

"Nothing in This House Is by Chance": Design Ethnography for the Well-Being of Children with Autism

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Abstract. The aim of this paper is to explore how design can contribute to fostering the well-being of children with Autism Spectrum Disorder (ASD) in their home environment. We report on a single case study that involved an in-depth study of the lived experiences of a child with ASD and their family at home. This qualitative and exploratory research followed the principles of design ethnography, favouring naturalistic data collection that occurred in real-world settings. The results show that technical standards, guidelines, and best practices for interior spaces are important and often appropriate for general purpose. However, ASD manifests differently for different people and this means customised solutions are required. Designers do not always have the tools and time needed to devise solutions that are not only functional, but also suited to the individual needs of a person with ASD. The research described here thus contributes to informing best practices for designing home environments that are appropriate, safe, comfortable and, above all, that respect the privacy, individuality, and preferences of children with ASD and of their families.

Keywords: Interior design \cdot ASD \cdot Home environment \cdot Design for inclusion \cdot Family

1 Introduction

According to the United Nations, it is believed that there are more than seventy million people with autism in the world [1]. There is a high rate of people diagnosed with Autism Spectrum Disorder (ASD) worldwide and a general lack of understanding of the condition has a great impact on individuals, their families, and communities that live with ASD. There is no known cause for the increase in diagnoses in recent years [2], but it has been speculated that it may be due to wider diagnosis criteria since 2012 (now understood as a spectrum) combined with greater knowledge and visibility of ASD within society.

A diagnosis is usually made in childhood, at around two or three years of age [3], which is when the most common signs tend to appear. There is a wide range of social,

behavioural, and communication characteristics associated with autism. Additionally, there are unusual responses to sensory experiences and resistance to changes in the environment or in daily routines [4]. This means children with ASD can have more difficulty adapting to certain environments. Here, design can have an important role to play in terms of developing an appropriate sensory environment and mediating its relationship with ASD behaviour [5–7]. Designing for children with ASD benefits from trying to see things through their eyes, to think like they do, by including them in the design process [7]. We argue that design is a tool capable of creating solutions that suit each person by understanding their unique needs and desires, and so informing meaningful interventions.

Homes are places for living, but they are also spaces for relationships and development. It has been said that "there is no place like home" [8] because, even though it is embodied in a physical and perhaps not unique structure, the home has been filled by its occupants with feelings and attachments that infuse it with meaning for them. Here, the notions of Place and Placelessness by Relph [9] are particularly relevant. Place has a personal identity that we have shaped – it holds meaning for us and evokes certain emotions. Placelessness refers to a lack of a unique identity, somewhere impersonal and without meaning. Designing only according to recommendations and guidelines for accessibility implies a risk of creating placelessness. We therefore identified an opportunity to explore how design can contribute to promoting the well-being of children with ASD in their home environment, by investigating a real-world case that demonstrates appropriate and meaningful solutions.

The contribution of this paper lies in a more sensitive and social perspective of the home for children with ASD and their families. The following section provides a review of relevant literature on three key themes for this research: interior design, the home, and autism. We then present the methods and results, which we discuss with a view to offering recommendations for designing meaningful home environments for families with children with ASD. The conclusion identifies opportunities for future work on this topic.

2 Background: Interior Design, Home and Autism

The American Society of Interior Designers (ASID) views interior design as an activity capable of impacting the human experience and influencing the way people live [10]. In fact, ASID states that, when designing interior spaces, a designer is directly contributing to enhancing the health and well-being of its occupants. Further highlighting the significant responsibility of interior designers, other authors have noted that the design of an interior space has the potential to influence human behaviour, both positively and negatively [11]. Hirano (cited by [12]) notes that design not only involves the aesthetics of tangible and interesting objects, but is characterized by intangible concepts that aim to improve society.

Recent years have seen an increase in research on how physical aspects of the environment can influence the development of children with ASD. Many authors and researchers have looked to the home as an important focus for autism-friendly environments [13– 17]. Even though they have approached the issue in different ways, there is consensus that the built environment can be designed to respond to the needs of people with ASD, specifically in terms of sensory stimuli, thus creating spaces of relaxation and stability. Interior design can be a decisive experiential factor when the focus is on the built environment, given that a space can exert both a direct and indirect influence. It is necessary to use processes that focus on obtaining rich knowledge about each individual through a personalized approach, to understand what the real needs and interests are and how to create solutions that can contribute to minimizing personal challenges. Any approach to designing autism-friendly home environments also needs to consider the comfort and well-being of all other long-term occupants [7, 16].

A greater social awareness of people with ASD means that many professionals such as interior designers are being increasingly requested to design, adapt, and build homes that best meet the needs and desires of these individuals. Designing for accessibility in architecture is not only a challenge but also a duty, because if a house does not meet the needs of its inhabitants, it can never be considered a Home. The home is more than just a place where one lives: "It is a 'territory of meaning', a place where pleasure, affect and aesthetics are deeply interwoven with the functional and utilitarian dimensions" [18, p. 1]. Although it is typically embodied by a physical structure, it is much more than that: "Home is a series of feelings and attachments" [8, p. 10].

There are not currently many examples of design-related projects focusing on people with ASD in the literature. Magda Mostafa is one of the world's most prominent researchers and practitioners in the field of architecture for people with ASD, with projects that include the Advanced Special Needs Education Center [19]. Another noteworthy example of architecture for people with ASD is Sweetwater Spectrum [20], a permanent housing solution for individuals with ASD and their support staff. From a domestic perspective, design researcher and fashion and product designer Maureen Selina Laverty used sensory ethnography in what she termed wardrobe interviews with people with ASD [21].

3 Methodology

This research was based on a qualitative and exploratory case study, focused on a child with ASD and their family. Pursuant to design ethnography principles [22], several methods and techniques were used, such as non-participant observation, field notes, unstructured interviews, and photographs of the home and of interactive devices used by the child with ASD. This allowed a deep and naturalistic understanding of how a home environment is experienced by all its occupants. The rationale for this methodology was informed by the notion that autism is a spectrum that encompasses a wide range of symptoms types and levels of severity, which differ from person to person [23]. This is in line with recommendations in the literature on conducting research on ASD and with people who have ASD [24].

Although the study protocol envisaged involving just one family with a child with ASD, participant recruitment was a particularly challenging aspect of this research. Many recruitment strategies were applied and the one that proved successful in the end was to approach a local Social Solidarity Cooperative (SSC) with expertise in ASD. The president of that SSC held an initial meeting with the researcher to better understand the

purpose of the research and to establish boundaries that would safeguard the interests of all stakeholders who may become involved as participants. Beyond the child with ASD and their family, these included professionals from the SSC who provided various forms of support. In this sense, the president of the SSC acted as Gatekeeper [25] as he mediated access to the study participants and advocated for their interests throughout.

All participants gave their informed consent to take part in this research and any photographs taken were previously agreed on with the participants. The researcher took particular care to ensure that the children involved in this research were comfortable with her presence and willing to be part of the study – this was a crucial factor in the parents' decision to participate.

3.1 Data Collection

Data were collected through various methods and techniques, namely non-participant observation, unstructured interviews, a guided tour of the home, field notes, photographs of the home environment and of some of the child's personal objects, as well as the study of the house's architectural plans (Fig. 1). The researcher kept a fieldwork journal in which she recorded her objective as well as her personal observations.



Fig. 1. Data collection methods and techniques

Data collection took place over multiple visits to the home where the child with ASD and his family live. The non-participant field observation focused primarily on five behaviour therapy sessions carried out in the home, which followed an established structure and process. During these sessions, the researcher observed the child's behaviour and his interaction with the home's interior and exterior spaces, as well as interactions with people and everyday objects, through certain activities encouraged by the therapist. The sessions lasted between two and three hours, with the activities and duration of each session being previously arranged by the family and the SSC. In parallel with the observation, the researcher conducted informal interviews with the parents, the carer,

and the therapist, which allowed a deeper understanding and facilitated the mapping of this case.

3.2 Data Analysis

Data analysis occurred alongside data collection, with transcription and preliminary analysis of field notes happening soon after each home visit. A fieldwork journal containing detailed descriptions of the home environment, domestic routines, interactions that took place, interpersonal relations, and the researcher's initial impressions was written up in a digital file for rapid access. This facilitated early interpretation of the data, which in turn guided the planning and focus from one home visit to the next. Data analysis comprised two approaches: a descriptive analysis and an interpretive analysis (Fig. 2).



Fig. 2. Approaches to analysis

The descriptive analysis contained a summary of what had been objectively observed, such as: who was involved, how often they interacted, and what they did in a given space. The results from this approach are facts and there is no interpretation by the researcher. For the interpretive analysis, the digital field notes were shared amongst the authors for independent coding, which were subsequently discussed in data analysis meetings to identify common themes. This process observed guidelines for robust qualitative data analysis [26] and thus ensured the quality of the research results.

4 Results

The results include a brief characterization of the main participant in this study, which are presented in Table 1. As the main focus of this research was the child with ASD, we gave him the pseudonym Francisco; all other participants were attributed the label that identifies their relationship to Francisco.

As the study was carried out in a domestic environment, it was important to describe and contextualize the space as a whole. A family of four lived in the house at the time:

Participant	Description
Francisco	13 years old Diagnosed with non-verbal ASD
Mother	Full-time employment Actively oversees household management
Father	Used to be a stay-at-home dad to care for Francisco Follows the Mother's lead regarding household management
Twin brother	Diagnosed with ADHD Caring and protective towards Francisco
Carer	Has worked with the family daily since 2019 Involved in all the children's routines and activities Manages previously established household tasks
Behavioural therapist	Assists Francisco in learning to work with various materials Seeks to help Francisco develop general life skills
Gatekeeper	President of the SSC that provides ASD support Advocate for the family's rights and well-being during the study Mediated the researcher's access to the family and research setting

Table 1. Participant characteristic	cs
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Francisco, his twin brother, and their parents. Other people who were regularly present in the home included a carer, who was there every day, and a behavioural therapist, who visited up to five times a week according to a flexible and agreed schedule. The family bought the house while it was still being built and so was able to influence certain aspects of its interior design. The house was not designed specifically for the child with ASD, although it did consider his safety as well as the well-being of all. There was an initial project and it was adapted to Francisco's routine requirements based on the family's experience and knowledge. Visiting this home, it was evident that it is not necessary to design a special house for this or that person. However, it is possible to make adjustments, even if minimal, in order to adapt a house to people's individual needs, and it is very important for architects and designers to think from this perspective.

Nothing in this house is by chance. Everything was thought through: what is there and what is not there. (Mother)

This home had its own identity and, despite Francisco's needs informing much of the family's routine, they chose not to have this represented visually. Every space had a role: resting, working, learning, cooking and other typical roles of domestic spaces. Yet the same space performed different functions and was differently occupied, depending on the day and time of day. There was a clear relationship between the spaces, the routines or activities taking place there, and the household occupants involved. Figure 3 shows what spaces of the home were used for various purposes.

One of the strategies used to facilitate multiple uses of a space was through the choice and arrangement of furniture. For example, the large TV cabinet in the living room stored all the children's games, which meant the room could rapidly gain a new



Fig. 3. Spaces and purposes of the home

identity as a space for playing. A particular interesting space was the garden, traditionally a leisure space, but also used by the family as a place for learning and working. Some of Francisco's occupational therapy and exercises were conducted in the garden because he was often rewarded for his effort by having some play time on the grass or the trampoline, both of which he enjoyed immensely. The parents were keenly aware of the importance of appropriate sensory stimulation for Francisco and invested a lot in objects of this kind. In addition, there were some electronic tools aimed at children with ASD, which can facilitate and stimulate communication and interaction skills.

5 Discussion and Recommendations

This case study involved a family that had been able to influence and adapt the interior spaces of a house while it was still in construction. Moreover, their many years of lived experience of having a child with ASD had equipped them with a strong understanding of effective strategies for ASD and family living. We therefore argue that best practices in terms of domestic interior design for a child with ASD can be confidently inferred from this case study. By reflecting critically on this research project, its results, and the relevant literature, we offer some recommendations for the design of home interiors that are appropriate and desirable for children with ASD and their families.

Existing legislation and guidelines serve their purpose, but interior designers need to be critical and use good design practices only as a starting point to create suitable domestic spaces. In this case study, the family followed such norms and guidelines, but they also made adaptations to their living spaces based on their own experiences and Francisco's needs. This is echoed in the literature by several authors, who offer recommendations for ASD-friendly interior design [7, 15, 16, 27, 28].

An interior designer who is creating domestic spaces for children with ASD must work closely with the client family and other people who regularly use the home, and involve them in the design process. Findings from our study support the position of Mostafa [7] regarding the importance of people in the design process. The house in this case study had been designed to be inclusive of the needs of all its occupants, so that, in addition to being appropriate for a child with ASD, it was also a home for the entire family. Clients may have just as much or even more expertise than a designer regarding their needs for a space for living and should be actively involved in solutions for them.

It is important that a designer creates spaces that are dynamic and adaptable to different functions. The interior spaces of a family home have multiple purposes. It is the Home, but also a space for work and leisure for a variety of people (residents and non-residents). Although some general recommendations have been put forward [19–21], there is no single standard for designing appropriate spaces for children with ASD and their families. This means that it is essential that designers are aware of this plurality of situations and consider them in the design process.

Interior designers should understand the family's reality and family routines in order to create spaces that promote well-being and facilitate the routines of children with ASD and their family. A particularly interesting finding from our study resonates with a call for applying qualitative and interpretive research approaches to this issue [28, 29]. The ethnographic methodology used in this case study allowed the researcher to gain an in-depth understanding of the habits and needs of the child with ASD and his family in relation to their home. Such participatory and ethnographic approaches are necessary to counter the generalization of domestic interior design and create true Places [9] for living.

Interior designers must create domestic spaces where environmental sensory stimuli are adequate for the child with ASD. The Advanced Special Needs Education Center [19], the Sweetwater Spectrum [20], and Sensory Nourishment [21] are three projects that demonstrate a fundamental preoccupation with matching sensory stimuli from the built environment and from products to the needs of people with ASD, based on the knowledge that poor sensory experiences can be disturbing or even disabling for them. Appropriate stimuli, on the other hand, have the power to comfort and foster well-being. The slow but steady increase in designers seeking to include the people for whom they are designing in the design process will in turn mean a better understanding of how to moderate sensory stimuli for people with ASD.

There is an opportunity for design, as a discipline, to sift through the dense information collated in standards, guidelines, and scientific papers, and create tools that support families with children with ASD. As Hirano (cited by [12]) says, design has a calling to improve society. The family involved in this research was very knowledgeable and experienced in handling ASD issues. Findings from this case study can be leveraged to impress upon designers the need to develop tools to help other families who are not yet at this stage, or who still do not know what is important, thus contributing to a fairer and more inclusive society.

6 Conclusion

This paper sought to explore the experiences of home of a child with ASD and his family, taking a design ethnography approach. This approach was deemed particularly suited to an in-depth and naturalistic study of a child with ASD. The researcher immersed herself in an unfamiliar domestic routine to gain a holistic view of how a child with ASD uses and relates to his home, while also acknowledging that the home is a dynamic space that is shared by multiple people who each have their own needs and desires. In this sense, design must be inclusive of all the people who regularly live in the home. By studying a family who has lived with ASD for a long time and who has a robust system in place for their son with ASD, we were able to identify some best practices that informed six recommendations for designing domestic interior spaces for similar family contexts. We believe that this paper makes a timely and necessary contribution towards encouraging more sensitive and inclusive research approaches in interior design, in particular for children with ASD. Future research could build on this work, both in terms of scale and in terms of related living contexts such as holiday dwellings and hotels. Collectively, these could serve as a basis for the development of policies to support designers in creating interior living environments that are inclusive and meaningful for children with ASD and their families.

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