisis.

The outcome is no longer to specify how exactly it should be but show what to consider/take into account and what it is important to know. More specifically, it describes organisational and functional variables that technical offices in charge of planning need to decide in phase of programming, and that a designer must know to start the briefing of the project. Additionally, it describes what the designer should take into consideration to attempt to create an Autism Friendly Day Centre for children on the spectrum. Therefore, the product of the research is a set of indications developed in the form of a strategy, which are not prescriptive but descriptive. They are organised in two parts: the first part regarding planning and management strategy; whereas the second is concentrated on design strategy. The two sets of indications have different format but share a common form of reasoning. They are developed around dilemmas and suggestive related spectrum of possibilities that interpret the dilemmas. Thus, they are not telling which is the right solution, but they are offering an evaluation tool to help take the right decision in every circumstance. Every choice is a matter of finding the balance in the spectrum of opportunities and relationships, so, the final solution should be the harmonious combination of a series of established equilibriums.

IX.2 Planning and management strategy

The first part deals with the programming strategy of Day Centres for children with autism at preschool age. Supposedly, this stage should anticipate the design and it is carried by the technical officers who are in charge of the planning and managing interventions dedicated to individuals on the spectrum. This process falls beyond the basic knowledge and expertise of an architect, however, this research analyses it as choices at this step can be particularly significant to children with autism and strongly impact the design of the relevant care facilities. Accordingly, this study will cover only features at the strategic decision level and will be limited to topics that are significant to autism and the design of friendly spaces to those diagnosed with autism.

The development of the strategy revolves around 12 topics. The latter are the product of a careful deliberation over hot spots identified during the literature review and further investigated through on-site visits to the Centres for Autism and interviews with parents and autism experts. These 12 topics consider the planning and the management of Day Centres so highly correlated as to find them indistinguishable. The list of topics is reported by the Tab. 16 and each topic depicts an associated descriptive range. This range can be conceptualized as a spectrum of possibilities bounded by the two extremes, i.e., an array of suggestive opportunities. Each of them has its own upsides and downsides and their propriety hinges upon the surrounding circumstances. Thus, each description offers a detailed explanation of the issues

PLANNING AND MANAGEMENT STRATEGY

topic	range
age range	preschool | childhood
location	urban | rural
services	monoservice | multiservice
focus	autism oriented | mainstream
treatments	specialised | wide array
architectural character	precise | ambiguous
integration level	low | high
construction type	new build | refurbishment
configuration	individual therapy | group therapy
operation mode	on appointment | full time
intervention size	small | big
human resources	continuous presence | periodic visits

Tab 16 Planning and Management relevant topics for autism and the design of Day Centre

Fig 70 Concept of the Day Centre for children with autism

troubling that topic and an overview of the possible answers to the problems, but it does not give precise indications, viz., it does not provide a solution to a certain issue, but it recommends what to take in consideration while dealing with such issue. In this light, the person in charge of programming interventions at Day Centres for children with autism has the freedom to interpret these guidelines according to the circumstances and choose the most suitable features to that specific context. The final output can be described as the result of the permutation of 12 choices in 12 spectral ranges of possible solutions, as shown by the Fig. 70.

Before delving further into these 12 topics, I should note the way commissioning bodies plan to address the demands over Day Centres for children with autism. A spectrum of viable modes that could solve the problem exists here, as well. The two main solutions – which might be considered the extremes of this spectrum – could be described as following: 1| response to the demands through single interventions that provide care and support to a certain number of families; 2| systematic solutions to the needs for Day Centres at a wider scale. The focus of the first solution is narrower, for the private service providers fill the gaps left out by the public institutions to assure profits out of these interventions. On the other hand, a more coherent institutional vision of programming interventions is engendered when a masterplan strategy is necessary to overcome the lack of certain services in a specified area. The program's goal, in this case, is to provide that service to the community by using the available resources in the most efficient. This division between the public and the private can sometimes be fuzzy due to possible public-private partnerships and limited or earmarked funds. The interventions spectrum at the higher level affects the reading of the following descriptions. Reasoning on a network of centres for autism compared to reasoning on single episode responses weighs on decisions on its/their planning and management. The fact is that every intervention needs to be collocated and fully immersed in a specific context, but at the same time, connected to the network of the service providers at a larger scale. This is crucial because coordination and cooperation are the essential keys to success of every care effort.

The next paragraphs lay out in detail these 12 topics. The presentation sequence is an attempt to provide some order, based on the reasoning to follow during the programming phase — which however remains flexible according to the specific circumstances and restrictions. All topics' descriptions follow a common layout. The description starts by asserting what the relevant topic stands for and then continues to explicate its importance to autism and the design of the Day Centres. Through narrative descriptions, the following paragraphs elaborate on the concept of the spectrum and the range of opportunities. The narrative winds up showing how a certain topic is related to the others — there exists a general interrelation among all of them. To not reiterate certain mechanisms, a description will be made only if it is anew, viz. this study avoids the duplication of comments on interrelations.

PRESCHOOL AGE RANGE CHILDHOOD

What is the age range of children that could be accommodated at the Day Centre? Should it be dedicated specifically to preschool age children, or it can welcome even older children and accompany them through childhood?

Important to autism

because of the efficiency of therapeutic interventions in the early years and the difficulties of individuals with autism with transitions.

Important to design

because different group ages have different needs that require to be satisfied through the architectural intervention.

Description

It has been highlighted more than one time that the focus of this research are children with autism of preschool age. However, the reason why it comes out as a topic in this section is because during the research it was found out that there is not a common age range distinction applied by the Day Centres. First of all, it is important to precise that age range is a relative and conventional concept. Saying preschool age means a certain range in a country, such as up to 6 years in Italy, up to 5 in the UK or up to 7 in Albania, depending on the internal educational policies. Furthermore, it is conventional because nothing precisely happens or changes at a precise moment of life; life is a continuum. Therefore, saying preschool age refers to not mandatory school programme in a certain context, without specifying the age range.

The dilemma about this topic was fuelled by the case studies where it was verified that Day Centre for children with autism provided access to even older children than preschool age. The maximum limit encountered during this research was in the US; up to the adult age of 21. Therefore, age range becomes a topic with a spectrum of possibilities where at one end there lies the simple Day Centre dedicated to preschool age children, and at the other extreme, cases where it can welcome also older children. The advantages of the first extreme – that of dedicated to preschool age – it can be linked to the traditional idea of the division of the non-mandatory school from the primary school and to the philosophy of learning through play. Considering that children with autism are at the end similar to their peers, the same principle could be applied. Instead, on the other hand, the advantage of having such an uncommon centre at the other extreme is linked to the continuity. Individuals on the spectrum have particular difficulties with adapting to new situations, new arrangements, new staff members and new environments. Therefore, in this case there is no need to be worried about the transition process as it comes less until a certain age. The Centre provides a longer therapeutic intervention and guarantees a continuity through the years inside the same facility and with the same staff members. It must be remembered that, as children grow up, their needs change and as a result, the environment needs to adapt to their new needs. Therefore, in this case, there is this difficulty of making a setting that fits to child's needs as well to a teenager's, which is not an easy task.

However, in between these two extremes there lies a wide range of opportunities, not only regarding the max age limit a centre could accommodate, but also regarding the relation of the child with the Day Centre as he/she grows older. The centre can provide a gradual transition environment - which can be for a few months up to a few years – assisting the child to settle down in the new setting and reducing this way the stress of transition. The child frequents the new environment, but also goes to the old centre for some hours of the day or with a certain frequency until he/she is completely settled in the new structure.

Linked to

- Location - because it can dictate whether an intervention is more suitable and sustainable for children of preschool age only, or it should include even older children.
- Services – because providing service to a wider age range might request the addition of more educational services, as children frequenting might need more support in learning.
- Focus – because it is linked to the fact that some children might receive the diagnosis later in age and because it might be necessary to widen the focus to make the intervention worthy.
- Treatments – because different age ranges need different kind of treatments.
- Architectural character – because it should represent the final user and adapt also to the aesthetic needs.
- Integration level – because socialising and integration to the community are very important to overcome their difficulties with social interaction. In addition, there are many even 'neurotypical' children that need help, then why not offer opportunities of shared activities.
- Construction type – because the refurbishment of an existing building might not be appropriate to young age children; consider a multi-floor building which is not adequate and safe for preschool age children.
- Operation mode – because if it is opened to a wider age range, it might be necessary to be compatible with mandatory school programmes.
- Intervention size – because it is important to make the investment worthy.
- Human resources – because preschool age children might need more staff to do individual therapies and a series of activities dedicated to the follow up.

URBAN LOCATION RURAL

What is the best location for a Day Centre for children with autism of preschool age? Should it be pushed more toward urban areas, or rural ones?

Important to autism

because it makes a difference for children with autism and their family in terms of travelling time and it makes a difference in their wellbeing in base of the quality of surrounding.

Important to design

because the architectural intervention is strongly related to the context's features; designing in urban areas requires completely other considerations compared to designing in the countryside.

Description

The problem here is that it can't be thought of the same Day Centre replicated everywhere. It is not a spaceship landing on this planet, but it is an intervention that it is inserted in an existing context; it is influenced by the features of that context, and yet, every solution modifies the context re-establishing new equilibriums. The difficulty that comes out here is picking up one context and saying that is the perfect one for this kind of facilities; whether in the heart of the city, in its margin, or go toward the countryside. The first issue is that children with autism are distributed all over the territory, so they are not all concentrated in urban areas. Secondly, a Day Centre it is not like a hospital that no matter where it is, you would have to go once or a few times once a while. The Day Centre for children with autism of preschool age it is part of the everyday life where they go at least several times a week, if not every single day. As a result, the reachability is very important. Having to travel for 30min or walking around the corner in the neighbourhood to reach the Centre, it makes a great difference for the child, but also for his/her parents who will accompany him/her. In the urban areas, this seems to be easier to fulfil compared to the rural areas. At the same time, there is also the problem of how you reach the centre. It is not always possible to reach by walking; therefore, it comes out the problem of transportation. In the urban areas usually, the problems are related to the parking areas for those who use private cars and the fact that public transportations can be crowdy sometimes making the journey a nightmare for individuals on the spectrum. In the countryside instead, the biggest problem is often the lack of public transportation for those who can't afford to travel privately.

Another issue regarding the location of the area where to build a Day Centre is related to the quality of the surrounding environment – the acoustics, the air quality, the nearby settings and the view around. It is not the same being surrounded by the traffic noise, crowdy streets, noisy nearby activities and most probably with high levels of air pollution - which is highly likely the situation in dense urban areas - or being in a quiet, calm and with fresh air area. The same can be said about the exterior view. In the countryside it is much easier to find a pleasant landscape around the centre, which fosters the relationship of children to the nature. It is also less distracting atmosphere compared to the lively one found usually in the urban areas.

Linked to

- Services – because it might take advantage of services and activities taking place in adjacency; if the Day Centre is near a hospital, certain clinical services are less necessary to be included; if it is near a park, it is less necessary to think about outdoor activities.
- Focus – because in order to make the investment worthy in a certain area, it might be necessary to widen the focus of end users.
- Treatments – because the adjacency or not to other facilities might require providing a wider array of treatments or not.
- Architectural character – because the historical, cultural, social, geographical features of the context may suggest certain solutions more than others.
- Integration level – because in base of the surrounding context it changes the possibility to include and involve the community in the Day Centre activities.
- Construction type – because the countryside gives more opportunities for new built compared to the dense urban fabrics where it is more difficult to find an area to build a new Centre.
- Operation mode – because a centre which is on daily basis needs to be even more easily reached by children.
- Intervention size – because the demand goes along with the size of the intervention, as a result having higher requests in urban areas, but less possible areas that fit; whereas in rural areas is less likely to be worried about having more generous spaces, but more likely to be concerned about the number of children that could be assisted.
- Human resources – because due to the difficulties to find qualified staff that could reach the centre and the presence or not of a highly requested professional nearby the site.

MONOSERVICE SERVICES MULTISERVICE

What kind of services should offer a Day Centre for children with autism of preschool age? Should it provide only a certain service, or it is better to offer all possible services?

Important to autism

because treatments and counselling serve as a prosthesis for individuals on the spectrum to help them cope more effectively in the everyday life and support parents rear that child.

Important to design

because form and content are interdependent; it is quite impossible to design a space without knowing the final use and user.

Description

Autism is a lifelong condition. Our effort is trying to modify that condition through treatments and counselling in order to help individuals on the spectrum become more independent and interact more easily in this challenging environment for them. The problem is that it is not a matter of a single treatment, or a couple of treatments, or a of a single person who is qualified, but it is a goal that needs patience and persistence involving everyone around that person with autism. At the same time, it is not a matter of intervening for part of the day, but all day and during the whole year. As a result, the intervention includes all stakeholders of different competences and various enabling and supportive contexts. There can be identified four main categories of services important to those on the spectrum. The first category is educational services. In this category the activities that take place are mainly focused on therapeutic interventions working on autistic traits to make an individual with autism more autonomous and improve his/her education attainment. The second category is clinical services, which aim to take care of their physical and mental health. The third category is social services. It includes activities focused on support of individuals on the spectrum and their parents through training and counselling, and to foster their integration in the community so they don't feel abandoned. The last regards residentials services helping those on the spectrum learn to live on their own and providing to their parents a sense of relief from all the burden of care. This last is less relevant in case of children with autism of preschool age because of their young age and the strong affection to their parents. Inside these categories, there is a long list of possible activities that contribute positively in the overall intervention. Some of them might be more important or predominant in certain situations and moments, but all of them contribute on the overall result.

It might be obvious that all three services and the subsequent activities should be offered to children with autism and their families. However, that doesn't mean that it is obligatory that a Day Centre should provide all of them contemporary. It depends on the surrounding context. It may be needed to provide all of them, as it could be enough providing one of them, because there is another centre offering the rest of services. In other cases, the centre might offer some of the activities of each service and be the interface for others that are provided elsewhere. It is good having all services at the same place because there is a better coordination and efficiency inside, but it may not turn in an overall rational choice. For instance, offering a certain clinical service, when there is a specialised hospital in adjacency, it is not convenient choice. A qualified person can help more people in a bigger structure like the hospital, that it might help at a Centre which has a limited number of children visiting. Therefore, there is a wide spectrum of possibilities of combination of services and activities that a Day Centre could offer going from monoservice model to a centre that offers all the necessary services to children with autism.

Linked to

- Focus – because depending on the final users it might be needed to add or subtract some services or activities.
- Treatments – because treatments are part of the services and activities a Day Centre offers.
- Architectural character – because the architectural solution reflects what is going on inside; if the centre is providing more clinical services, it is hard to hinder its clinical atmosphere.
- Integration level – because depending on the integration level aimed there can be thought activities that involve the community or other peers.
- Construction type – because it might be hard to adapt an existing building to a certain required activity.
- Configuration – because they influence each other on the way the therapeutic intervention is organised; whether individually or in groups, with other peers or also with parents, with peers coming from outside or with people from the community.
- Operation mode – because certain activities might need to be correlated to other activities children have to participate out of the centre, but also because some services might be provided part time in a full-time operating facility.
- Intervention size – because it is in direct proportion to the number of services and activities it provides.
- Human resources – because to provide a certain service, qualified staff members are requested which need to be arranged efficiently in order to use in the best way the available resources.

AUTISM ORIENTED FOCUS MAINSTREAM

What should it be the focus of a Day Centre where children with autism go? Should it be focused only to children on the spectrum, or it can go the other extreme and be a mainstream Day Centre that welcomes all children of preschool age?

Important to autism

because one of the main difficulties of individuals with autism is social communication and interaction.

Important to design

because it changes the final user group and consequently their spectrum of needs that need to be fulfilled.

Description

The big dilemma is whether children with autism should be welcomed in specialised facilities dedicated only to them or there should be an effort toward their integration with other peers. To the will of integrating as much as possible every person in the community by somehow enforcing the 'mainstream', corresponds the ugly reality unable to make that happen. The removal of 'dedicated' structures and services should be flanked with implementation of accessible community-based services (transport, healthcare, culture, leisure, etc.), adequate for the needs of every citizen (Ratzka, 2007). It is the ambition and the desire of every stakeholder and of most of the people to help children on the spectrum engage in the everyday life of the community, but no one is yet sure that placing children with autism – at least not all of them - at the same environment with other 'neurotypical' peers is the best strategy. Recognizing their difficulties to engage in social relationships, it is hard to say that that is what a child with autism needs, if that maybe makes him/her feel uncomfortable most of the time. Universal design is the best aspiration, but yet utopic to satisfy the special needs of every person. On the other side of the spectrum, focusing too much in a single direction, it is a good strategy in short terms, but not in long ones. Providing a too personalised and comfortable environment to children with autism runs the risk to make them walk away from the reality of the everyday life. This last contributes to their segregation and to a certain form of discrimination. As a result, it is difficult to judge which is the best way to solve it out. At the end of the day, who are we to force them stay in an environment that we think it is 'normal', but at the same time why make them stay separated and deprive them from being part of the community?

In between these two extremes there is a spectrum of possibilities, yet doubtful, however. The question is whether these facilities should be specialised in a single category or they can include also other forms of disorders or disabilities. Just considering how many disorders and disabilities are identified, it would seem irrational to think about having a specialised facility for each of them. Therefore, an idea would be to group them according to certain criterions, but the dilemma then would be 'based on which criteria'. The problem according to some experts is that in case of pairing two or some disorders and/or disabilities, runs the risk of making the intervention counterproductive; children of preschool age tend to learn also by copying behaviours from their peers. Therefore, a critical thinking needs to precede the intervention in finding an equilibrium between the 'mainstream' and the personalisation.

Linked to

- Treatments – because different final users need different treatments.
- Architectural character – because, mainly, if it is mainstream, it has to have a more mainstream appearance.
- Integration level – because they are strongly interconnected; if it is 'mainstream' oriented, the integration is quite obvious, whereas in a specialised facility it might be completely absent.
- Construction type – because it might be the case to refurbish the existing mainstream building to make them more inclusive.
- Configuration – because depending on the final user group there can be decided the organisation of activities.
- Operation mode – because mainstream activities dictate certain working hours which the Day Centre needs to follow or arrange the other activities.
- Intervention size – because as the spectrum of users widens, there increases the number of possible contemporary users and there increases the demand for bigger structures.
- Human resources – because the way a centre is oriented changes the staff qualification requirements.

SPECIALISED TREATMENTS WIDE ARRAY

What kind of treatments should a Day Centre provide to children with autism? Should it be focused only to a specific treatment and be a specialised Centre for that, or offer more than one up to all those available and evidence based?

Important to autism

because therapeutic interventions are a key element in the prognosis of the autistic traits in a person, but the fact is that each person has a personal specific treatment plan.

Important to design

because each treatment requires different spatial arrangement; knowing specifically which treatment is going to take place in a certain environment helps the designer take more accurate measures that would facilitate the development of the therapy.

Description

The dilemma here is whether a Day Centre for children with autism should offer only a specific treatment, some of the available ones and in that case which ones, or even all of them. First, it is important to point out that there isn't one applied therapeutic programme that works on all autistic traits or that fits to everyone. There is an array of available treatments which have been object of evidence-based studies (see § I.2). However, due to their weak and not enough scientific evidences and the short experience in time, they are not commonly and unanimously accepted by the scientific community. These treatments have different principles and apply different methods. One might work well for a person on the spectrum, whereas it is not efficient for someone else. Therefore, even here it is hard to say which is the best strategy. On one end, specialising in one direction has the advantage of reaching expert levels in that treatment. People hired are especially qualified to handle cases presenting those specific problems and can research on how to improve the treatment delivery. However, at the same time it means offering not a complete care to a child and that needs to be coordinated to other facilities providing the other therapeutic interventions – which is quite always a critical point. Providing some of the available treatments, often means to choose in a preferential way a set of treatments that one believes are more effective than others. As aforementioned, there aren't many evidence-based treatments, but there still can be found preferences among experts toward one treatment more than an equivalent working on similar traits. Even in this case, the risk is that of not providing a complete intervention that a child might need; each of them is different and has different treatments combined in his/her care programme. Providing all of the available treatments seems at first sight the best strategy, because it gives the possibility to check and adjust the treatment plan according to the specific needs of each child. A child can start with a programme, and if that is not working, it can be changed inside the same centre without having to go out. Anyway, it is not always possible configuring the centre to offer all treatments due to management difficulties; treatments are expensive to implement and require extensive resources to execute effectively. If offered, it often leads to inaccessible costs for many children and their families. Another problem is that of staying updated. It must be highlighted that this is a work in progress field where there is a continuous research on possible improvements and new techniques. Therefore, at the same time, at every moment there should be a flexibility to stay attuned to the updates. There must be left space for future mutation and modifications through scientific explorations.

Linked to

- Architectural character – because the kind of therapeutic interventions it delivers might dictate a certain appearance.
- Integration level – because certain treatments are more opened to the involvement of the community, others are more specific to those with autism.
- Construction type – because interventions on existing buildings might not be appropriate for certain therapies.
- Configuration – because some of the treatments are group based, while other tend more toward individual sessions.
- Operation mode – because not all treatments require the same frequency of intervention.
- Intervention size – because, in order to make the investment worthy, there should be a corresponding demand.
- Human resources – because treatments require highly qualified staff to implement.

PRECISE ARCH. CHARACTER AMBIGUOUS

How should a Day Centre for children with autism of preschool age look like? Should it look like a specific typology, such as educational, clinical, civic or it can be whatever?

Important to autism

because the way a centre looks can generate different moods; one of the three pillars of architecture described by Vitruvius was the aesthetic.

Important to design

because designers have to translate the needs of children with autism into an architectural solution; there are many ways to do it, each having different effects.

Description

As Le Corbusier would say, architecture transmits emotions and touches the heart of those who walk around it. Therefore, it can't be ignored the way a building looks. Regarding the Day Centre for children with autism there is a background issue connected to the service it basically provides: therapeutic interventions. It is the word 'therapy' that draws back a medical – healthcare - connotation and confuses a bit the things. It is usually associated with medical treatments, even though in case of treatments for autism, they are of different nature. Speaking about a disorder - as autism is - and reminding healthcare interventions, it is hard to dislocate the character of a setting that delivers treatments for autism from the clinical aspect. There would be nothing wrong with having a clinical image if it wasn't for the fact that they are only preschool age children and that is a place where they would spend part of their day. By that, it is not asking a hospital not to look as so, or to look as home; but it is about shifting the clinical aspect to something more welcoming, with less reminiscences of environments we frequent when we are sick, and that makes the stay more pleasant. In fact, the typology of interventions for children with autism is a wide spectrum including various activities of learning, playing, training, socialising, exercising, - other than taking care of their mental and physical health. Considering that, the tendency of some care providers has been simulating educational environments, so children with autism do not feel discriminated. They will attend scholastic activities as their peers, but the difference that these activities are tailored to their autistic traits. Other providers have tried to mask the clinical sense through giving a community aspect. The aim has been that of giving the message of inclusion, support and fostering their social engagement. Despite all these efforts, it has still been hard to get rid of the feeling of 'specialised' or 'for disabled people'. To overcome that, someone has even tried to emphasize the image of autism showing it proudly in every aspect. Whereas, other have tried to hinder that: some by enlarging the scale of intervention as never seen before and putting lots of things inside, others attenuating the impact of the intervention through the incorporation of the facility inside another building camouflaging in that way the reality. It is hard to evaluate which is the best strategy that should guide the design process. Maybe it can be any of these, or other variations of those mentioned, however, it is important to remind that the efforts should go on making the child with autism and his/her family feel supported and part of this world.

Linked to

- Integration level – because, if it will be integrated to a school, it will draw back educational features, whereas if it is integrated to a healthcare setting it will show more clinical aspects.
- Construction type – mainly in case of refurbishments, where changes could be limited and there is less margin of expression.
- Configuration – because it affects the way spaces are structured.
- Operation mode – because it might be connected to other activities that the building is integrated.
- Intervention size – because, if it is dedicated to larger group of users, it is more difficult to create intimate environments which have a domestic scale or aspect.

LOW INTEGRATION LEVEL HIGH

What is the integration level to the community that a Day Centre for children with autism of preschool age should have? Should it be maximised, partially present or quite completely missing?

Important to autism

because it could be a way to work on the difficulties of children with autism in engaging in social relationships.

Important to design

because it changes the reference of the final users' group, as a result also the atmosphere it can be created, and it changes the privacy level of various spaces.

Description

The dilemma is on the fact whether there should be a certain degree of integration of the Day Centre to the community or not. It is about the relationships that could be established between the autistic community visiting the centre and the local community. The Day Centre spaces, or part of them, can be opened to public permitting a high level of integration to the society, or it can be completely reserved to those on the spectrum and their caregivers. In between these two extremes, there is a broad spectrum of possibilities such as: opened to volunteers willing to help by participating in leisure activities, opened to other children and their parents allowing common activities, or for example, opened to the autistic community that do not frequent the centre for treatments but to get in touch with other families, share their stories and run raising autism awareness campaigns. In addition to the social relationships, it can be discussed also about the physical integration of the facility to existing public buildings or the use of shared spaces for certain public activities of the local community.

It is a complicated situation to judge which one is the best strategy. Everybody wants the integration of children on the spectrum, but no one should force things. Individuals with autism have difficulties in engaging in social relationship and communication, but that doesn't mean they don't want to have contacts with others. From one side, we don't know whether telling them to stay with other people is helping them work out on their ability to interact or is it making them feel more uncomfortable than staying alone. It is hard for them to speak to strangers, but this limit needs to be overcome if they want to become more autonomous. They have difficulties talking with other childre of the same age, but play can be a great tool of interaction. Therefore, it is hard to find the balance between the integration accompanied by the fear of contact, and the comfort of not having to face unpleasant situations filled will loneliness. So, having low levels of integration has the advantage of not putting the child in front of stressful situations on meeting strangers, talking to other people, unwanted socialising, but at the same time it is not working to defeat the symptoms and help them get out the virtual autistic prison. High integrative settings on the other side, can have the opposite negative effect also, because an overwhelming situation will still not help them learn how to deal with making new friends, interacting and socialising, but making them feel more stressed about the chaos of a not social comfort environment.

Linked to

- Construction type – because the physical integration might be conditioned by the existing buildings.
- Configuration – because involving the community or their presence at the centre requires more generous spaces in order to allow group activities take place.
- Operation mode – because based on which part of the community is aimed to reach and which mainstream facilities to collaborate, it is necessary to agree upon about the shared activities and meetings.
- Intervention size – because the centre can host more or less people from outside and permit a certain area to share.
- Human resources – because it can take advantage of volunteers from the community that participate in daily activities.

NEW BUILD CONSTRUCTION TYPE REFURBISHMENT

What kind of construction does a Day Centre for children with autism require? Should it be new build, or it can also be a refurbishment or extension of an existing building?

Important to autism

because an inappropriate environment not only doesn't make users feel comfortable, but it also reduced the efficacity of the activities taking place there.

Important to design

because dealing with the refurbishment of an existing building requires to take into account and address additional issues.

Description

The dilemma that arises here is about whether it can be used the existing building heritage and transformed to autism friendly or there should be insisted on new build. There are, of course, arguments in favour of both: new build and refurbishment. The first thing to say is that it is not always a matter of money, because a refurbishment can cost as much as a new build. Basically, there is almost no doubt that it is easier to make it new than having to renovate an old building because interventions on existing buildings face a series of limitations. For instance, dimensionally and as an organisational layout it is pretty difficult to change; the structural part, the distribution, the number of floors, the vertical connection, the existing ceiling heights being some of the limiting factors. It might be okay for other uses and user groups, but it might be difficult to fulfil the needs of children with autism. It is the sum of small details that make the quality difference. The problem is when you have too many restrictions and it becomes difficult to overcome them in order to satisfy the needs of the end users. Therefore, new build has an advantage start from this point of view. However, the reality suggests us that we cannot continue forever building everything from zero. There is an existing heritage that needs to be appreciated for its historic value that it draws back and for its architectural qualities. Furthermore, mainly in the urban areas, it is each time more difficult to find unbuilt areas. As a result, the refurbishment of existing building remains the only option, other than knocking down completely the old structure and building the new one. Refurbishment can either be a 'cut and carve' exercise with a combination of demolition and partial rebuilding or more a cosmetic exercise involving the upgrading of finishes, lighting and acoustic ceilings. But sometimes, it can also be highly disruptive, for example plant installations are likely to be old and in need of total replacement. One of the major impediments for refurbishments is when the services cannot close down for the period of demolition and reconstruction.

Linked to

- Configuration – because in case of a refurbishment it is more difficult to change the spatial organisation as demanded.
- Operation mode – because depending on the working hours it might be easier and more convenient to refurbish an existing building.
- Intervention size – because in addition to the renovation of an existing building, it might be necessary also an extension.
- Human resources – because knowing the organisational chart helps to understand the needs of each member of the staff and how to satisfy them, as the layout might condition the development of certain activities.

INDIVIDUAL THERAPY CONFIGURATION GROUP THERAPY

What kind of internal organisation does a Day Centre for children with autism require? Should it be structured for individual therapies, or based on group therapies?

Important to autism

because the way a therapy is delivered matters to the way a child's attention is called, the way he/she interacts and with who; it impacts the wellbeing of children with autism and the effort of the therapist.

Important to design

because, if it will be dedicated just to a child or there will be more children in the same room, it changes completely the way that space it is configured.

Description

The dilemma that rises in this section is about the therapy room configuration. The two extremes are: on one end the individual therapy in a dedicated room; the other end is the simulation of a classroom. The first extreme has the advantage of a one-on-one intervention, which can be highly personalised to the particular needs of each child. In this case, it is also much easier to get the attention of that child and, therefore, there is a higher efficiency because the teacher can dedicate all the effort to a single child. But, on the other hand, that child is always alone; he/she is not in presence of other peers and that it is not helping him/her defeat the difficulties in social engagement and communication. The other extreme, works more efficiently on the opposite features. It is a great way to make the child stay among other his/her peers. It is more helpful to learn how to socialise and establish relationships. At the same time, the human resources are distributed more conveniently. But in a context where there are many other children, it is hard to focus precisely on the needs of each child, not even through the presence of support teachers/therapists who are trained to deal with children with autism. In that context, it is also much easier that a child gets distracted; or even to feel overwhelmed because of sensory overloading. There is also a risk that the presence of other children might not be a pleasant experience for them. In case of 'neurotypical' children, there might be a risk for bulling as they feel less capable to protect themselves. In case of other children on the spectrum, the risk is that of feeling stressed from the challenging behaviours of other children during the therapy session. In addition to the last case, their cohabitation for long time might turn not to be effective the way wanted due to the tendency of learning through coping others' behaviours.

In between these two extremes there lies a world of possibilities with three variables: number of children, number of staff, and the kind of interactions among children. There might be group therapies but where there can be even only two children working with the same therapists. Another case could be that of several individual therapies delivered on the same room each occupying a certain part of the space. In this last, there can be common activities on schedule using the same room or they are just sharing the same space. In this spectrum of opportunities there are arguments in favour and disfavour. Just consider, the last case mentioned, how distractive and acoustically stressful can be the presence of two or more one-to-one therapies taking place at the same room. Meanwhile, it is a great idea that of having the opportunity for individual care and the possibility to interact with other children without leaving the room. Another interesting consideration could be on the staff background participating during the therapy sessions. It could be very efficient to make use of therapy rooms for assessments and follow-ups because in this way the child doesn't perceive it as a healthcare procedure, but as a daily routine playing session.

Linked to

- Operation mode – because it impacts the way therapies are delivered and how to maximise the efficiency of the facility.
- Intervention size – because, in order to assist the same number of children, the size of the intervention can markedly change according to different types of configurations.
- Human resources – because the way treatments are organised require more or less staff members.

ON APPOINTMENT OPERATION MODE FULL TIME

How should a Day Centre for children with autism of preschool age work? Should it be offering a full day service, or should it be working on appointments?

Important to autism

because it is about the time children will spend in Day Centres working on their capabilities and giving a sense of relief to their families.

Important to design

because it influences the flow layout of the facility; different operation modes produce different flow lines of children, parents, staff members and visitors.

Description

The dilemma on this topic is about the timetable of the services a Day Centre will provide to children with autism of preschool age. The two extremes are: on one end there lies the full-time version of the Day Centre which naturally melts with the traditional concept of preschools; and on the other side, the idea of a complementary service delivered occasionally according to a care diagram. In regard to the first option, the advantage of having a facility with a full day programme is connected to the fact that the child doesn't have to move from one structure to another. It is an advantage for him/her because in this way it is guaranteed a certain continuity in the daily activities. The child gets used to the facility and to the staff by being there and seeing them every day. At the same time, it is also a relief for parents who don't have to worry about them for that part of the day during weekdays. It is also less time consuming for parents compared to having to accompany their child in different facilities. On the other side, a facility which apparently provides services when needed according to the care plan has also its advantages. First of all, by having children seek therapeutic interventions in sessions/workshops of few hours, the centre can welcome dozens more children than a centre which offers a full-time programme. The other advantage is the flexibility to adjust to the needs of each child; if a child needs more therapy sessions, he/she will visit the centre more frequently than someone else that needs less hours of interventions. It is flexible also over time because the treatment plan can change in base of the progress and efficiency of each treatment after sequential check-ups. Being a service that occupies several hours a week of a child, it can be considered a complementary activity to other things that child can follow according to his/her passions and needs. In between these extremes, there is a wide variability of opportunities, as for example a daily basis service but which is half day and it is integrating other services of the other half of the day.

Linked to

- Intervention size – because depending on the operation mode, there can vary the number of children that can make use of the available treatments.
- Human resources – because knowing for how much time a person will be working can help organise better and more efficiently the services.

SMALL INTERVENTION SIZE BIG

How big should a Day Centre for children with autism be? Should it be a small size building, or it can also be a big facility?

Important to autism

because it gives a sense of how many children can benefit from these services and how many families will rely on these facilities, but also with how many other children they will have the opportunity to interact.

Important to design

because it affects the outline of the building and its internal organisation. Designing for 10 children is not the same as for 100, but just enlarged proportionally; spatial organisation changes - where some spaces need to be replicated, others just re-dimensioned, others can be simply shared -, the flow layout changes, the character changes.

Description

The dilemma in this section is about the dimensions of a Day Centre and its capacity. It is a very complicated topic because there is no official regulation or indications from previous studies – at least from all the research done in this area – that describes the number of children a Day Centre should assist. Being a facility that hasn't been studied before and having an infinite number of variations - as it has been verified during this research –, it is out of the competences to give precise indications on the size of these kind of interventions. However, just to create an idea of the variability of presentation of such a centre, there will follow some considerations derived from the investigation phase. Just as indicative markers, it was chosen to describe the extremes of this dilemma with 'small' and 'big', aware that it is impossible in this case to describe how exactly 'small' or 'big'. Starting from the lowest extreme, it can be said that the advantage of having a relatively small facility is the intimacy it can offer to children with autism. Dealing with fewer children, is easier to maintain a domestic atmosphere inside the Day Centre. Considering the young age of children visiting the Centre and their difficulties in adapting to new situations and environments, it can be positive to have a domestic scale of intervention. In this case, other than the minute size of the overall facility, also the number of those visiting the Centre, gives a stronger sense of familiarity. It is easier for them to engage in relationships and less possible to be scared by frequent stranger encountering. On the other side, having a big facility, allows more children and families to get supported. There must be taken into consideration the reality in which we are living, that it is hard to find resources of all kinds to build specialised centres for a specific group of users. The advantage of having a high capacity centre is exactly that of reaching more families, connecting them, and building a community. In addition, a big centre has usually more resources to further invest on research and updates in treatments. It is sometimes much easier for them to be highly specialised and offer more services. The disadvantage, other than the difficulties to create intimate and domestic spaces, it is also related to its position. Having a high capacity centre, most probably it will not be easily reached by all families, compared to smaller interventions distributed over the territory. It is similar to the discussion of a hospital and neighbour clinics. In this spectrum, there can lie unlimited possibilities which of course, are influenced reciprocally to the topics discussed previously.

Linked to

- Human resources – because obviously a bigger facility requires more staff members, which makes the coordination much more complicated.

CONTINOUS PRESENCE HR PERIODIC VISITS

How should the human resources be organised at a Day Centre for children with autism? Should they be hired full-time, or they can be hired part-time?

Important to autism

because it affects the way children with autism and their family get a certain service.

Important to design

because the way it is structured the organigram of the Day Centre and their presence at the facility influences the flow layout and the use of spaces.

Description

Other than discussing on the kind of staff members' background, which is more linked with the type of services a Day Centre will provide, the current topic is about the way human resources are organised in a Day Centre. The spectrum of possibilities lies on the line whether the staff should guarantee a continuous presence, or not. A continuous presence means that you have a professional figure during all working hours. He/she is able to deliver the activities of his/her competence during that time period. The advantage is that of having a continuous available service. In addition, that person can contribute more to the overall growth and quality of the Centre. But at the same time, it can be a wrong decision in terms of efficiency. An expert in one field might give a greater contribution in bigger structures by assisting more people. Consider a qualified child neuropsychiatrist; it is obvious that his/her knowledge is highly requested at a Centre for Autism, but his contribution at a child hospital might be way bigger. In addition, it is a cost for the centre to hire a professional when his effective contribution doesn't pay off, not due to the incompetence, but due to low levels of workload. Therefore, his/her presence at the Centre for Autism changes the dynamics of certain activities in that centre. In this spectrum there are many possibilities, such as half day commitment or periodic visits. There is nothing wrong that a certain member of the staff, who is an expert of a specific field, visits the Centre with a certain frequency, as demanded. The limit is that his expertise contribution is according to a schedule and not always present, but at least the service is offer internally.

IX.3 Design strategy

The second outcome of this research regards the elaboration of a strategy for the design of Day Centres for children with autism. The goal is not to describe in general how it should be a Day Centre, but to give insight on features that contribute to making the environment more autism-friendly. The reason why dealing with that is connected to the impact it has on their life. A Day Centre – in this case - is typically a place that offers care and support to children on the autistic spectrum and their families. Its role is to accompany them and make sure these children have a safe and healthy growth – as much as possible – in the early years. They need to get the appropriate treatments and support in order to better cope in the everyday life, improve the educational attainment, and hopefully negate as soon as possible the long-term reliance on care centres. And in all these, the environment where they grow up is very important because it has a great effect on their wellbeing. The physical and social features of the environment can foster or hinder the adaption or the person-environment fit process. Considering that individuals on the spectrum have difficulties to adapt to the environment, then this last must create the conditions to adapt to their needs and expectations.

As a result, the work for this phase starts from the table of needs elaborated in the first part of this study (see § III.2). The referring table was developed focusing on the significant traits of those diagnosed with autism and analysing the particular needs of individuals with autism to overcome those limits and enhance their potential. The next step is to shift the focus from the person on the spectrum to the surrounding environment; therefore, shifting the attention from their needs to the required environmental traits. That operation means that the needs of individuals with autism now have to be translated into spatial requirements in order to satisfy them. This is a process fuelled from the enriched knowledge from the previous steps and personal reflections on this topic. The following table Tab.17 presents the transposition of the table of needs – which are now represented as faded – into the table concerning the features of an autism-friendly environment. There are 27 keywords reported in Tab.17 that describe ‘how spaces for individuals with autism should be …’.

AUTISM TRAITS	**ENVIRONMENTAL TRAITS**		
	be SAFE	be AUTONOMOUS	feel MOTIVATED
	ensure SAFETY	**favour AUTONOMY**	**foster MOTIVATION**
altered sensory perception	non threatening sensory stimuli with no sensory threats	clear and harmonious sensory stimuli sensory comfortable	sensory interests seeking sensorial
awkward behaviours and motions	low harming risks protective	usability accessible	encouraging challenges challenging
focus on details and systemizing obsession	simplicity simple	order ordered	flexible order adjustable
inability to generalise/ resistance to change	stability stable	comprehensibility readable	controlled change interchangeable
weak imagination to foresee	familiarity familiar	predictability predictable	fantasy stimulation intriguing
difficulties to engage in social relationship	strangers avoiding intimate	social relationships social	control over social interaction socially diversified
compromised ability to understand and reply	simplified danger notification gently communicative	communication tools facilitating communication	alternative means of expression expressive
weak short-term memory to perform operations	supervision monitored	orientation & wayfinding with a clear layout	visual support enriched with visuals
reduced attention span and planning flexibility	spatial shifting spatially generous	no distractions non distractive	shift time with smooth transitions

Tab 17 Framework of environmental traits for autism-friendly spaces

These keywords try to build an image of what can be considered as an appropriate environment for the wellbeing of people on the autistic spectrum. However, the idea of autism-friendly spaces is not something new that no one has tried to do before; many researchers and architects have spent their efforts in developing design guidelines or indications for autism (see § IV.4). Their work was guided by different principles and has produced different tools useful to design; different on the strategy chosen and on the scale of intervention which they refer. In order to get an overview of the problems the architects and researchers have tried to address through their work, there follows an attempt to structure their work in a summary table Tab.18 according to the laboured table of environmental traits Tab.17. The architects and researchers chosen for this task were those described in chapter IV (see § IV.4) and specifically the research work annotated in Tab.18. The aim was to have a comparison of the topics covered and discussed by the previous works to the actual research. Each topic is accompanied by 15 boxes representing the 15-research works referenced. In case that topic wasn't mentioned in the researches, it has been coloured with brown; otherwise, it has been left with the background colour. And as it can be seen from this overview in Tab.18, some topics are described by all researchers, others from almost no one. This analysis shows a series of gaps that this research tries to bridge through the selected approach of transposition of the needs of individuals with autism to environmental traits that satisfy those needs. It also suggests a reflection on the turn the research should take to read the outcome.

	ENVIRONMENTAL TRAITS		
AUTISM TRAITS	ensure SAFETY	favour AUTONOMY	foster MOTIVATION
altered sensory perception	with no sensory threats □□■■□□□■□■□□□■□	sensory comfortable □□□□□□□□□□□□□□□	sensorial □□□□□□□■□□□□□□□
awkward behaviours and motions	protective □□■□□□□■■■□□□■■	accessible □□■□■■■■□■■■□■■	challenging □■■□■■□■■■■■■■■
focus on details and systemizing obsession	simple □□□□■■□□□■□■□□■	ordered ■■□□■■□□□□■□□□■	adjustable ■■■□■□■■■□■■■□■
inability to generalise/ resistance to change	stable ■□□■■■□□■■□■□■■	readable □□□■■□□■□■■□□□■	interchangeable ■■□□■□□■■■■■■■■
weak imagination to foresee	familiar ■□□■■□□■■■■■□■■	predictable □■□■□□□■■■□□□■□	intriguing ■■■■■■□■■■■■■■■
difficulties to engage in social relationship	intimate □□□■□□□■□■■■□■□	social □□□□□□□■□■■□□■□	socially diversified □□■■■□□■■■■□□■■
compromised ability to understand and reply	gently communicative □■■■■□■■■■■■■■■	facilitating communication □■■■■□■■■■■■■□■	expressive ■■■■■□■■■■■■■■■
weak short-term memory to perform operations	monitored □□■□□□□□□□■■□□□	with a clear layout □□□□□□□□□□□□□□■	enriched with visuals ■□■□■□□□■■■□□□□
reduced attention span and planning flexibility	spatially generous ■■□□□□■□□□■□□□■	non distractive □■□□□□■□□□□□□■■	with smooth transitions □■■■□□□■■□□□□□■

Tab 18 Evaluation of popularity of environmental traits in selected scientific literature

[1] Ahrentzen et al, 2010; [2] Balisha, 2017; [3] Baumer et al, 2010b; [4] BB 102, 2018; [5] Beaver, 2011; [6] Brand, 2010; [7] Gaudion et al, 2012; [8] Humphreys, 2011; [9] Khare et al, 2009; [10] McAllister et al, 2012a/b; [11] Mostafa, 2015; [12] Sanchez et al, 2011; [13] Schrameijer, c; [14] Scott, 2009; [15] Whitehurst, 2006.

There are many ways to read the table of environmental traits Tab.17 and consequently think about design strategy to elaborate; however, there can be distinguished the main three of them. First, if each cell is seen individually, there can be drawn out and developed a series of indications regarding that specific trait. It is somehow the way researchers have done so far. Therefore, the strategy, in this case, would be running to fill the void and try to elaborate a more complete set of indications. The second option would be trying to link the various traits and read the table per column. This means to describe the environment according to the three main categories: ensure safety; favour autonomy; and foster motivation. Therefore, for each column, there would be a description of how the environment should be to fulfil the leading requirement. The third way goes on a similar direction as the second – connecting the various features – and proposes to read the table per row. It means describing the environmental traits based on the autistic traits; what the environment should do to help individuals on the spectrum overcome a certain difficulty and enforce their ability. It is a very interesting mode of reading because, as it can be noticed, there is a certain level of contrast among keywords of the same row. This way of reading explores the same problem from different viewpoints passing from being protective on one side, to being encouraging on the other extreme. This association sometimes reinforces the image through complementary information; while in other cases the concept is enlightened through contrasting tendencies.

Believing that this last would give a major contribution and a new way of describing environments for individuals with autism, it was chosen as the strategy of developing the design indications. Each row will be developed recalling the trio of keywords and exploring the range of flexibility required to respond to the demands. In this way, the research assumes also a unitary character following even in this case the mindset of autism; a parallel can be drawn between the nature of autism and the requirements for creating friendly environments to those on the spectrum. Having a spectrum of presentations of autism demands for a spectral atmosphere. For instance, it can't be just calm, nor it can be only exciting; it needs to be calm and exciting. It is a strategy driven by flexibility in order to accommodate a wide spectrum, so everyone can feel included and perceive it as personalised. It is a difficult challenge for designers to provide flexible environments where individuals on the spectrum can feel safe, supported and encouraged at the same time.

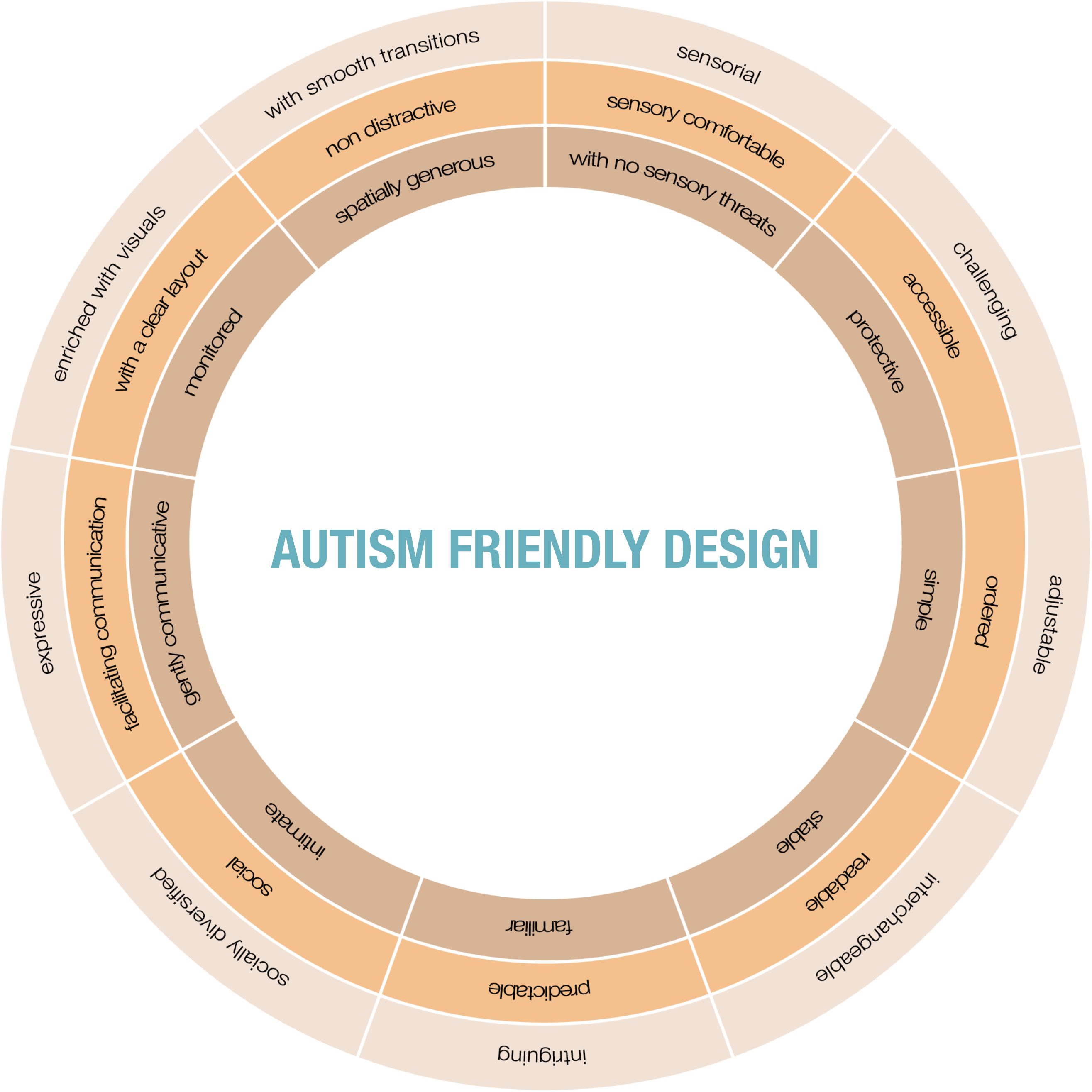


Fig 71 Scheme for designing autism-friendly environments

In the next paragraphs, there will be described the nine trios following the order of presentation on the table. They are high-level priorities to which environments for individuals with autism should respond. Each trio will be described in a narrative way dragging the attention on the cohabitation of the trio and showing the relative importance to the wellbeing of future end-users.

WITH NO SENSORY THREATS
SENSORY COMFORTABLE
SENSORIAL

Pay attention to the environmental sensory stimulation

Because of

altered sensory perception.

In order to

avoid threatening sensory stimuli; have clear and harmonious sensory stimuli; and have the possibility to seek their sensorial interest.

Description

The altered perception of the environment makes individuals with autism more vulnerable to sensory threats, but also peakier to the quality of environmental stimulation. Their vulnerability is connected to their inability to recognise danger coming from sensing – such as touching, smelling, leaking – building materials and furnishing. People with autism may be more sensitive to chemicals and substances found on the surrounding environment leading to allergies, poisoning, etc. Furthermore, having sometimes a higher pain threshold, makes them more delicate to physical affliction. As a result, design needs to pay particular attention on choosing finishes – as for example, choosing smooth, non-sharp edge, nontoxic, hypoallergenic, preferably chemical free materials – and appliances – which appliances, how they are installed, and how they will be used. For instance, consider the accidental injuries that may come from the mis choose, misplace and misuse of a stovetop.

Once safety is ensured, the goal is to reach the sensory comfort zone. Individuals with autism may be less tolerant to environmental stimulation. There is a wide range of perception deviation – from oversensitive to under sensitive – and it may regard all senses – simultaneously and in various combinations. That means that this topic is related to every feature of environment and furnishing, such as lighting, reflections, shadows, colours, acoustics, echoes, temperature, odours, air movement, softness of surfaces, smoothness, etc. Each of these features may easily cause stress, agitation, fear, disorientation, but also delight to those on the spectrum. Therefore, one of the major challenges of design is to find the common ground for a group of autistic users where there are different needs, often even contradictory. The favourite strategy seems to be that of designing neutral and harmonious – as much as possible - sensory environments; it provides a more calm, serene and gentle space.

However, it is not enough being precautionary; preventing people with autism from hurting themselves or from feeling overwhelmed or stressed. At the same time, they need to be able to seek their specific sensory interests; at a certain moment to be able to find an even quitter angle, or a more stimulating atmosphere. Seeking their sensory interests helps individuals with autism to relax, re-centre, recalibrate their senses and modify behaviours. People on the spectrum are continuously exploring and they have to be aware of their senses, so it is important to design spaces flexible enough to offer a rich variety of sensory experiences. The last request may seem conflicting with the previous two – a rough surface for better acoustics and touch stimulation, or a smooth one as more pleasant for touch and less risky for injuries or pain. Nonetheless, the effort is working on their balance; for instance, providing extra stimulation through removable sources or limited in parts of the environment.

PROTECTIVE ACCESSIBLE CHALLENGING

Adapt the environment to their physical limitations and challenging behaviours

Because of

awkward behaviours and motions.

In order to

avoid risks of self-harming; enhance the usability of the environment; and encourage physical activity for good health.

Description

Due to altered proprioception and vestibular problems with balance, and due to the presence of repetitive and stereotyped behaviours, people with autism may be more exposed to injury risks. Such bodily clumsiness may result in collisions with objects, furniture, walls, etc; slipping or falling; the exertion of inappropriate force which might result in breaking things; or even aggressive behaviours, such as hit, kick or head banging. Therefore, the first thing design should take into account is to minimise the risk of harm. Safety provisions regard all building systems, choice of materials and finishes, choice of furniture, fixtures, etc. There is a world of considerations that can be thought on this aspect and which may range from the use of robust and well anchored elements; to the use of round-edged and bumping materials to minimise the impact; to the use of safety glass or Plexiglas; or to the safe opening of windows to avoid risk of climbing and falling. However, it is important the appearance of these measures and the appeal of materials; they need to look familiar and feel homier.

In addition, there is something interesting to notice about the safety considerations. If they are combined with the accessibility measures, there comes less the necessity to think about many of them, because they give a further contribution to reduce risks of accidents. For example, having zero-step thresholds and using ramps limits tripping risk; providing more space around furniture and equipment reduces the risk to hit them; or ground floor accommodation which allows safe and easy access to outdoor without worrying about staircases or the risk of window falling; or placing objects to an easier reaching place. Considerations on accessibility not only enhance safety, but also facilitate the use of a space to a wider group of users and favour a more comfortable use of that environment.

Design should minimise risk of harm, facilitate the use, but without being restrictive for people on the spectrum. It is important that they develop life skills such as climbing stairs, grabbing, reaching, body coordination. On the other side, also vestibular and proprioceptive activities, such as jumping, running, spinning, bouncing, swinging, help them calm down, release stress, get to know better the surrounding environment. In addition, these are all physical activities that are crucial to improve mood and enhance wellbeing. Therefore, design should challenge individuals with autism through accommodating their personal interests and encouraging their involvement in physical activities. One of the best tactics is to integrate activities with their interests. For instance, as regarding children, the environment can be adapted to a range of play activities – area for jumping, painting, puzzle play, rocking, etc.

SIMPLE
ORDERED
ADJUSTABLE

Bring order in their surrounding environment

Because of

particular focus on details and obsession to systematise.

In order to

provide simplicity and order; but at the same time also the possibility to bring order according to their interests.

Description

It is usually said that people with autism see the trees but not the forest. It is not that they miss completely the context, but it may take much longer to them to get the ‘whole picture’ due to their focus on details. Therefore, the first measure design should take is to simplify the context. Simplifying can be associated with reducing details. Having less things to focus on or that attract attention reduces the complexity of the scene and helps with the overall feel of calm. Considerations for this aspect regard the layout of the structure and the pallet of materials and objects. Physical structure helps to set clear boundaries, whereas limiting the juxtaposition of different elements assists clarity of that space. So, one of the main recommendations on this context is to use clean lines and avoid overloading with non-fundamental things.

However, simplicity alone has difficulties to reach the goal of calmer and more comfortable spaces; it needs to be accompanied by ‘order’. Even though, there are now less details and a simpler structure, it is important that spaces, furniture, fixtures and objects are arranged according to a certain logic and order. Systematisation is usually one of the greatest obsessions of individuals with autism, therefore design should provide that sense of order for them. Other than the physical order of things, it is crucial that even the combination of the different environmental features – such as light, colours, odours, etc. - support the idea of hierarchy, system, atmosphere of that space rather than confusing it.

Design should bring order to the autistic world, but at the same time needs to leave margins of flexibility. The desire for systematisation needs to be respected and what the designer may consider as ordered may not match to their aspirations. In addition, their needs are personal and may change throughout the day. Therefore, even in that simply and ordered environment there should be left space and opportunities for another style of order. Individuals with autism – in person, or with the help of caregivers – should be able to bring the instantaneous order according to their preferences. In order to allow that to happen, design should take into account the flexibility of a space, so users can adjust it to their expectations. To accommodate this preoccupation with order, design provisions regard the possibility to change, move, store and hide furniture, fittings and equipment. That means for example, using furniture that are easy to move or change the atmosphere of the environment through lights, projections, etc. One of main provisions for learning environments is to have accessible and hidden storage that support a range of learning styles giving the possibility to place the unnecessary things at a certain moment of the day and help children on the spectrum concentrate.

STABLE
READABLE
INTERCHANGEABLE

Facilitate the legibility of a certain environment

Because of

the inability to generalise and the resistance to change.

In order to

maintain stability; favour comprehensibility; and give the possibility to control changes.

Description

Since the first definition of autism by Kanner in 1943, it was noticed the 'insistence on sameness' as one of the most striking behaviours characteristics. Their particular focus on details makes them less able to conceive of a general principle; to see the similarities and generalise the concept. This difficulty is transmitted in the capacity to apply what is learned in one situation to another. As a result, each time something changes may be perceived as something completely new. This leads to the strong necessity to maintain a stable environment. Consistency helps to the overall sense of calm and being comfortable with an environment they have seen before. In this context, the design task is to think about reference points and highlight them.

The idea of stability is tightly bonded to the readability. In order to become familiar to a certain space, I need to be able to read it. The easiest is to comprehend an environment, the fastest is the gain of confidence with that specific environment. Therefore, design should put the emphasis on the understanding of spaces and their functions. There are two fundamental elements that constitute the remedy of this issue: the physical and visual structure of the building. Consistent spaces with a clear physical structure help to delineate the space, whereas using visual structure through oversight and visual cues facilitates the legibility of the environment and the different functions of various spaces.

Meanwhile, design should not forget about the changing needs of users the possibility that spaces may change function over time. It was mentioned also in the previous argument the flexibility of spaces in order to suit different needs. So, at this point there comes out an even stronger conflicting request: stability versus changeability. The dilemma is which strategy design should follow; whether it should maintain stability to provide confidence to individuals on the spectrum to use that space, or whether the designed space should have the potential to be modified as required to meet changing interests and aspirations. Both considerations are very important to those with autism. As a result, instead of choosing one option and having to quit the other, design can make a further effort and find a pleasant compromise. Through design it may be possible to provide consistency over time but also permit re-arrangement for different activities and changing needs according to two conditions. The first regard the flexibility of spaces for different users or different activities, which means an X user will always find the space arranged in a certain way when seeking a certain activity, but another user at a different moment may find it differently. The second – and maybe the most important – condition regards who commands the required change. If an individual with autism is in control of a specific change, that is not conflicting stability anymore; he/she wants that change and is happy to achieve it. As a result, arbitrary change needs to be avoided and design should work on facilitating those possible changes to be performed by individuals on the spectrum.

FAMILIAR PREDICTABLE INTRIGUING

Favour the spatial recognition

Because of

the weak sense of imagination to foresee situations.

In order to

be in familiar situations; favour predictability; and stimulate fantasy.

Description

Individuals with autism have difficulties to imagine things that are not clear or obvious, and to anticipate certain situations. In order to overcome their struggle, design should consider a series of provisions how to favour the space recognition. One of the first considerations would be that of providing familiar environments. It means creating a harmonious intervention – in scale and in style – which regards the building in itself and the interior spaces, to look similar to other similar interventions and integrated in the whole context. A familiar environment can offer a hold point and inspire confidence; being familiar with something provides a sense of security and control. Therefore, design needs to make sure spaces are easily recognised and the best way to do it is remaining 'natural'.

The second step which integrates familiarity is working on predictability: helping them find out what they are about to encounter. Knowing what to expect helps individuals with autism minimise stress and assists in keeping low arousal levels. Predictability is connected, even enhanced, by readability. Therefore, the physical and visual structure are the key elements to take into consideration. It is important to elaborate clear sightlines and smooth transitions in order to increase visibility and awareness of what is happening in adjacency. For instance, one of the main recommendations is minimising blind and narrow corners. However, there can be used other senses as well to integrate predictability cues. Consider the use of light fragrances or changes in flooring consistency to indicate different atmospheres or situations.

At the same time, design should not remain limited to their weak imagination - understood as the ability to interpret the double meaning of things -, but it should also work on stimulating their fantasy. The environment needs to offer a spectrum of imagination exercising opportunities which involves them spontaneously. Considerations on this aspect range from 'small details' – such as visual signs used to enrich the legibility –, to a series of fantasy stimulation activities that encourage the participation of individuals with autism through play, or even specific environments such could be a garden. Natural environments with elements from the wild spaces stimulate exploration and engagement in another dimension. In short, it is important to think about attractive solutions which manage to engage individuals on the spectrum and awaken their curiosity.

INTIMATE

SOCIAL

SOCIALLY DIVERSIFIED

Provide a variety of social engagement opportunities

Because of

difficulties to engage in social relationships.

In order to

avoid unplanned social encounters or strangers; favour social engagement; and have the possibility to control the social interaction level.

Description

Design needs to recognise the difficulties of individuals with autism to engage in social interactions and establish relationships. As a result, it should take measures to avoid uncomfortable situations for them. Due to limitations in verbal and non-verbal communication individuals on the spectrum usually have, they may fear meeting people they don't know. Sometimes, even contact with relatives, caregivers, or peers may become too much and staying alone may be more preferable. It helps to get away from distractions and stimulations and regain control of themselves. So, what is requested is to have an environment with an intimate atmosphere where privacy is respected, but at the same time where they are aware of the potential social interactions. Giving clear views of the space and arranging it to have it under control can help those on the spectrum stay more comfortable without fearing of being approached from unexpected angles, but also are calmer to enter in a room where they can see who is in there.

However, on the other side, engaging in social interactions is a significant therapeutic activity. It is true that it may be a big challenge for individuals on the spectrum, but it is fundamental to fight their isolation and the feeling of being excluded and to develop the necessary life skills. Most of the time, it is not that they want to be alone, but it is the fact they are not feeling comfortable enough and confident to be with others. They need to be given opportunities to, first of all, strengthen connections with familiars and caregiver. Secondly, it is important for them to be able to interact with peers and get a feeling of inclusion, and step-by-step, why not establishing positive relationships with the wider community. Therefore, design should take provisions on how to create and include opportunities that may encourage people with autism to talk, share, and interact.

These two environmental traits seem to conflict each other: from one side requesting privacy, whereas from the other asking for social interaction. The good news is that through a balanced design of the environment they may cohabitate. This balance can be achieved through providing a variety of opportunities which give to a person the possibility to engage in social interaction according to his/her own terms. The key element is having the possibility of choice and allowing him/her to control the desired level of social interaction. Enabling a person with autism to adjust the privacy level or social engagement helps to manage social discomfort more easily; allowing retreat if the social activity gets overwhelming. That means design should provide a range of different interaction types, from those active ones to the quite ones. It must be highlighted that it is a range, because even among privacy-providing solutions there may be considered withdrawal spaces that permit a visual contact from distance, but not a physical contact to the social environment.

GENTLY COMMUNICATIVE
FACILITATING COMMUNICATION
EXPRESSIVE

Facilitate communication and self-expression

Because of

compromised ability to understand and reply.

In order to

be able to understand danger notifications; favour communication; and have the opportunity to express themselves in alternative ways.

Description

Possible deficits in verbal and non-verbal communication and the deviated sensorial perception may reduce in individuals with autism the ability to communicate their thoughts, moods, feelings and needs, but also the reception of messages from others or from the environment. One of the biggest issues in this context is the fact, that this may compromise the ability to understand danger notifications or cues. For instance, the fire alarm, it may not only be perceived as so, but it can also have very negative effects to those who have auditory hypersensitivity due to high pitches of the alarm tones. As a result, in the best case they just get overwhelmed, feared or stressed, but in the worst scenario, their life may be put on risk. Therefore, design should also take care about the way it informs autistic users. It needs to find a simplified and more gentle way to send a message that minimises the stress response and at the same time clarifies the core of the situation. That means integrating devices and equipment to the environment in a different way from the traditional and institutional model. There can be considered making use of visual explanation, voice-kind-danger messages, or even soft sensory integration ones.

Furthermore, for those with speech and language limitations, it may be worthy to provide assistive techniques that could help them communicate. There is a wide variety of possible techniques ranging from simple symbols, to photographs, up to the use of advanced technological devices. These communication styles provide support to individuals with autism and help them live more independently, but at the same time they also support staff assistance. They can be used as an information exchange system between autistic users, between these lasts and staff members, parents or peers. In addition, they may also include task prompting systems for the daily routine. These communication approaches need to be incorporated to the environment and permit a safe and easy use.

However, individuals with autism need to have the possibility to freely express themselves even for things that are not strongly connected to their first needs. They need to be able to share their instantaneous feelings, their thoughts and their passions. The surrounding environment should create opportunities for that to happen. Architectural solutions, if elaborated in an imaginative way, can open up a world of innovative expressive ways. Solutions may range from a simple pin board to a highly technological and sensory stimulating installed equipment. So, the challenge for designer is to consider how building and information technology can be integrated providing useful and innovative solutions for self-expression and communication.

MONITORED WITH CLEAR LAYOUT ENRICHED WITH VISUALS

Favour orientation and wayfinding and facilitate performing daily activities

Because of

weak short-term memory to perform operations.

In order to

be supervised; be able to wander freely; and be aware of his position, direction and task.

Description

Weak short-term memory which may be present among individuals with autism makes them struggle in performing a series of operations. They regard a wide range of tasks which go from the simply daily routine activities – such as dressing, bathing, washing, etc – to carrying out required tasks from caregivers, until the orientation in space and in time. Being unable to perform certain tasks or to orient themselves in an environment may make them severely distressed or agitated, not to mention risk of being lost and in trouble. Therefore, design needs – first of all – to ensure safety through continuously monitoring people on the spectrum and containment. Supervision is important so caregivers or staff members can check instantaneously the activity of a person and his/her wellbeing, particularly where inappropriate behaviour can occur and where activities involve risk. Supervision can be delivered through direct observation in communal areas or classrooms, or through nonobtrusive ways – such as indirect observation – so not to transmit the feel of being watched. In addition, there may be used assistive technologies in order to reduce the physical monitoring through use of cameras and sensors, but without compromising a certain level of privacy. Instead, as regarding containment, design need to provide secure solutions to allow wandering freely without feeling restricted. Thus, in all monitoring solutions, a balance between security and independence is needed.

However, other than being supervised, a person with autism needs to also feel autonomous in moving around in an environment. He/she needs to perceive the build environment easily and locate himself/herself in the space. Therefore, design needs to make sure the physical structure aids spatial understanding and orientation. Simple and clear solutions minimise confusion and reduce stress to everyone. As a result, a clear, simple and logic selection and organisation of forms, shapes and spaces help maximising clarity and building a comprehensible layout of the building. Clear sightlines are an added value for both: users and staff members assisting them. Furthermore, adding details to the physical structure – such may be colours or objects as landmarks – may help users better orientate and facilitate wayfinding.

In case a clear physical and visual structure isn't enough to support individuals with autism, visualisations may come to help improve the visual clarity of design. They can enhance orientation and wayfinding, also facilitate task performing. They could be anything such as text, pictures, colours, shapes, symbols, icons, etc. They help to indicate directions, functions, contents, programmes, timetables, routine tasks, etc. In conclusion, visualisations can act as a supplement to many features. However, in order to work out as a complement of the physical structure, they need to be clear, elaborated and limited to necessary detail, so, to avoid overloading or complexity.

SPATIALLY GENEROUS NON-DISTRACTIVE WITH SMOOTH TRANSITIONS

Enhance concentration and comfort flow

Because of

reduced task flexibility/attention/planning.

In order to

permit spatial shifting; reduce distractions; and give more time to switch task or activity.

Description

Individuals with autism may present difficulties with planning ahead, focusing, and being flexible to change routines. In order to reduce the effects of these shortcoming, even the environment can intervene; so, design can take a series of measures. First of all, in order to concentrate and perform a task or activity, a person with autism needs to be at his/her ease. Therefore, the first consideration should regard the proxemics; which is the amount of space a person needs to have around, so his/her sense of safety and comfort are not compromised. This distance from objects or other persons is something personal, and it may be greater or smaller according to each one's sensitivity. People on the spectrum – mainly those with severe autism – may be very sensitive, thus requiring more space around them so the space is less infringed. Sometimes, they have even an exceptional aversion against physical contact or crowd. Generous space standards may therefore address this concern by reducing the impact of this infringement and avoid unwanted contacts. That helps also to reduce the negative feeling of oppression, pain or discomfort.

Once the personal space is ensured, design needs to work on how to minimise distractions, so individuals with autism can focus on their activities. It is a difficult challenge because even the smallest details of the built environment may attract attention. Thus, reasoning on that, means working through all the different experiences that happen in that space: social interaction level; the presence of other people; the kind of activity; and including all senses seeing, hearing, smelling, touching, feeling, etc. Therefore, there must be dealt an infinite variable such as acoustics – noise coming from outside, and noise produced indoor -, visual – details, lighting, reflections, shadows, sightlines, materials textures -, touching – finishes, surfaces, softness – physical structure – layout, flow lines, arrangement, furnishing – etc. In short, reducing complexity may help to increase attention span and reduce distractibility.

Coming to help to the previous two considerations is 'shifting time'; giving more time to individuals with autism and prepare them for possible changes. Design can affront this necessity through the provision of smooth transitions between different spaces. These lasts allow a more gradual accommodation to new upcoming situation, thus giving time to recalibrate sensorial perception, re-centre and approach more confident. These areas – which could also be called buffer zones – give to the person on the spectrum the possibility to self-control the time when he/she is ready to move on and face the new experience. This way, the buffer function of these spaces also minimises unpredictable situations which might trigger uncomfortable experiences.

CHAPTER X

FINAL STATEMENTS

This chapter discusses the results as research findings and quality considerations. The first section evaluates the generalisability of the research. Section two identifies the limitations of the study. Section three delineates the implications of the research, and the final section provides directions and insights for possible future developments of the research.

X.1 Generalizability

Generalisability assesses the extent to which the research outcome can be applied. This research aimed to study the therapeutic interventions for children with autism at preschool age in four different countries to propose a programming and design interventions strategy for autism-friendly environments. Regarding the first stage of the drafted strategy – the programming of day centres for children with autism – the following considerations are in order. Firstly, this research was concentrated in four countries – Albania, Italy, United Kingdom, and United States – for a series of reasons discussed above. Due to limited resources, the study was confined to a few cities of these countries. However, having studied, visited, and analysed a large variety of cases and, consequently, having gathered a lot of qualitative data from autism experts, parents of children with autism, and autistic parents during four years of research, the outcome may represent an ample context. Furthermore, the approach chosen for the first product of the research, planning and management strategy of Day Centres — that of describing the wide spectrum of possibilities — makes the study even more inclusive. Therefore, the outcome may be deemed as applicable almost globally.

The second consideration is about the selected age range. While the research was focused on preschool age children, the methodology applied can seamlessly be adopted also for older individuals with autism. Most of the parameters and the reasoning behind the methodology would be valid for different age ranges. Therefore, there does not exist any barrier in applying the elaborated strategy more widely. Last, about the typology of the facilities, this study described the broad array of the functions that the Day Centre may assume, therefore, leaving open the possibility to apply the research products to other facilities as well.

Regarding the second stage of the research, the design strategy for autism-friendly environments in Day Centres for children with autism, similar considerations can be made. The design tool laboured stands at a high and generic descriptive level regarding the environmental traits that compound friendly spaces for children with autism. As a result, this tool may be adaptable all over the world, without restrictions of age, and to different contexts – living, educational, and healthcare.

X.2 Reliability | Limitations of the study

This section evaluates the reliability of this study, i.e., the extent to which a similar study would produce similar outputs with a particular focus on the vulnerability of the research. During this work, I took great care and attention to plan, implement, analyse, and elaborate my research at every stage. Each choice made, including the method selected and the operationalization of parameters or variables, was clearly described and justified consistently throughout the study. Nevertheless, this study is not airtight. This section recognises the research's limitations next to its strengths, most of them due to limited resources, human, i.e., available time, and financial. While I am aware that every step of a research involves a check and balance task, which can further improve the product, below I list some of the most important limits of this study grouped according to the key stages of the research.

Limitations of the Study

I | Background Study

The background part of this study was based on a scientific literature review, but the latter is in constant evolution because autism is a hot academic topic given its high prevalence and ambiguous nature. Therefore, it is next to impossible to include every relevant study or to keep up with all the latest updates. Moreover, as inherent to the academic studies, I have had to made various judgment calls regarding the dominant academic line on various features of autism because of conflicting opinions and viewpoints found in different peer-reviewed sources.

The framework of the needs of people with autism (Tab.1) was developed for the first time by this paper using a different and 'innovative' approach compared to previous studies. This part of the research was discussed and reviewed with a research team on autism at the Department of Psychology of the Kingston University. However, presenting it to a group people with autism and implementing their remarks could have strengthen the reliability of this framework.

II | Investigation

This study limits its geographical scope to four selected countries – Albania, Italy, the UK, and the US. They were chosen because of their contribution to autism research and intervention and because of the author's personal experiences in these countries. Furthermore, the investigation did not cover these countries' whole territories, but it was limited to parts of them.

Regarding the case studies, numerous Centres for children with autism were considered and visited, albeit the study analysed in detail only four of them, one of them for each country. They were chosen to distil a wide array of characteristics, but this study does not presume to have covered the whole range of possible cases. Furthermore, given the broad variability, this research could not provide a detailed comparison among the case studies in terms of their design and environment.

Additionally, for each case study, this study assessed the environmental quality according to the framework of the needs of individuals with autism, based on a check-based form (Tab.3). To get a more accurate picture of the facilities, it could have been useful to ask the staff members to fill this form. This option was not viable due to the complexity of the framework and the requirement to take a series of steps before completing the form.

This research includes the interviews with four parents of children with autism to get information on their experiences with the existing care system for autism and their views on future possible improvements. In fact, during the research progress, I met hundreds of parents but decided to report only four in-depth interviews made to four public figures with a contribution to raising autism awareness in the communities they live in. This choice was affected by resources constraints, i.e., being impossible to present an overview of hundreds of experiences, and methodological approximations, i.e., believing that the chosen public figures could represent and share the sensitivity of the autistic community in their countries. Therefore, this paper did not presume to delineate all the practical complex mechanisms regarding children care, but to draft a blueprint of the everyday problems that these parents face when taking care of their autistic children.

Similar limitations are present with respect to interviews with autism experts. While four renowned professional figures with years of experience in the field were interviewed, this study cannot claim to have included all existing viewpoints and to have reached universal consensuses regarding many traits of autism. All these choices are, inevitably, ‘tainted’ by a certain degree of subjectivity. They are limited to the best of personal knowledge and my network of interpersonal connections.

One may also claim as a supposed general limitation of the study the absence of interviews or surveys with individuals with autism. The focus of this research were children with autism at preschool age, whom I could not have involved in this process. Nonetheless, I believe to have included, at least indirectly their interests, needs, aspirations, and desires through the review of autistic authors’ autobiographies. Furthermore, parents of children with autism, caregivers, and autism experts were consulted to express their observations and thoughts. On this subject, it is noteworthy that two of the interviewed parents with a remarkable influence in their home countries, Italy and the United Kingdom, were diagnosed with autism. So, they can be considered as an added value to the research, given their dual contribution as parents and as individuals on the spectrum.

III | Proposal elaboration

The outcome of this research is a set of programming and designing strategies for Autism Friendly Day Centres for children with autism. Regarding the programming of these interventions, as said, it mainly concerns those in charge of care policies. Therefore, being outside the general expertise of an architect, this research was limited in elaborating on a series of topics that are crucial for children with autism and that greatly impact the design of these interventions. The 12 topics identified as key variables in describing a Day Centre derive from long research and personal reflections on issues that concern the realisation of these types of facilities.

X.3 Practical Implications

The goal of this research was to elaborate a strategy for the conception of interventions capable to support children with autism both in their early years and throughout their childhood, while offering relief to their parents. These interventions should be provided in adequate environments that welcome these children and respond to their needs. This study considers Day Centres as optimal settings to host these interventions. Therefore, the focus was on how to develop autism-friendly Day Centres for children on the spectrum at preschool age. The outcome of this study depicted two strategy definition tools that describe the interventions at two different levels. The higher-level deals with the programming of such interventions referring to their planning and management issues. The lower level envisages design strategies in creating autism-friendly environments. In general, this study aims to serve as a comprehensive guideline on therapeutic and support interventions for children on the spectrum and their parents.

The higher-level strategy offers an overview of the problem's complexity and addresses the difficulties in formulating appropriate and cost-effective interventions. These interventions should not provide only the necessary services to guarantee the best support for children on the spectrum and their families, but also to create a cohesive and comprehensive network to overcome the disorientation of the involved stakeholders. The drafted strategy could be a useful tool for public administration, institutions, foundations, and all public/private organisations that are active in policymaking and interventions' planning. Furthermore, this research may help to prepare assistance policies and intervention measures for children with autism, such as, the correct identification of the areas to locate the Day Centres, the definition of the management methods, and the organization of design competitions with the consequent evaluation of the presented projects.

The other tool reviews the environmental features that affect the wellbeing of individuals with autism and proposes a design strategy for therapeutic and support environments, which can accommodate both physical and sensory limitations while enhancing children's growth potentials. This implies means additional meaningful layers to design and, therefore, new challenges for the architects and the designers to interpret the particular needs of those on the autistic spectrum through architectural options. Through the second research output, this challenge should be faced with diligence and creativity, given the profound complexity that the design process implies. Thus, the second tool can serve as a helpful tool for architects and designers to handle the design tasks of Day Centres.

X.4 Recommendations for Future Research

Research on autism is in continuous evolution. Given its complex nature, the progress over the years has been slow and moderate. Furthermore, the interdisciplinarity nature of the phenomenon requires a combination of information stemming from different fields and a periodic update on the ongoing researches. The researches in architecture for autism combine the theoretical studies with the practical examples build over the territory. Thus, refreshing this research with the latest findings and with recent on-site experiences should be one of the most obvious future steps to take.

In addition to keeping up to date, it could be useful for the future to test the findings of this research. In this light, it could be helpful to discuss the two products with stakeholders. Architects, designers, individuals on the spectrum and their parents, caregivers, and autism professionals working with autistic people in therapeutic settings could be involved in a general review of the two instruments to strengthen the case for their validity.

In a second instance, future researches could attempt to expand further the two strategic tools elaborated through this work. These tools described interventions at Day Centres concentrated on the higher level of the decision-making process. This paper depicts the strategy on how to program and design this kind of facilities, however, this strategy is, deliberately in a certain way, generic. If we were to have a general understanding of the significant topics and issues related to the Day Centres for autism, it would be easier to consult the interested parties. Therefore, future developments of this research could involve the description of these outcome tools with illustrative and explaining examples coming from the best practices and innovative suggestions. Another possibility is to transform this work into a catalogue that provides operational solutions in an open system of variables that could be adapted to every specific assignment.

Future research may also extend the target age range of individuals with autism. This study was focused on preschool aged children, covering them from the diagnosis moment until their enrolment to primary school. Nevertheless, autism is a lifelong disorder condition, which means that individuals on this spectrum will probably need care and support during their entire lives. Therefore, considering Day Centres as a foundation stone in the care chain, it is crucial to provide services through these facilities for people with autism regardless of their age. These structures can guarantee continuous support to those with autism and their families. Using this study's methodological approach, future researches can build on it to make dedicated Day Centres available for all ages.

Another possible area for future research developments concerns other contexts of care for individuals on the spectrum. As autism colours the way of being, the care required for those with autism covers a broad range. Thus, autism demands an organic system of services and support and not reliance on single episodes of care. The methodology elaborated in this thesis regarding Day Centres may be applied to study and explore other chain rings of the care system, such as the study of residential, educational, and healthcare contexts.

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ABBREVIATIONS

ABA: Applied Behaviour Analysis;

ASD: Autism Spectrum Disorder (hereby referred also as ‘autism’);

CBT: Cognitive Behaviour Therapy;

CDC: Center for Disease Control and Prevention;

CRPD: Convention on the Rights of Persons with Disabilities;

DSM: Diagnostic and Statistical Manual;

ICD: International Classification of Diseases;

ICF: International Classification of Functioning, Disability and Health;

IQ: Intelligence Quotient;

OHCHR: Office of High Commissioner for Human Rights;

PDD-NOS: Pervasive Developmental Disorder Not Otherwise Specified;

PDD: Pervasive Development Disorder;

PECS: Picture Exchange Communication System;

SCD: Social Communication Disorder;

TEACCH: Treatment and Education of Autistic and Communication Handicap Children;

UN: United Nations;

WCC: Weak Central Coherence;

WHO: World Health Organization;

APENDIX

Autism Spectrum Disorder | Diagnostic Criteria

A| Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

1| Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2| Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3| Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

B| Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1| Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2| Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).

3| Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).

4| Hyper- or hypo reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

C| Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).

D| Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E| These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Specify if:

- With or without accompanying intellectual impairment.
- With or without accompanying language impairment.
- Associated with a known medical or genetic condition or environmental factor.